

Impact of the Transition from Pediatric to Adult Medical Care on Health  
Service Utilization in Inflammatory Bowel Disease (IBD)

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## GLOSSARY

Adult gastroenterologist: internists with reported or certified specialty in gastroenterology, or internists who performed >100 colonoscopies per year and whose practices were made up primarily of adults [5].

Control period/Non-Risk period: from diagnosis until the 1st adult gastroenterologist visit (afterwards alternating visits to both pediatricians and adult gastroenterologists) or the beginning of transfer period.

IBD related: Diagnoses in the text refer to all diagnostic codes classified as IBD-specific, IBD signs/symptoms and extra-intestinal manifestations listed in Supplementary table 3.

IBD specific: Diagnosis codes as 555.x or 556.x under ICD-9 or K50.x or K51.x under ICD-10.

Loss to follow-up: The age at last IBD related visit was beyond 18<sup>th</sup> birthday and had less than 2 adult gastroenterologist visits at the end of the observation period (either 0 or 1).

Pediatric gastroenterologist: pediatricians with reported or certified specialty in gastroenterology, pediatricians who performed colonoscopies on >5 children per year, or adult gastroenterologists whose practices were made of >70% children under 18 years old in a given year [5].

Risk period: from the end of the washout period to 2 years after the end of the transfer period with only adult gastroenterologist visits (at least 2 adult visits).

Transfer period: between the 1st visit to an adult gastroenterologist and the last visit to a pediatric gastroenterologist. The patients would visit both adult and pediatric gastroenterologists alternatively during this period until their healthcare responsibilities are transferred to adult gastroenterologists. If the patients did not visit pediatric gastroenterologist after first visit to an adult gastroenterologist, the transfer period is defined as 1 day.

Transfer failure: during the first year in risk period, no regular outpatient visits with a gastroenterologist was recorded in Ontario administrative database.

Transition: the whole process including medical, psychosocial, and educational preparation and actual transfer period. It is a multi-faceted active approach to address the needs of adolescents as they move from child-oriented to adult-oriented care [58].

Unsuccessful transition: no IBD-related or IBD-specific adult gastroenterologist visit for 1 year or 365 days following the transfer period. We also defined loss to follow up as having either none or only 1 adult gastroenterologist visit as the last visit recorded in OHIP database.

Washout period: 6 months starting from the first adult gastroenterologists. This is defined as a washout period as any events that occur in this period are likely secondary to events in the pediatric care period that carried over beyond the date of transfer.

## ABSTRACT

**OBJECTIVES:** Inflammatory bowel disease (IBD) is a chronic condition with increasing pediatric incidence. Transition from pediatric to adult care is associated both with disruption of links with familiar caregivers and differences in health care delivery. This study explored the impact of the transfer from pediatric to adult care on health services utilization for pediatric-onset IBD patients.

**APPROACH:** A population-based retrospective cohort study identified all children diagnosed with IBD 1994-2008 and treated by pediatric gastroenterologists from within Ontario health administrative data. Self-controlled case series analyses compared health services utilization in the 2 years before and after transfer to adult gastroenterologists, with a 6-month washout period at transfer. Outcome evaluated included IBD related/specific hospitalization, emergency department (ED) utilization, outpatient visits, and laboratory utilization. Relative incidence (RI) in the post-transfer was compared to pre-transfer periods using Poisson regression analysis controlling for transfer starting age. Analyses were stratified by IBD types: Crohn's disease (CD) and ulcerative colitis (UC).

**RESULTS:** 536 patients were included in the study (388 CD, 148 UC). ED utilization rate was higher after transfer for both CD (RI 2.12, 95% CI 1.53-2.93) and UC (RI 2.34, 95% CI 1.09-5.03). Other increases in health care provision included outpatients visits (CD: RI 1.56, 95% CI 1.42-1.72; UC: RI 1.48, 95% CI 1.24-1.76), and laboratory investigations (CD: RI 1.43, 95% CI 1.26-1.63; UC: 1.38, 95% CI 1.13-1.68). There was no statistically significant change in hospitalization (CD: RI 0.70, 95% CI

0.42-1.18; UC: RI 2.41, 95% CI 0.62-9.40). Sensitivity analysis revealed similar results when only the first year post-transfer period was assessed.

**CONCLUSIONS:** In the largest study to date examining the transfer from pediatric to adult IBD care, health services utilization increased significantly in the two years after transfer for measures of access to health care providers. Understanding causation and rigorously evaluated transition programs may help to better manage the resources and meet the needs of pediatric-onset IBD patients.

## CHAPTER 1: INTRODUCTION

Inflammatory bowel disease (IBD) is a complex, multifactorial disease characterized by chronic inflammation in the gastro-intestinal tract in a genetically predisposed host. It is a chronic inflammatory condition that can affect both children and adults with two main forms: Crohn's disease (CD) and ulcerative colitis (UC) [1]. Canada has one of the highest reported incidence and prevalence of IBD in the world. There are approximately 233,000 Canadians living with IBD: 129,000 with CD and 104,000 with UC. Over 10,200 new cases are diagnosed every year – 5,700 with CD and 4,500 with UC. The prevalence of IBD currently in Canada is nearly 0.7%, equating to more than 1 in every 150 Canadians. It is estimated that economic burden attributed to IBD is \$2.8 billion per year in Canada [2]. There are 5,900 children living with IBD in Canada, and approximately 10-15% of newly diagnosed IBD patients are children or adolescents. Prevalence of pediatric-onset IBD has increased by 50% in Ontario since 1994, and incidence has increased most rapidly in children under 10 years of age [3]. Between 1994 and 2009, standardized increase has changed from 9.4 (95% CI 8.2-10.8) to 13.1 (95% CI 11.8-14.6) per 100,000 children [4].

There have been substantial changes in health services provision to pediatric IBD patients. A greater proportion of the care of children with IBD is now under the purview of pediatric gastroenterologists, which has been associated with the increase in pediatric gastroenterologist supply in Ontario over the past 20 years [5]. Transition is defined as the whole process including medical, psychosocial, and educational preparation, and physical transition from a pediatric to an adult provider. It is a multi-faceted active approach to address the needs of adolescents as they move from child-oriented to adult-oriented care [58]. Transfer period is only part of the whole transition process (Glossary). It has been

suggested that children with chronic diseases have difficulty with the transition from pediatric to adult care, with the transfer being associated with adverse outcomes [6,7]. This issue is not just in IBD patients but also in other chronic diseases. Identification of the extent of this issue will be beneficial to disease management over the patients' lifetime.

In recent years, ideas on how to smoothen the transition from pediatric to adult care environment have gained attention [8-17]. The risks of the transition period have been documented in children with chronic diseases such as diabetes mellitus and end stage renal diseases with findings such as increased specific disease-related hospitalization and emergency department visits [6,7,18]. The importance and the difference in physical and psychological needs of children and adults with IBD have been acknowledged [9,13,14]. Many pediatric centres now have checklists to ensure acquisition of milestones as adolescents with IBD transition to adulthood. The American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Ontario Provincial Council for Maternal and Child Health, and National Association for Colitis and Crohn's Disease in Childhood Research Association also provide recommendations for this critical period [19,20,21,22]. The transition recommendations from the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) include promotion of patients' self-reliance, education of family members, identification of adult gastroenterologists who understand the special needs of the IBD patients being diagnosed in childhood, and flexible transition time due to special needs such as pregnancy or neurologic delay [23].

Existing transition programmes for pediatric-onset patients with chronic illness in Canada were compared and evaluated based on the Canadian Pediatric Society and the Society of Adolescent Health and Medicine's recommendations. "Given the commonalities which exist between adolescents in

transition with chronic illness and developmental disabilities, clinical and research collaboration between these two should be a future consideration.” [24] Goodhand et al and Sebastian et al both reviewed structured transition care for IBD patients. Sebastian et al found “transition care is associated with better disease-specific and developmental outcomes” based on 52 patients [25, 26].

Although the transition from pediatric to adult health care for patients with chronic diseases has been recognized as problematic and the effectiveness of different transition models has been studied, the implication of the transition process on the health system has not been well evaluated. Samuel et al. found that the period of adaptation to adult specialists is associated with a higher risk of graft failure in pediatric renal transplant patients [7]. In a retrospective cohort study, Nakhla et al. found that there is an increased risk of diabetes mellitus-related hospitalizations following transition of pediatric diabetics to adult care [6].

Better understanding of the unique needs and challenge of transition for pediatric IBD patients may help minimize the risk of adverse events following it [27, 28]. Both qualitative and quantitative analysis on transition from pediatrician to adult specialist is needed to gain a comprehensive understanding of the issue. There have been multiple qualitative studies focusing on variety of aspects relating to transition such as: perceptions and experience of patients, physicians especially adult gastroenterologists, and parents, and comparisons among them; patients’ pre-transfer behavior, knowledge, and readiness; quality of life, transition care including nutrition and psychosocial development; and social workers’ role in transition process [29-52]. Unfortunately, there is a lack of quantitative and health services research on this subject for adolescents with IBD. Bollegala et al. assessed the health resources utilization the year before and the year after the transition, including emergency department (ED) visits,

hospitalizations, and clinic visits. For the small sample of 96 subjects in the study, fewer clinic visits during the year after transition were observed with statistical significance [53]. More studies with larger sample size are needed to assess negative event rates following transition to adult care, differences in health care utilization during transition, and factors associated with the difference.

This study explored the impact of the transition from pediatric to adult care by determining health services utilization patterns before and after, using a patient as his/her own control. In so doing, we aimed to assess the burden placed on the health system, and the risk of undesirable health service outcomes after transfer period from pediatric to adult health care. The objective of this study is to assess difference in health services utilization before and after the transfer from pediatric to adult care, specifically IBD-related and IBD-specific hospitalization, emergency department visits, outpatient visits, and laboratory utilization. The *a priori* hypothesis was that during the risk period after the transfer, the number of outpatient visits would decrease, but hospitalization and emergency department visits would increase. Transition from pediatric care to adult care usually happens at the time when patients may move away from home, resulting in increased independence for their disease management. Regular IBD related outpatient visits would help to better manage the disease. However, after the transfer, I hypothesized that patients may not schedule the visits due to a busy schedule or forgetfulness, which may lead to worsened conditions and subsequent higher emergency department utilization and hospitalization.

## CHAPTER 2: METHODS

### Study Design

This was a population-based retrospective cohort study of patients with pediatric-onset IBD. It used a self-controlled case series (SCCS) approach to assess the changes of healthcare utilization pattern of IBD patients transferred from pediatric to adult gastroenterologists. The control period started with the date of diagnosis of IBD until the first visit to an adult gastroenterologist. The transfer period was defined as the period between the first adult gastroenterologist visit and the last pediatric gastroenterologist visit. If the patients did not go back to pediatric gastroenterologists after their first adult gastroenterologist visit, their transfer period length was assigned as 1 day. The washout period started from the first adult gastroenterologist visit and ended 180 days or 6 months later. A washout period was necessary to exclude any events that occurred early in the transfer from pediatric to adult care. These events were likely secondary to the success/failure of treatment in the pediatric care period rather than due to the transfer process. If the transfer period for a patient was longer than the washout period, the risk period started from the last day of the transfer period. However, if the transfer period was shorter or equal to washout period, the risk period was defined to start from the end date of the washout period (Figure 1,2,3).

Figure 1 Transfer Timeline (Transfer Period  $\leq$  6 months or 180 days)

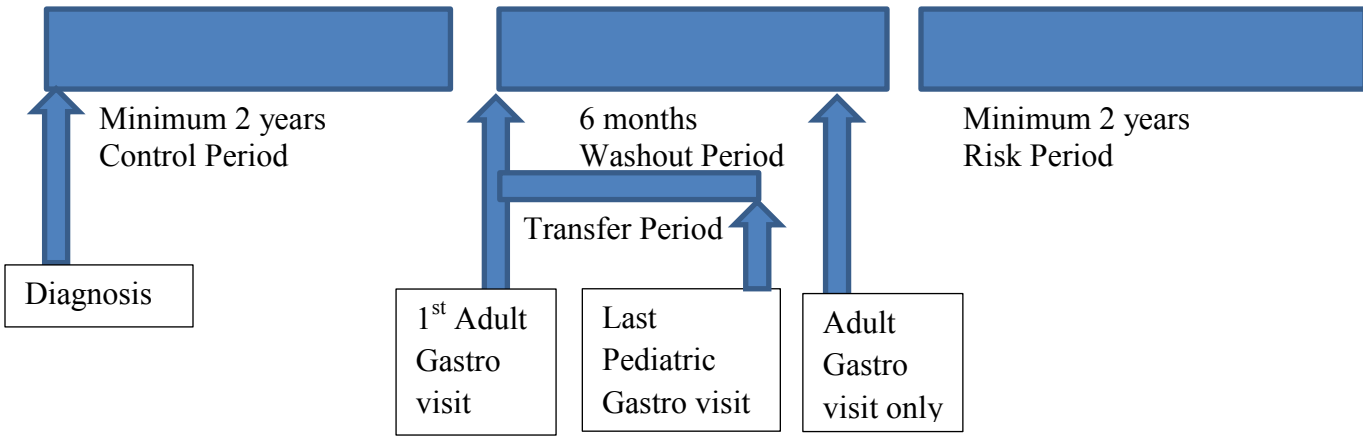


Figure 2 Transfer Timeline (Transfer Period - 1 day)

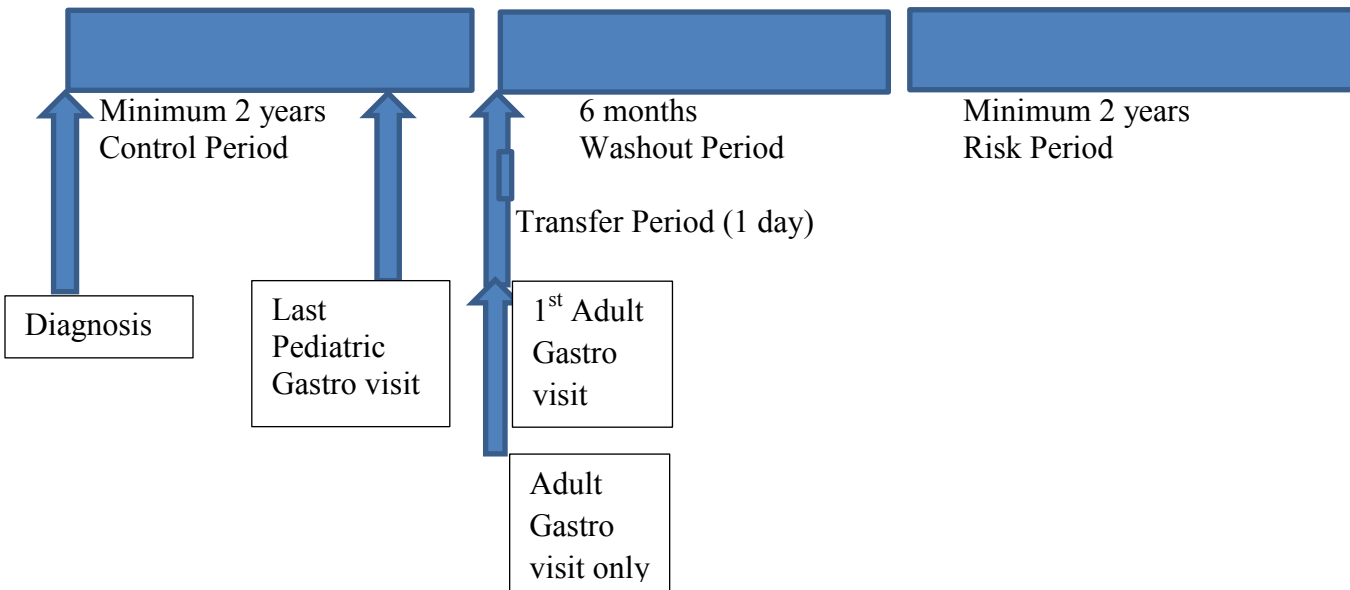
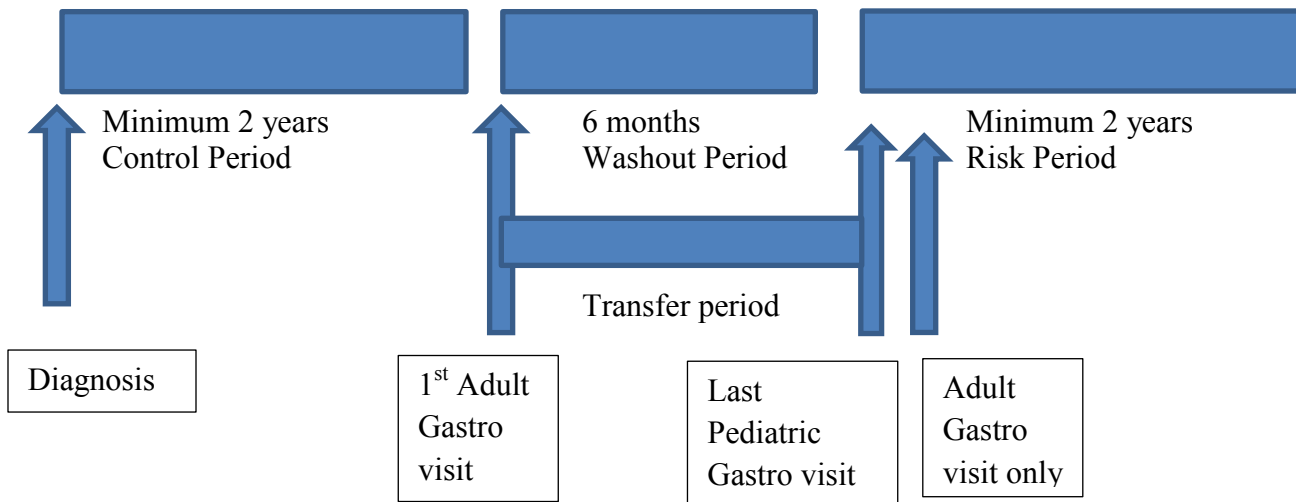


Figure 3 Transfer Timeline (Transfer Period > 180 days)



## Participants

The cohort consisted of all patients with initial diagnosed age under 18 years old who were diagnosed with IBD between April 1, 1994 to March 31, 2009, with maximum follow-up date up to March 31, 2012 in Ontario. The total number of patients diagnosed between April 1, 1994 and March 31, 2009 was 4,380 (Supplementary figure 1).

In this study, customized definitions of adult and pediatric gastroenterologists were used to define transfer periods (Glossary). In order to classify visits to specialist physicians, we used the ICES Physician Database (IPDB), which records certification status of all physicians in Ontario [54]. We defined pediatric and adult gastroenterologist based on four main specialty types of medical doctors reported in IPDB. The four types are gastroenterology, internal medicine, general pediatrics, and pediatric gastroenterology (Supplementary table 1, supplementary figure 1). Not all physicians functioning as gastroenterologists are certified as such, as their licensure may have preceded speciality certification examinations. Therefore, internists who performed >100 sigmoidoscopies or colonoscopies

per year, and pediatricians who performed >5 sigmoidoscopies or colonoscopies per year were considered gastroenterologists. Colonoscopies were identified by using OHIP fee code Z555, Z496A, Z497A, Z498A, and Z499A. Sigmoidoscopies were identified using fee code Z580 in OHIP.

Patients qualified for this study had to have at least two adult and pediatric gastroenterologist visits each. In this study, patients need to have sufficient long period of control and risk period which defined as at least 730 days or 2 years and reasonable length of transfer period (less or equal to 365 days or 1 year). Patients were excluded if their transfer period was longer than 365 days. This exclusion criterion aimed to exclude patients experiencing no transfer but simply visiting both adult and pediatric gastroenterologists at the same clinic setting. They also need to have clear diagnosis as either CD or UC (Glossary, supplementary figure 2).

## Data sources

Pediatric-onset IBD patients qualified for this study was identified from the Ontario Crohn's and Colitis Cohort (OCCC). OCCC is a population-based cohort of all children diagnosed with IBD in Ontario, Canada, derived from Ontario health administrative database with information on date of initial IBD diagnosis, age, date of last contact (if applicable), and quarterly eligibility under the Ontario Health Insurance Plan. Validated algorithms were used to identify all children in Ontario diagnosed with IBD under age 18 since April 1, 1994 [3]. Diagnosis of IBD type (CD, UC, or IBD type unclassified) was also based on a validated algorithm [3]. The chosen algorithm was a two-step procedure with 3 years look back period to distinguish incident from prevalent cases. The algorithm chosen depended on whether the child underwent sigmoidoscopy or colonoscopy. If the patients underwent colonoscopy, the

classification of IBD required at least four outpatient physician contacts or two hospitalizations associated with codes for IBD within 3 years. If the patients did not undergo colonoscopy, classification as IBD required more stringent criteria of at least seven physician contacts and three hospitalizations. IBD codes were derived from the International Classification of Disease, Ninth Revision (ICD-9) for data before 2002 (555.x or 556.x) and International Classification of Diseases, Tenth Revision (ICD-10) after 2002 (K50.x or K51.x) (Supplementary table 3). IBD type was assigned based on the last 7 visit diagnosis codes available for each patient. If a patient had 5 of the last 7 visits assigned a CD diagnosis, they were classified as having CD. If 5 of their last 7 visits were assigned a UC diagnosis, they were classified as having UC. Otherwise they were assigned a classification of “IBD type unclassified”. Validation revealed algorithm sensitivity 89.6% (95% CI 84.0%-93.5%), specificity >99.9% (95% CI 99.9%-100%), PPV 59.2% (95% CI 53.1%-65.0%), and NPV >99.9% (95% CI 99.9%-100%). For patients younger than 12 years old, it had a higher PPV of 76.0% (95% CI 68.9%-82.0%) [3]. The OCCC also contains a unique patient identification number which allows individual deterministic linkage to all other health administrative data and population data housed at the Institute for Clinical Evaluative Sciences (ICES).

Healthcare utilization studied in this thesis project included IBD-related and IBD-specific outpatient visits, emergency department visit, hospitalization, and laboratory investigations, and IBD-related surgery for both Crohn’s Disease (CD) and Ulcerative Colitis (UC). The Registered Persons Database (RPDB) provided date of birth, date of death (where applicable), and mean neighbourhood income quintile on the date of diagnosis. Information of the specialty of health care provider for each visit came from ICES Physician Database (IPDB) and Ontario Health Insurance Plan database (OHIP). OHIP also provided information of outpatient physician visits for IBD related care, laboratory claims,

colonoscopy/sigmoidoscopy procedures, and emergency department visits. The Canadian Institute for Health Information (CIHI) Discharge Abstract Database (DAD) provided hospitalization and surgery information.

## **Variables and Measurements**

The outcomes are IBD-related and IBD-specific number/likelihood of hospitalizations, emergency department visits, outpatient visits, and laboratory investigations. (See Supplemental table 3 for list of IBD-specific and IBD-related codes used in this study.) Death and potential loss to follow up were also investigated. Only hospitalizations longer than 24 hours in duration were included. The outcomes were measured by number per patient year. How transfer affected the likelihood of having IBD-related surgery for patients diagnosed with either CD or UC was analyzed as well. IBD-related surgery procedures were defined based on the list of codes for CD and UC in CIHI DAD Database (Supplemental table 4).

We defined an unsuccessful transition as those patients without a single IBD-related outpatient visit to an adult gastroenterologist during the first year of the risk period. Income quintile measures neighbourhood socioeconomic status ranging from low to high or 1 to 5, the larger the number, the higher the income. In each neighbourhood, each quintile has approximately 20% of the population. The income quintile in this study was calculated based on postal codes of the patients' residency at the time of the diagnosis. The assumption here is that the family's financial status would remain in the same quintile over time.

## Self-Controlled Case Series (SCCS) Analysis

The SCCS design was first developed to investigate the potential association between vaccines and adverse events. Only cases were used in this method, with each case serving as his/her own control. The observation time for each case was divided into control and risk periods. There can be more than one control and risk period. The major advantage of using this method is that it provides complete control for time-invariant individual characteristics that are potential confounders. In this study, each IBD case serves as his/her own control with observation time divided into control (before transfer) and risk (after transfer) periods [55].

The SCCS methodology requires the independence of the event occurrence from the probability of exposure. Furthermore, events cannot happen at the same time for all patients. Both requirements were met in this study. Whether a patient transferred to adult specialist was not affected by his/her health service utilization such as emergency department visits. The outcomes such as hospitalization or outpatient visits would rarely happen at the same age for all the patients. One drawback of this method is that only estimates of relative incidence can be produced. However, this study focused on change in health services utilization over time, so relative incidence would be appropriate measure [55]. For potential confounding factors that varied over time, such as age, they can be explicitly modelled.

Previous studies demonstrated that children with IBD from lower socio-economic status were more likely to be hospitalized and require surgery [56]. Using SCCS to study the impact on health services utilization of transfer for pediatric-onset IBD patients, we can remove factors that vary among different patients but are fixed over time for the same patients. So the impact of major confounding factors such

as disease severity, sex, socio-economic status, and clinical phenotype would be controlled. This is especially helpful in pediatric IBD study because of the small study population. Even with a large population, controlling the potential confounders could be difficult. Misclassification could be a source of bias with administrative data research. According to Glazier et al study, socioeconomic misclassification did exist in Ontario's health registry [57]. With the SCCS method, even if there is an issue with misclassification, it would not affect the results as it was within-patient comparison. In summary, the SCCS methodology is particularly beneficial for studies with small study population and unmeasured confounding factors. SCCS has not previously been applied to study the transition from pediatric to adult health care in a chronic disease. In this study, we decided to use this method.

## **Statistical Analysis**

For descriptive statistics, we calculated medians with interquartile range (IQR) or means with standard deviation (SD) where appropriate. We also described means with (SD) for health services used before and after transfer: hospitalization, emergency department visits, outpatient visits, and laboratory investigations. We compared the number of patients having any of the above events in the pre- and post-transfer period. For surgical outcomes, we used only binary variables (yes/no) instead of number/count. Surgical events were not analyzed by SCCS due to rarity of the outcome.

Using SCCS, we assessed whether the rate of IBD-related hospitalization, laboratory investigations, emergency department, and outpatient visits changed in the post-transfer period compared to the pre-transfer period, reporting the results as relative incidence (RI) with 95% confidence interval (CI) in the post-transfer risk period, with the pre-transfer control period as the reference. Sensitivity analysis was

performed to assess the risk of events in a 1-year risk period (instead of 2-year risk period for the main analysis), compared to the 1-year control period. The transfer starting age for the qualified patients in this study ranged from 14 to 25. With such a wide range, there might be potential underlying risk associated with different ages the patients started transfer. In crude model, we only compared the events happened during risk period to control period without adjustment of different transfer starting age. For adjusted to main effect model, we set up 3 transfer starting age categories – under 18 (<18), under 19 but at least 18 (18-19), 19 and older ( $\geq 19$ ).

SAS macros developed by Bart Spiessens were used to fit a Poisson regression model. (<http://statistics.open.ac.uk/scs/sas.htm>) The statistical significance of the findings was determined by 95% Confidence Interval, with significance assigned at  $P < 0.05$ . All analyses were stratified by IBD type (CD, UC). All analyses were conducted using SAS v9.1.3 (SAS Institute, Cary, NC).

## CHAPTER 3: RESULTS

The OCCC contained 4314 children <18yr diagnosed with IBD in Ontario from fiscal years (FY) April 1, 1994 to March 31, 2009. Of these, 1969 children had at least one visit to both pediatric and adult gastroenterologists and 1,357 patients had at least 2 visits to both adult and pediatric gastroenterologists (Supplementary figure 2, supplementary table 2). There were 66 patients excluded from the study due to incomplete follow up (see Glossary). In total, 536 patients qualified for inclusion in the study cohort.

The descriptive characteristics of the cohort (Table 1) were consistent with other studies' description of populations with pediatric-onset IBD. Of 536 children included in this study, 388 (72.4%) had CD and 148 (27.6%) had UC. 59% of the patients in this cohort were boys. More patients came from families with higher socioeconomic status. Sixty-one out of 536 or 11.4% patients included in the study cohort had unsuccessful transition, defined as a lack of adult gastroenterologist visit in the first year following transfer (Glossary). 88.6% were diagnosed between the ages of 11 and 16 years. 58.8% started transfer at the age of 18. 86% of patients were past their 18<sup>th</sup> birthday when the risk period started. Median age at the start of risk period was 18.6 years old with IQR 0.8. Most of the patients had a transfer period of only one day in duration (473 of 536 (88%)) and only 8 patients (1.5%) had a transfer period that was longer than washout period (180 days). All patients who died (<6) did so after 2 year risk period.

Table 1 Characteristics of Ontario Crohn's and Colitis cohort study population for pediatric-onset IBD

patients diagnosed between April 1, 1994 to March 31, 2009 in Ontario (n=536)

CHARACTERISTIC		n	%	Median	IQR
Latest Diagnosis	CD	388	72.4%		
	UC	148	27.6%		
Sex	Male	316	59.0%		
	Female	220	41.0%		
Income Quintile	1 (lowest)	59	11.0%		
	2	86	16.0%		
	3	100	18.7%		
	4	126	23.5%		
	5 (highest)	165	30.8%		
Age at Diagnosis (y)				13.6	2.9
Age at First Adult					
Gastroenterologist Visit (y)				18.1	0.8
Age at Start of Risk Period (y)				18.6	0.8

Abbreviations: CD: Crohn's disease; IQR: interquartile range; UC: ulcerative colitis; y: years.

Without using SCCS methodology, simple comparisons of total number of visits of all patients in the cohort before and after the transfer period showed that total number of hospitalizations decreased but total emergency department visits and laboratory investigations increased. Outpatient visits were relatively unchanged after the transfer (Table 2, 3). These results were different from the results using SCCS.

Table 2 Likelihood of an event among IBD patients in defined risk and control periods between fiscal years (FY) 1994 and 2011

	Period	Diagnosis			
		CD		UC	
		n	%	n	%
Hospitalization	Control	71	18%	15	10%
	Risk	48	12%	7	5%
Emergency Room (ED) Visit	Control	88	23%	22	15%
	Risk	117	30%	29	20%
Outpatient Visit	Control	372	96%	143	97%
	Risk	376	97%	140	95%
Laboratory Investigations	Control	271	70%	111	75%
	Risk	322	83%	123	83%
Surgery - CD	Control	32	8%		
	Risk	28	7%	n/a	
Surgery - UC	Control			<6	1%
	Risk	n/a		<6	2%

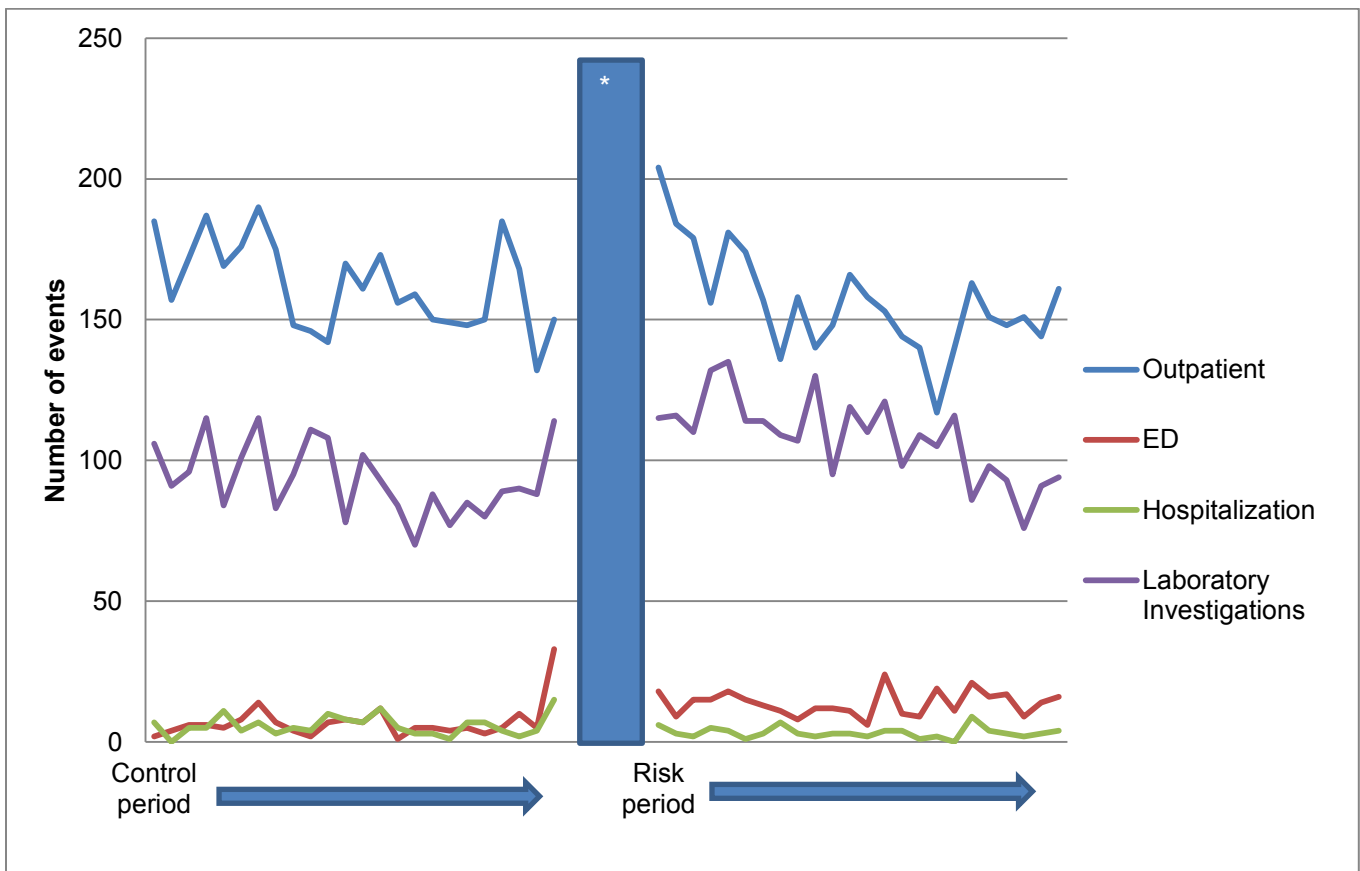
Table 3 Health services utilization (mean number per year with standard deviation (SD) among IBD patients in defined risk and control periods between fiscal years (FY) 1994 and 2011

Health Service	CD (n=388)				UC (n=148)			
	Control		Risk		Control		Risk	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Hospitalization	0.32	0.8	0.19	0.62	0.11	0.36	0.06	0.29
Emergency Department Visits	0.35	0.81	0.7	1.53	0.24	0.7	0.43	1.04
Outpatients Visits	8.19	7.2	7.68	6.11	5.27	4.7	5.62	4.9
Laboratory Investigations	4.34	6.18	5.01	5.25	3.94	6.26	4.59	5.66

We also divided the 2-year control and 2-year risk periods into 30 day intervals and calculated the total

numbers of each of the four health services events occurring during each interval. This exercise was to analyze whether the health service utilization would be different during time periods closer to the transfer period than the ones occurred at times farther away from the transfer period. The frequencies reported in Figure 4 showed that at the beginning of the risk period, both outpatient visits and laboratory investigations were higher than before the transfer period. Subsequently, they gradually decreased during the remaining risk period. Emergency department visits and hospitalizations did not have the same pattern. There was a spike of emergency department visits immediately before starting of the transfer period.

Figure 4 Number of IBD related events during control and risk periods (30 day interval)



Abbreviations: ED: emergency department; \*: Washout period / Transfer period

Health services event rates in risk compared to control periods are demonstrated in Table 4. The crude model only included the health services utilization outcomes. The adjusted model included the age at the beginning of the transfer period. Based on the adjusted model, ED utilization rate was higher in the risk period for both CD (RI 2.12, 95% CI 1.53-2.93) and UC (RI 2.34, 95% CI 1.09-5.03). However, there was no significant increase in hospitalization rate (CD: RI 0.70, 95% CI 0.42-1.18; UC: RI 2.41, 95% CI 0.62-9.40). Outpatient visits occurred more frequently in the risk period (CD: RI 1.56, 95% CI 1.42-1.72; UC: RI 1.48, 95% CI 1.24-1.76), as did laboratory investigations (CD: RI 1.43, 95% CI 1.26-1.63; UC: 1.38, 95% CI 1.13-1.68). RIs for the risk period were larger in the adjusted model than the crude model. This indicated that without considering underlying risk of different ages at which transfer began, the effects of the transfer were diluted. We also determined the health services utilization rates in the different transfer age groups. Using oldest transfer age group which was at least 19 years of age as reference group, younger age groups were associated with increased outpatient visits and laboratory investigations (Table 5).

Table 4 Relative incidence (RI) of health services utilization in defined risk and control periods among IBD patients between fiscal years (FY) 1994 and 2011

	Model	CD				UC			
		RI	95% CI	P value	RI	95% CI	P value		
Hospitalization	Crude	0.59	0.44	0.79	0.0004	0.56	0.26	1.20	0.1361
	Adjusted	0.70	0.42	1.18	0.178	2.41	0.62	9.40	0.2043
Emergency Department Visits	Crude	2.06	1.68	2.53	< .0001	1.75	1.16	2.64	0.0074
	Adjusted	2.12	1.53	2.93	< .0001	2.34	1.09	5.03	0.0291
Outpatients Visits	Crude	0.94	0.90	0.99	0.022	1.07	0.97	1.18	0.1712
	Adjusted	1.56	1.42	1.72	< .0001	1.48	1.24	1.76	< .0001
Laboratory Investigations	Crude	1.13	1.06	1.21	0.0002	1.14	1.02	1.27	0.018
	Adjusted	1.43	1.26	1.63	< .0001	1.38	1.13	1.68	0.0016

Table 5 Association between the relative incidence (RI) of health services utilization rates in defined risk periods and control periods stratified by transfer age categories

	Transfer Age Categories	CD				UC			
		RI	95% CI	P value	RI	95% CI	P value		
Hospitalization	1	1.18	0.65	2.14	0.5901	6.30	1.35	29.41	0.0192
	2	0.56	0.33	0.94	0.0297	0.98	0.24	3.97	0.9804
	3	REF			.	REF			.
Emergency Department (ED) Visits	1	1.04	0.71	1.54	0.8323	1.40	0.59	3.32	0.4441
	2	0.98	0.74	1.30	0.9107	0.64	0.33	1.24	0.1821
	3	REF			.	REF			.
Outpatients Visits	1	1.91	1.71	2.13	< .0001	1.56	1.27	1.92	< .0001
	2	1.15	1.06	1.25	0.0005	1.18	1.01	1.37	0.0322
	3	REF			.	REF			.
Laboratory Investigations	1	1.39	1.20	1.61	< .0001	1.27	1.01	1.59	0.0449
	2	1.22	1.10	1.35	0.0001	0.77	0.64	0.92	0.0044
	3	REF			.	REF			.

Age Categories: 1 - Younger than 18 years old;  
 2 - At least 18 years old but younger than 19 years old;  
 3 - At least 19 years old.

The sensitivity analysis consisted of assessing health services rates in one year risk and control period (instead of two years). This analysis revealed results that were consistent with the main analyses. The results were quite similar for CD patients for all five outcomes (hospitalization: RI 0.61, 95% CI 0.34-1.11; ED: RI 2.02, 95% CI 1.38-2.96; outpatients visit rates: RI 1.53, 95% CI 1.37-1.72; laboratory investigations: RI 1.40, 95% CI 1.21-1.62). However, for UC patients, only outpatient visits and laboratory visit rates were increased in the one-year risk period compared to control period (outpatient visits: RI 1.50, 95% CI 1.21-1.86; laboratory investigations: RI 1.43; 95% CI 1.13-1.81) (Table 6).

Table 6 Sensitivity analyses: Relative incidence (RI) of health services utilization using a one year risk period, compared to a one year control period.

	Model	CD				UC			
		RI	95% CI		P value	RI	95% CI		P value
Hospitalization	Crude	0.64	0.43	0.96	0.0291	0.33	0.09	1.23	0.0994
	Adjusted	0.61	0.34	1.11	0.1072	1.03	0.19	5.68	0.9686
ED Visits	Crude	1.75	1.32	2.32	< .0001	1.47	0.82	2.64	0.1920
	Adjusted	2.02	1.38	2.96	0.0003	1.70	0.67	4.31	0.2611
Outpatients Visits	Crude	1.03	0.96	1.11	0.3433	1.12	0.97	1.28	0.1204
	Adjusted	1.53	1.37	1.72	< .0001	1.50	1.21	1.86	0.0002
Laboratory Investigations	Crude	1.31	1.19	1.43	< .0001	1.33	1.14	1.55	0.0004
	Adjusted	1.40	1.21	1.62	< .0001	1.43	1.13	1.81	0.0027

## CHAPTER 4: DISCUSSION

### Key results

Using SCCS analysis and a population-based cohort of patients with pediatric-onset IBD, we demonstrated increased rates of outpatient visits, laboratory investigations, and emergency department visits in the years following transfer from pediatric to adult gastroenterology care. The majority started transfer around their 18th birthday, and transfer to adult gastroenterologist care without shared care being provided with pediatric gastroenterologists. This study demonstrated similar health services utilization changes after transfer of CD and UC patients for outpatient, hospitalization, emergency department, and laboratory investigation rates. The age at initiation of transfer was associated with health utilization, especially outpatient visits and laboratory investigations. Patients who were younger at the time of transfer initiation had greater increase in rates of health services utilization after transfer. This relationship was generally present for both CD and UC patients.

### Interpretation

Transfer affected the health services utilization of our patients in terms of post-transfer increases in emergency department utilization, outpatient visits, and laboratory services utilization. No significant change in hospitalization rate was noted. Emergency department visits were more than doubled after the transfer for both CD and UC patients. This increase indicates that either the patients' disease was worsened after the transfer, or having difficulty in accessing adult specialists urgently. Hospitalization was more likely an event associated with worse disease severity, and not likely an outcome subject to patients' distress or reduced access to care after transfer. The finding that there was no statistically significant change in hospitalization rates after transfer may indicate that the patients' disease severity did not worsen.

Outpatient visits were increased as well. This was a surprise as the *a priori* hypothesis was that we expected to observe fewer outpatient visits after the transfer. Our findings may be due to the different style of practice of adult specialists. Patients may feel comfortable while treated by pediatricians and felt their needs were not sufficiently addressed during the more rapid visit with an adult specialist, resulting in booking another visit for the same issue. The increased number of laboratory investigations following transfer may be due to current issues related to limitations of access of the adult gastroenterologists to previously-performed laboratory test results, and a desire to repeat these tests. It is plausible that an accepting physician, in this case the adult gastroenterologist, would order tests to have baseline measures for a new patient in order to adequately assess the extent and severity of disease activity.

The finding that changes to health services utilization were dependent on the transfer age is important. We found that patients who were younger at the beginning of the transfer period had a greater increase in health services utilization. Younger patients may have required more support following transfer, and therefore were seen more frequently by their adult gastroenterologists. However, we cannot exclude that younger patients had more severe disease, thus require them to have higher usage of outpatient facilities and more laboratory investigations. This study might shed light on how to better manage the service to adult IBD patients and how to better prepare the pediatric-onset IBD patients, especially younger patients, after the transfer period.

Future studies could determine whether there are other patient or health systems factors that may have resulted in the observed differences in health services utilization in the risk and control periods. A case control study would help to identify temporal confounding factors such as patient or physician

behaviour. Comparing with the health service utilization changes of other pediatric-onset chronic diseases such as diabetes with IBD could help to better understand the transition impact as well as any uniqueness of transition of IBD patients. Several qualitative studies were conducted to study the readiness, perceptions and behaviour of patients [29,33,36,43]. Conducting surveys of patients and physicians about perceived causes of higher post- transfer health services utilizations found in this study, and evaluating the quality of the health system would be beneficial. In addition, a survey focusing on the causes for patients' emergency department visits could shed light on the reason behind the dramatic increase of these visits after the transfer. Pediatric IBD specialists usually work in multidisciplinary teams, including doctors, nurses, and other allied health professionals. Adult specialists, especially in the community setting, typically use administrative assistants to answer calls, and do not work as closely in large multidisciplinary teams. These differences could be a factor affecting rates of emergency health services utilization. If inadequate after-hours or urgent access to the specialist is perceived, the patients may attend the emergency department more frequently. Future research comparing utilization patterns amongst patients attending different types of clinics (such as IBD subspecialty teams or community private practice physician without nursing support) would help to evaluate whether having nurses answering urgent phone calls from patients would reduce the health services utilization.

## **Limitations**

### **SCCS methodology**

In this study, we used the SCCS method to eliminate certain potential confounding factors such as family socioeconomic background, severity of the disease and onset age. However, only patients with long enough longitudinal follow-up (2 years of risk, and 2 years of control periods) were included in this study. Nearly three quarters of patients in the overall Ontario Crohn's and Colitis Cohort did not qualify

for this study as they did not visit both adult and pediatric gastroenterologists. The final cohort therefore included 536 children with incident IBD.

The SCCS method relies on several key assumptions. The first important assumption is that the events being analyzed cannot affect subsequent exposures. For our study, if patients were experiencing disease flare-ups, they were less likely to be transferred to an adult gastroenterologist from pediatricians. Pediatricians may wait until the disease is in remission before transferring the patient. Therefore, the patients might be healthier during the control period before the transfer. We assessed this possibility by graphing health services utilization over time (Figure 4). At the end of the control period, total outpatient visits was decreasing, whereas emergency department visits, hospitalization, and laboratory investigations were increasing. During the risk period, total numbers of outpatient visit and laboratory investigations were higher at the beginning but gradually reduced over the 2 years' risk period. Emergency department visits and hospital admission numbers remained relatively stable over the same period. These observations reflected the total numbers of events happened to all the patients in the study cohort, not at individual level. It is noteworthy that a decrease in health services utilization (such as that observed for outpatient visits) in the final period before the transfer may have contributed to the relative increased incidence ratio seen after the transfer and washout. For example, if patients were at their healthiest immediately prior to transfer, they would appear to have more health services utilization in the risk period simply by returning to their baseline status. In immunization research, this is termed the healthy vaccine effect, and could play a role in the transfer process [61]. However, increased emergency department utilization and laboratory investigations in the period immediately prior to the transfer may have resulted in the opposite effect, a blunting of the relative incidence after transfer. Therefore, I

believe that my observation regarding increased emergency department visits after transfer is likely a true event, and not due to a healthier patient at transfer.

The other assumption of SCCS analyses is that each health service event was independent. If the first outpatient visit led to the following one, this assumption would be violated. This could be the case in this study and may have resulted in overestimation of the increased rates of health services utilization, especially outpatient visits after transfer. Adult specialists would treat patients in different styles than pediatricians. Patients being transferred to adult specialists may feel the need to schedule multiple outpatient visits instead of only one for the same symptom after the transfer. This would increase the number of events happened after the transfer. For future studies, events occurring within short period of time could be grouped into one to reduce the possibility of having events dependence.

The SCCS method controls for potential confounding factors that are fixed over time. However, any confounders or patient characteristics that may change over time in association with transfer would not be controlled for in this analysis. For example, different remuneration methods for adult gastroenterologists and pediatricians may have affected our results. If patients moved out of parents' home for school or work, they would have increased responsibility for managing their disease instead of relying on their parents. This change may affect the patients' behaviour. In addition, while unlikely, disease activity and risk of complications may progress over time. This was unlikely in such a short period of risk compared to control, however we could not measure disease activity, severity, or risk of complications using health administrative data. We investigated the possibility of using a tracer diagnosis to see whether our increased utilization is truly due to IBD-related visits alone, or is present in other conditions. A tracer diagnosis is one that is unrelated to either IBD or progression from

adolescence to adulthood, but results in health services utilization in the teenager. Diseases of intestine, digestive, hepatic and biliary would be likely related to IBD, and therefore would not meet criteria as tracer diagnoses. Pediatric-onset chronic diseases such as asthma may be affected by the transition to adult care in a similar manner to IBD. Diagnoses associated with trauma or emergency department utilization may increase as teenagers gain independence and engage in risky behaviour. After discussion with my thesis committee, I could not find an adequate tracer diagnosis that was independent of both IBD and transitioning from adolescence to adulthood. Conducting a case-control study in which cases (those who experienced transfer from pediatric gastroenterologist to adult gastroenterologist) are compared to controls (those who were diagnosed by an adult gastroenterologist and remained treated by an adult gastroenterologist) may also overcome this risk of bias. However, in the absence of measures of disease severity in administrative data, a case-control study would introduce other sources of bias. Children who are diagnosed by an adult gastroenterologist and remain under the care of an adult gastroenterologist are different in many ways from those treated by a pediatric gastroenterologist: they may be older, less severe, live in a rural community, be of lower socioeconomic status, and have more difficulties accessing to health care. Therefore, we strongly feel that an SCCS method is the best way to examine issues of transition from pediatric to adult care using health administrative data.

### **Transfer starting age**

In the adjusted model, we included age group at transfer in the model based on the assumption that patients transferred at younger ages were different from those transferred at an older age. Our results demonstrated that younger age at transfer was associated with a higher relative incidence of outpatient visits and laboratory investigations. One possible explanation is that younger patients may still have been living with parents who scheduled their appointments, and helped them navigate the health system.

A qualitative study may further delineate why age was associated with such a difference in health services utilization.

### **Shadow billing**

Shadow billing might affect the number of pediatric outpatient visits before the transfer. In Ontario, pediatric gastroenterologists are salaried or on alternate funding plans, unlike adult gastroenterologists who are mostly paid on a fee-for-service basis. Therefore, it is possible that some pediatric gastroenterology outpatient billing would be missing from the health administrative data. However, this would not have altered our findings for hospitalizations or laboratory investigations. Previous studies have relied on physician billing data in children with IBD with adequate results [3,5,56]. In addition, awareness raised to salaried pediatricians by the Ontario Ministry of Health and Long-Term Care and the clinical departments of pediatric hospitals has resulted in far lower rates of visits without shadow billing submitted.

### **Clinic settings**

This study treated all types of clinics equally. While most adult gastroenterologists practice in private clinics, almost all pediatric gastroenterologists practice in academic centres. In addition, patients visiting different clinic settings may have different experiences. Patients might be more relaxed and willing to go to pediatric centres with family-centred care for regular visits or be more open to talk about their problems. Pediatricians might spend more time with patients than adult gastroenterologists. The pediatric centres were more likely to have specialized IBD nurses and a multidisciplinary team than a community gastroenterologist practices. This may have resulted in patients feeling their issues were not adequately addressed in one outpatient visit to an adult gastroenterologist, and made multiple

appointments. Further research on the role of different types of clinics would be helpful to determine if this could be a factor in the impact of transition on health service utilization.

### **Loss to follow up**

In our study cohort, the median ages at the beginning of the transfer and risk periods were 18.1 and 18.6 years, respectively. This is the age of many life changes for an adolescent. Some patients might move out of province for school or work. Ontario health administrative database does not contain visits made to physicians in other provinces, and therefore loss-to-follow-up may have resulted in a lack of visits to adult gastroenterologists after transfer. However, this likely represented a very small proportion of included patients, since most adolescents keep their health care provider in their home province. In addition, if patients registered for a health card in another province within the risk period, their Ontario health coverage would end, and they would not have been included in this study.

### **Customized definitions**

Customized definitions, such as service provider (pediatric vs adult gastroenterologist) and time periods (transfer, washout, control, and risk), were based on previous studies and the expertise of IBD specialists participating in this study. However, customized definitions may have resulted in misclassification bias. For this study, we defined adult and pediatric specialists based on four types of medical doctors. We attempted to properly define gastroenterologists, even if they were certified as pediatricians, internal medicine specialists within the ICES Physician Database, based on volume of endoscopic procedures performed. Generalists are highly unlikely to perform >5 endoscopies in children and >100 endoscopies in adults in a given year. In addition, we attempted to define physicians trained in adult gastroenterology, but who are practices primarily in pediatrics, as pediatric gastroenterologists based on

patient demographics and volume. While this method has been used previously [56], it has not been validated. In addition, the 2-year risk and control periods were defined by members of the thesis committee and expert clinicians based on face validity. We conducted a sensitivity analysis to assess whether shortened periods changed our results, and results were similar. However, if the specialty of physicians were misclassified, this may have resulted in improperly defined start dates for the risk, control, and transfer periods. Future research should validate specialty definitions in our IBD cohort.

In the analysis comparing the 2-year control and risk periods, patients with UC showed similar results as CD patients. However, in UC patients, the sensitivity analysis of 1 year risk/control periods resulted in alteration of RIs. This could be due to the relatively small number of patients with UC diagnosis, and imprecision of results. It would be beneficial to observe in larger studies whether there is an association between the types of IBD and different needs of health services utilization.

This study used population-based health administrative data, allowing the largest quantitative study on pediatric IBD patients to date. Still, only 536 patients qualified for the study. Larger studies, if possible, would help to further investigate whether there is any association between the type of IBD diagnosis and different health services utilization pattern changes.

### **Generalizability**

While this population-based study included only Ontario patients with pediatric-onset IBD, the characteristics of included patients demonstrated that sex distribution, age of onset, and socioeconomic status were consistent with other cohort studies of pediatric IBD patients. Nevertheless, replication of

this study in other Canadian provinces, and in other health systems (such as that of the United States) would be beneficial. More study with broader geographic area would be beneficial to see if other factors could be associated with the health services utilization changes after the transfer.

## **Conclusion**

Our study showed that there are significant changes in health services utilization after transfer from pediatric to adult care for pediatric-onset IBD patients. This finding was similar in both CD and UC patients. Patients had higher rates of emergency department visits, outpatient visits, and laboratory investigations. The biggest change after transfer was observed in emergency department utilization, where rates more than doubled after transfer. However, there were no significant changes in the risk of hospitalization after transfer. These findings are important in helping doctors, hospitals, and policy makers to better understand the needs of IBD patients transitioning from pediatric to adult care, and manage the limited health resources to better meet the needs of these patients.

## **OTHER INFORMATION**

The reporting of results in this thesis was based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines and the REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement [59,60].

### **Accessibility of protocol, raw data, and programming codes**

Glossary, supplementary tables and figures, and references were attached to this thesis. Privacy laws in Ontario, Canada (the Personal Health Information Privacy Act) allow only designated ICES scientists and staff to access raw data for this study and associated code. For enquires regarding access to the raw data, the ICES Privacy Officer should be contacted. Programming codes are available upon request.

### **Raw Data**

Raw data is held at ICES.

### **Protocol**

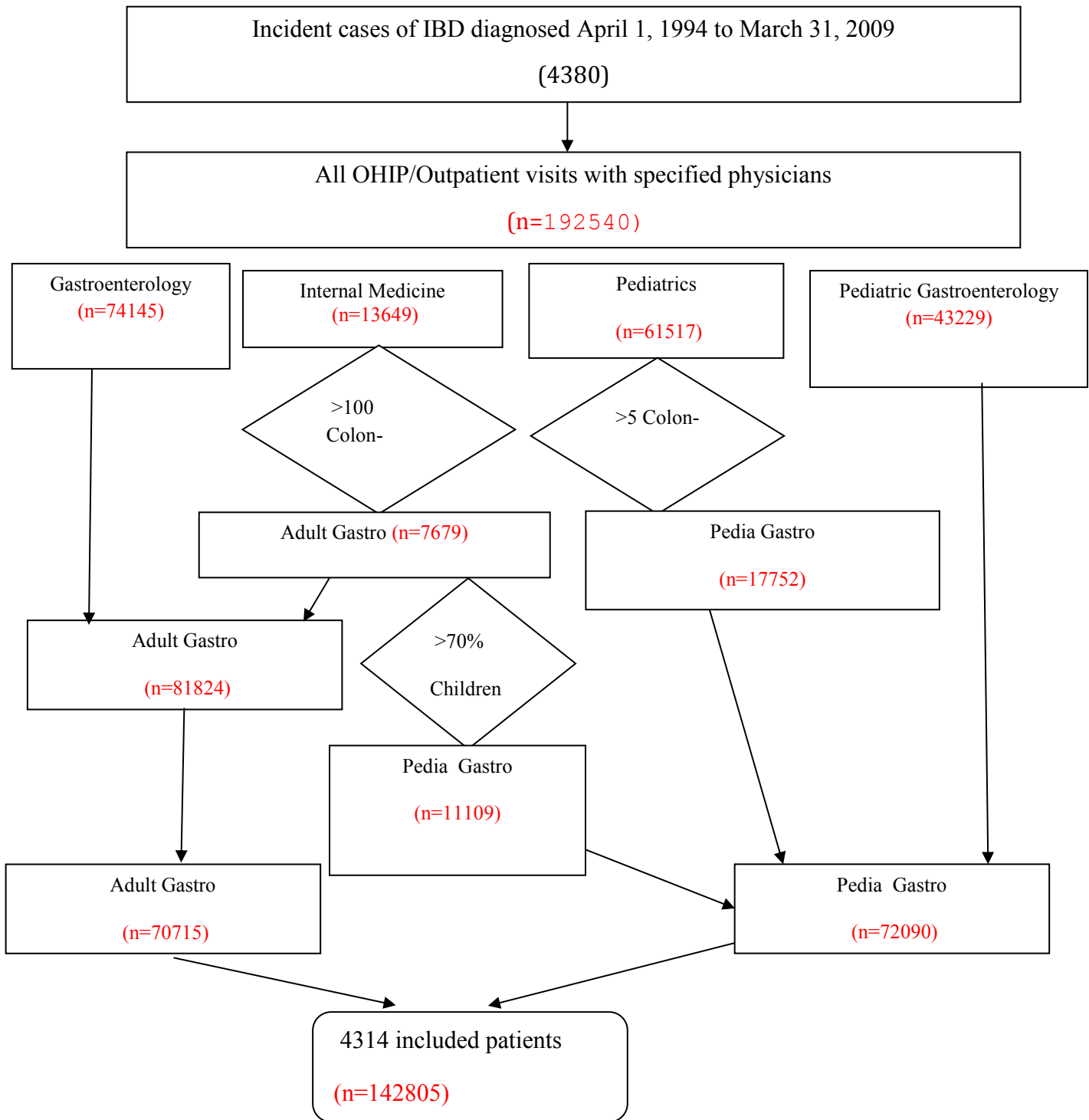
Provide upon request.

### **Programming Codes**

All the SAS codes.

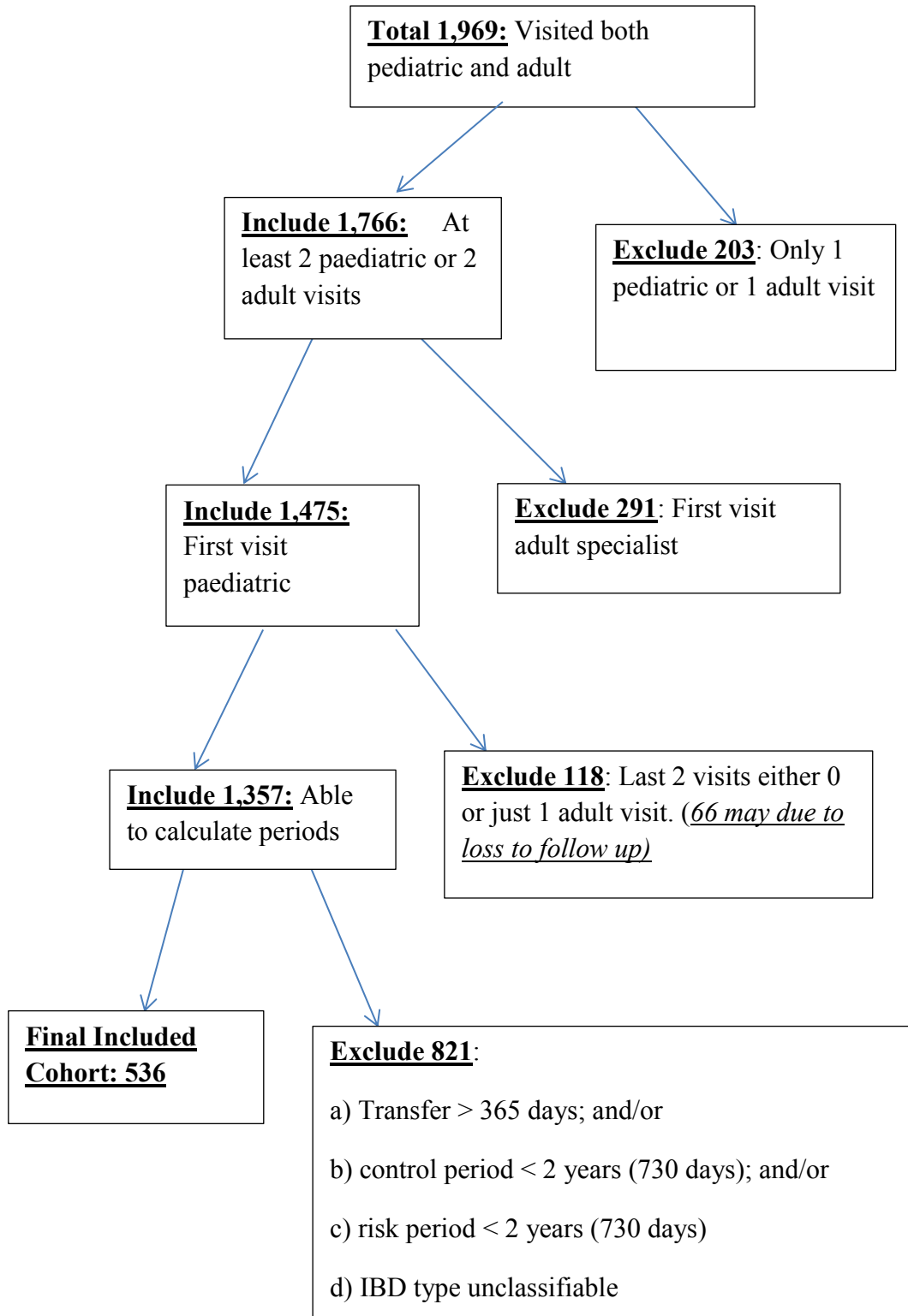
# ATTACHMENTS

Supplementary Figure 1 Definition of Physician Types (n represents number of visits)



- Colonoscopies were identified using fee code Z555, Z496A, Z497A, Z498A, and Z499A in OHIP
- Flexible sigmoidoscopies were identified using fee code Z580 in OHIP

Supplementary Figure 2 Inclusion and Exclusion Criteria for Patients Qualified for the Study



Supplementary Table 1 Definition of gastroenterologists based on main specialty reported in IPDB

Customized Definition	Main Specialty Reported in IPDB			
	Gastroenterology	Internal Medicine	Pediatrics	Pediatric Gastroenterology
Adult Gastroenterologist	<=30% Children patients (IBD).	>100 Colon/yr; >50% Adult patients (all); <=30% Children patients (IBD).		
Pediatric Gastroenterologist	>70% Children patients (IBD).	>100 Colon/yr; >50% Adult patients (all); >70% Children patients (IBD).	>5 Colon/yr	All

Supplementary Table 2 Inclusion and exclusion criteria for patients qualified for the study

	Inclusion (n)	Exclusion (n)	Exclusion Criteria
Original Cohort	4,314		
Visited Both Paediatric and Adult Gastroenterologist	1,969	2,345	No transfer between paediatric and adult gastroenterologist
At least 2 visits to both types of Gastroenterologist	1,357	612	No sufficient adult visit history (< 2 adult gastroenterologist visit after paediatric visit)
Final cohort	536	821	Less than 730 days' control and/or risk period and/or transfer period longer than 365 days and/or IBD type unclassifiable

Supplementary Table 3 Classification of IBD-related health services usage based on International Classification of Disease, Ninth Revision (ICD-9), International Classification of Disease, Tenth Revision (ICD-10), and OHIP diagnostic codes.

<b>CONDITION</b>	<b>ICD-9</b>	<b>OHIP diagnostic code</b>	<b>ICD-10</b>
<b>IBD-SPECIFIC:</b>			
Crohn's	555.x	555	K50.x
UC	556.x	556	K51.x
<b>IBD SIGNS/SYMPTOMS:</b>			
Anorexia	783.0	787	R63.0
Abnormal Weight Gain	783.1		R63.5
Abnormal Weight Loss	783.2		R63.4
Underweight	783.22		R62.8
Failure to thrive, child	783.41		R62.8 R62.9
Failure to thrive, adult	783.7		R62.8 R62.9
Symptoms involving digestive system, including: (787.0) Nausea and vomiting (787.01) Nausea w/vomiting (787.02) Nausea, alone (787.03) Vomiting, alone (787.1) Heartburn (787.2) Dysphagia	787.x	787	R11.x R12.x R13.x R14.x R15.x R19.x

(787.3) Gas/bloating (787.6) Encopresis, fecal incontinence (787.9) Other symptoms involving digestive system (787.91) Diarrhea, NOS			
Abdominal pain	789.0	787	R10.x
Dyspepsia	536.8	536	K30.x
Cachexia	799.4		R64.x
Oesophagitis	530.1	530	K20.x K22.1
GERD	530.81		K21.x
Gastric ulcer	531	531	K25.x
Duodenal ulcer	532	532	K26.x
Peptic ulcer	533		K27.x
GJ ulcer	534	534	K28.x
Gastritis/duodenitis	535.x	535	K29.x
Intestinal obstruction	560.8 560.9	560	K31.5 K56.6
Rectal/anal haemorrhage	569.3	569	K62.5
Other disorder of rectum/anus, including: (569.41) Ulcer (569.42) Pain (569.43) Sphincter tear (healed) (569.44) Dysplasia (569.45) Other specified, including proctitis,	569.4	569	K62.6 K62.8

inflammation			
Abscess of the intestine	569.5	569	K63.0
Other disorders of intestine, including: (569.81) Fistula (excl rectum) (569.82) Ulcer of intestine (569.83) Perforation (569.84) Angiodysplasia, no haemorrhage (569.85) Angiodysplasia, with haemorrhage (569.86) Dieulafoy (569.89) Other, including: - Enteroptosis - Granuloma of intestine - Prolapse of intestine - Pericolitis - Perisigmoiditis - Visceroptosis	569.8	569	K63.2 K63.3 K63.1 K55.2 K63.8
Malabsorption	262.x 263.0 263.1 263.2 263.8 263.9 579.8	579	E43.x E44.x E45.x E46.x K90.8 K90.9

	579.9		
<b>EXTRA-INTESTINAL MANIFESTATIONS:</b>			
Anal Fistula	565.1	565	K60.3
Anal Abscess		566	
Ureteral Fistula	593.82		N28.8
Urethral Fistula	599.1		N36.0
Fistula of stomach & duodenum	537.4		K31.6
Vesical fistula	596.2		N32.2
Fistula involving female GU	619.x		N82.x
Haemorrhoids, including: (455.9) Anal skin tags	455.x	455	I84.x
Rheumatoid arthritis	714.x	714	M06.99 M05.3 M08.x M09.x
Arthropathy associated with erythema nodosum	713.3		M14.8
Inflammatory spondylopathies, including: (720.0) Ankylosing spondylitis (720.1) Spinal enthesopathy (720.2) Sacroiliitis (720.8) Other inflammatory (720.9) Other unspecified inflammatory	720.x	720	M45.x M46.x M47.x M48.x
Scleritis & episcleritis	379.0	379	H15.x

Unspecified iridocyclitis (uveitis NOS)	364.3	364	H20.9
Chorioretinitis, unspecified (unveitis, posterior NOS)	363.2	363	H30.9
Acute and subacute iridocyclitis	364.0	364	H20.0
Erythema nodosum	695.2	695	L52.x
Acrodermatitis enteropathica	686.8		E83.2
Pyoderma	686.0	686	L08.0
Pyogenic granuloma of the skin and soft tissue	686.1	686	L98.0
Oral aphthae	528.2	528	K12.0
Short stature	783.43		E34.3
Osteoporosis	733.0	733	M80.x M81.x M82.x M83.x
Osteomyelitis	730.0 730.1 730.2	730	M86.x
Acute glomerulonephritis	580.x	580	N00.x N01.x N05.x
Nephrolithiasis	592.x	592	N20.x
Primary Sclerosing Cholangitis	576.1	576	K83.0
Venous embolism/thrombosis	453.x		I82.x

Supplementary Table 4 Canadian Institute for Health Information (CIHI) procedure codes IBD-related surgery procedure codes in CIHI Discharge Abstract Database (DAD)

<b>CIHI- PROCEDURE CODES- \$CIHI_PRCODE</b>	
<b>INPATIENT</b>	
<b>RESECTION AND COLECTOMY FOR CD</b>	<b>COLECTOMY FOR UC</b>
5741- multiple segmental resection of small intestine	
5742- Other partial resection of small intestine	
5743- Total removal of small intestine	
575- partial excision of large intestine	575- partial excision of large intestine
5751- multiple segmental resection of large intestine	5751- multiple segmental resection of large intestine
5754- resection of transverse colon	
5753-right hemicolectomy	5753-right hemicolectomy
5755-left hemicolectomy	5755-left hemicolectomy
576-total colectomy	576-total colectomy
5752- cecectomy	5752- cecectomy
5754- resection of transverse colon	5754- resection of transverse colon
5756- sigmoidectomy	5756- sigmoidectomy
5759- other partial excision of large intestine	5759- other partial excision of large intestine

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