ELLEN KUENZIG, PhD

Ellen Kuenzig is a Senior Research Associate at the SickKids IBD Centre at The Hospital for Sick Children and the Child Health Evaluative Sciences program at the SickKids Research Institute. Dr. Kuenzig is an epidemiologist and health services researcher. She is a member of Crohn's and Colitis Canada's Scientific and Medical Advisory Council and the Scientific Committee of the Canadian Gastro-Intestinal Epidemiology Consortium (CanGIEC), which conducts epidemiology, pharmacoepidemiology, outcomes, and health services research using the health administrative data from multiple provinces.

Affiliations: SickKids Inflammatory Bowel Disease Centre, Division of Gastroenterology, Hepatology and Nutrition, The Hospital for Sick Children (SickKids), Toronto, Ontario, Canada
Child Health Evaluative Sciences, SickKids Research Institute, The Hospital for Sick Children, Toronto, Ontario, Canada

GILAAD KAPLAN, MD, MPH, FRCPC, CAGF, AGAF, FCAHS

Dr. Kaplan is a Professor in the Cumming School of Medicine at the University of Calgary. Dr. Kaplan is a gastroenterologist who is internationally renowned for studying the global epidemiology of inflammatory bowel disease (IBD). He is an Associate Editor of Gastroenterology. In 2019, Dr. Kaplan was elected to the International Organization of the study of IBD (IOIBD). Clarivate, Web of Science named Dr. Kaplan a Highly Cited Researcher (2020-2023) in recognition of being in the top one percent of cited researchers. In 2021, Dr. Kaplan received Crohn's and Colitis Canada's Research Leader Award and was inducted into the Canadian Academy of Health Sciences. He is a Killam Laureate, receiving the Killam Annual Professor Award in 2022. His research has been widely cited in the news media including Time Magazine, BBC, The New York Times, and Scientific American.

Affiliations: Departments of Medicine and Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

ERIC BENCHIMOL, MD, PhD, FRCPC

Eric Benchimol is the Northbridge Financial Corporation Chair in Inflammatory Bowel Disease (IBD) and a pediatric gastroenterologist at the SickKids IBD Centre at The Hospital for Sick Children in Toronto. He is also a Professor in the Department of Paediatrics and the Institute for Health Policy, Management and Evaluation in the Temerty Faculty of Medicine of University of Toronto. Dr. Benchimol is also a Senior Core Scientist at ICES and Senior Scientist at the SickKids Research Institute. He is an epidemiologist, and chairs the Canadian Gastro-Intestinal Epidemiology Consortium (CanGIEC), which conducts epidemiology, pharmacoepidemiology, outcomes, and health services research using the health administrative data from multiple provinces.

Affiliations: SickKids Inflammatory Bowel Disease Centre, Division of Gastroenterology, Hepatology and Nutrition, The Hospital for Sick Children (SickKids), Toronto, Ontario, Canada
Child Health Evaluative Sciences, SickKids Research Institute, The Hospital for Sick Children, Toronto, Ontario, Canada
Department of Paediatrics, University of Toronto, Toronto, Ontario, Canada
ICES, Toronto, Ontario, Canada
Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

THE RISING BURDEN OF INFLAMMATORY BOWEL DISEASE IN CANADA: FINDINGS FROM THE CROHN'S AND COLITIS CANADA 2023 IMPACT OF INFLAMMATORY BOWEL DISEASE IN CANADA REPORT

Introduction

The Impact of Inflammatory Bowel Disease report, produced by the Canadian Gastro-Intestinal Epidemiology Consortium (cangiec.ca) for Crohn's and Colitis Canada is a serial policy report produced every 3–5 years that summarizes the existing literature on the epidemiology, burden, and impact of inflammatory bowel disease (IBD) in Canada and identifies knowledge gaps. Its goal is to inform people living with IBD and their caregivers, donors, physicians, researchers, policy makers, and other stakeholders about the current burden of IBD in Canada. It plays an integral role for Crohn's and Colitis Canada's advocacy efforts. In addition, the report informs the research funding policy of the health charity, which is the second largest non-governmental funder of IBD research in the world.[1] The latest iteration of this report was released on June 1, 2023[2,3] and is available here. This article summarizes the current epidemiology of IBD in Canada and discusses its implications for clinical care in 2024 and beyond.

Incidence of IBD in Canada

The incidence of IBD in Canada in 2023 is estimated at 29.9 per 100,000 people (95% prediction interval [PI] 28.3 to 31.5) and remained stable between 2007 and 2014 (average annual percentage change [AAPC]: 0.4%, 95% confidence interval [CI] -0.05 to 0.7).[4,5] However, in Canada, the trends in IBD incidence vary across provinces **(Figure 1A)**, age groups, and by type of IBD. Incidence rates and trends over time are similar for males and females.

In 2023, the incidence of IBD was predicted to be highest in Newfoundland (52.6 per 100,000 people, 95% PI 41.4 to 63.7) and lowest in Saskatchewan (16.1 per 100,000 people, 95% PI 10.1 to 22.2) **(Figure 1A)**.[4,5] These two provinces also have diverging trends in incidence over time – increasing by 1.4% (95% CI 0.4 to 2.0) per year in Newfoundland and decreasing by 7.7% (95% CI 2.6 to 21.6) per year in Saskatchewan. All other provinces have incidence rates that fall between these two values, increasing in some provinces, decreasing in some provinces, and stable in others.

Nationally, the incidence of pediatric IBD increased by 1.3% (95% CI 0.8 to 1.7) per year between 2005 and 2014.[4,5] The incidence of pediatric IBD was 14.4 (95% CI 13.5 to 15.3) per 100,000 children in 2014, and is estimated to have risen to 16.1 (95% PI 14.9 to 17.2) per 100,000 children in 2023, with a projected to rise to 18.5 (95% PI 16.3 to 20.8) per 100,000 children in 2035. The incidence of pediatric IBD was increasing the fastest among children diagnosed at <6 years of age (7.2% per year, 95% CI 2.8 to 11.6).[6] The incidence of IBD among adults (18 to 64 years) and seniors (≥65 years) has remained stable, with incidence rates of 34.7 (95% CI 31.5 to 37.8) and 28.8 (23.6 to 34.1) per 100,000 people, respectively, in 2023.[4,5]

In 2023, the incidence of Crohn's disease (CD) was 12.7 per 100,000 people and has remained stable in all age groups (overall AAPC -0.52%, 95% CI -1.44 to 0.21).[4,5] In contrast, the incidence of ulcerative colitis (UC) has increased overall (AAPC 1.0%, 95% CI 0.7 to 1.3) and in children (AAPC 2.0%, 95% CI 0.8 to 2.8). The overall incidence of UC was 15.5 per 100,000 people in 2014, estimated to have increased to 17.2 per 100,000 people (95% PI 16.4 to 18.1) in 2023, and is projected to reach 19.3 per 100,000 people (95% PI 17.8 to 20.9) in 2023. The incidence of UC in adults and seniors has remained stable over time.

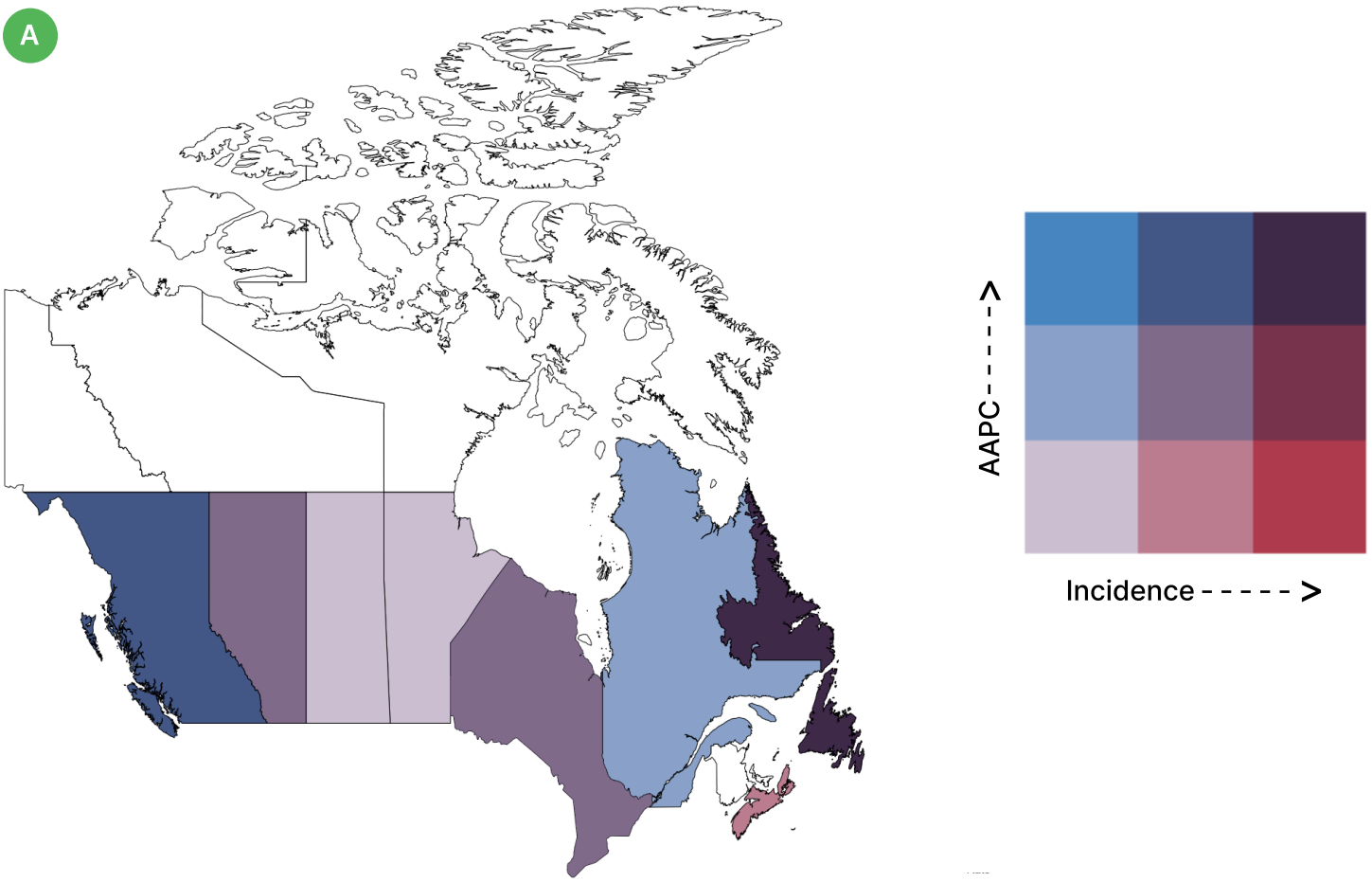
Prevalence of IBD in Canada

The prevalence of IBD is increasing across all provinces, age groups, and types of IBD **(Figure 1B)**.[4,5] In 2023, the estimated prevalence of IBD is reported to be 843 per 100,000 people (95% PI 828 to 859) (i.e. 0.843% of the population) in 2023 and is increasing by 2.4% (95% CI 2.3 to 2.5) per year. The prevalence is highest in Eastern Canada (Newfoundland: 1115 per 100,000 people; Nova Scotia: 1239 per 100,000 people) and lowest in Manitoba (720 per 100,000 people). The prevalence of IBD is increasing fastest among seniors, by 2.78% (95% CI 2.75 to 2.81) per year.[4,5] Seniors also represent the group with the highest prevalence, with an estimated 1174 (95% PI 1164 to 1184) per 100,000 seniors living with IBD in 2023. Based on current trends, we expect the prevalence of IBD to reach 1.1% of the Canadian population by 2035.

Special Populations

IBD is becoming increasingly recognized in populations previously thought to have low rates of IBD.[5] A study from Saskatchewan reported that the prevalence of IBD among First Nations individuals

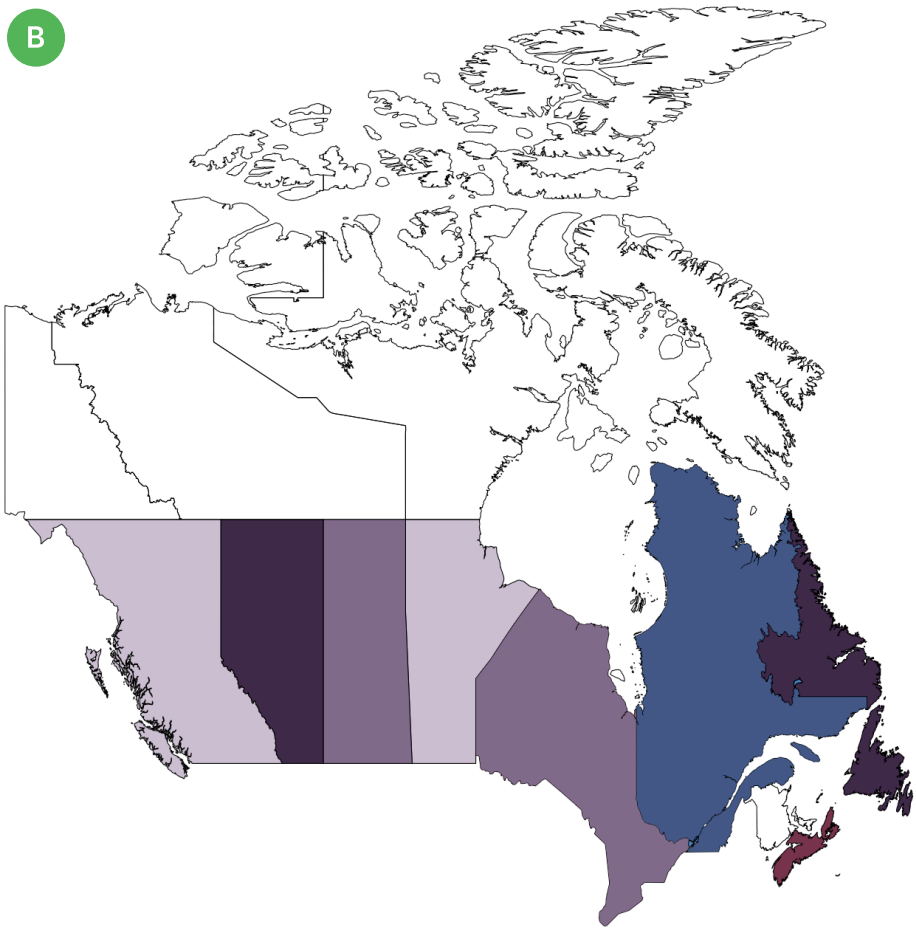
A

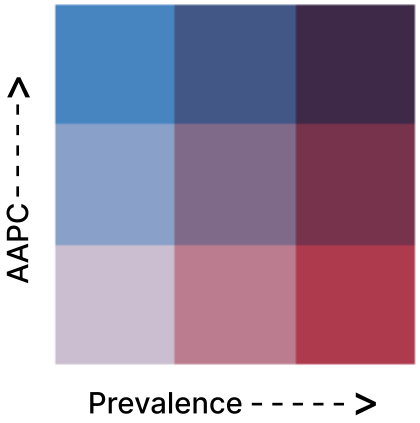


	Forecasted AAPC (95% CI)	Forecasted Incidence per 100,000 people in 2023 (95% PI)
Alberta	-0.75 (-2.29, 0.36)	33.6 (29.9, 37.2)
British Columbia	0.71 (0.45, 0.95)	34.6 (32.9, 36.3)
Manitoba	-0.93 (-1.51, -0.47)	24.2 (21.8, 26.7)
Newfoundland	1.35 (0.39, 1.96)	52.6 (41.4, 63.7)
Nova Scotia	-3.86 (-4.86, -3.04)	33.6 (31.2, 36.0)
Quebec	0.58 (0.15, 0.95)	22 (20.5, 23.6)
Ontario	0.83 (-1.55, 2.29)	28.8 (23.0, 34.6)
Saskatchewan	-7.72 (-21.58, -2.56)	16.1 (10.1, 22.2)

Figure 1A. Map describing the incidence of inflammatory bowel disease (IBD) in Canada and the changes over time, stratified by province with available data; Data are derived from Coward et al.[4]
Abbr: AAPC= average annual percentage change

B





	AAPC (95% CI)	Forecasted prevalence per 100,000 people in 2023 (95% PI)
Alberta	2.87 (2.17, 3.46)	951 (889, 1013)
British Columbia	2.02 (1.76, 2.28)	799 (785, 813)
Manitoba	1.84 (1.47, 2.17)	720 (688, 751)
Newfoundland	3 (1.23, 4.21)	1115 (920, 1309)
Nova Scotia	2.26 (1.64, 2.79)	1239 (1182, 1296)
Quebec	3.03 (2.39, 3.55)	810 (730, 891
Ontario	2.22 (2.05, 2.39)	812 (792, 831)
Saskatchewan	2.27 (1.38, 3.00)	811 (758, 864)

Figure 1B. Map describing the prevalence of inflammatory bowel disease (IBD) in Canada and the changes over time, stratified by province with available data; Data are derived from Coward et al.[4]
Abbr: AAPC= average annual percentage change

increased by 4.2% (95% CI 3.2% to 5.2%) per year between 1999 and 2016.[7] UC was more common (2016 prevalence: 87 per 100,000 people, 95% CI 86 to 89) than CD (2016 prevalence: 53 per 100,000 people, 95% CI 52 to 55), with both increasing at similar rates. Incidence rates were stable over time (AAPC -2.7%, 95% CI -6.2 to 0.8). Although the prevalence of IBD among First Nations individuals remains lower than that of the general population, it is increasing faster than in the general population.

Immigrants to Canada and their children represent another group of Canadians with underappreciated rates of IBD. While immigrants have lower rates of IBD relative to individuals born in Canada, individuals who come to Canada as children have a greater risk of developing IBD relative to older immigrants.[8] Furthermore, the Canadian-born children of immigrants from the Middle East, North Africa, and South Asia have a similar risk of developing IBD compared to children of non-immigrants,[8,9] an important finding considering Canada has amongst the highest rates of pediatric IBD in the world. This suggests individuals from these populations exhibit a genetic profile that interacts with Canadian environmental exposures early in life to increase the likelihood that they develop IBD.

Canada in Context

IBD has historically been a disease of the Western world, with the highest rates of IBD observed in Canada, Northwestern Europe, and Scandinavia. The regions that have historically had the highest incidence of IBD are now beginning to observe a stabilization in their incidence rates.[10] At the same time, IBD is becoming increasingly common in newly developed regions in parallel with Westernization.[11]

The shifting landscape of IBD epidemiology may follow four stages: **1.** Emergence; **2.** Acceleration in Incidence; **3.** Compounding Prevalence; and **4.** Prevalence Equilibrium **(Figure 2)**.[12] During the *Emergence stage*, IBD is rare. In the *Acceleration in Incidence stage*, IBD becomes increasingly common owing to accelerating incidence rates. In the *Compounding Prevalence stage*, incidence rates stabilize although the prevalence continues rising rapidly, since most individuals are diagnosed with IBD at a relatively young age and the mortality associated with IBD is low. Canada and other regions with historically high rates of IBD are now in this stage of IBD evolution. No regions have reached the *Prevalence Equilibrium stage*, in which prevalence remains stable because the mortality rates of an aging IBD population approximate the incidence rates.

Mitigating the Rising Burden of IBD

Decreasing the incidence of IBD will be instrumental in stemming the growing burden of IBD in Canada and around the world. In order to prevent IBD, we require additional knowledge about its complex pathogenesis, involving complex interactions between many factors, including the environmental

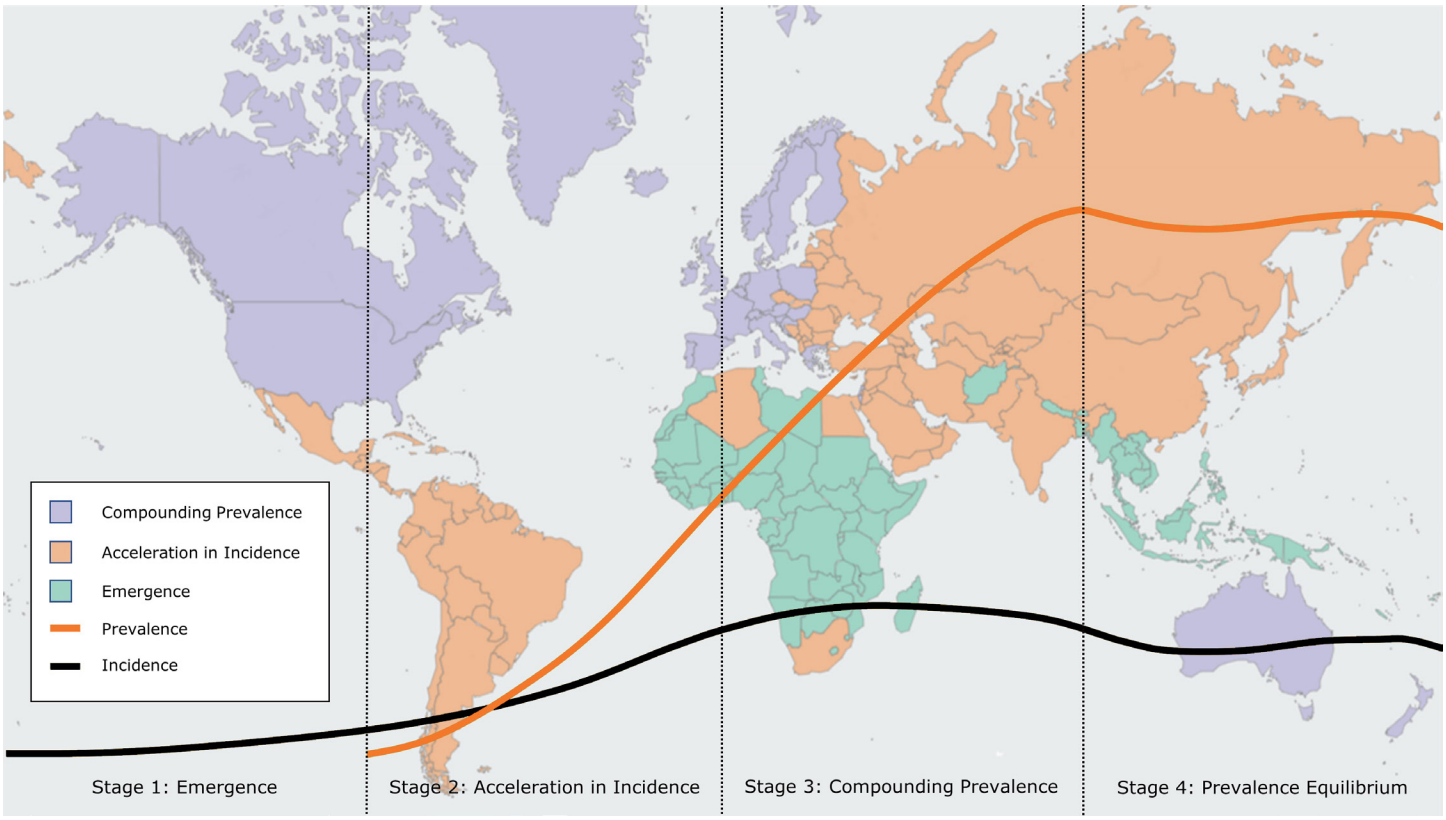


Figure 2. Theoretical description of the evolution of the epidemiology of inflammatory bowel disease (IBD) around the world, including a map of the current evolutionary stage of each nation. Reprinted from Coward et al[5], adapted from Kaplan and Windsor.[12]

exposures and the intestinal microbiome. It is vital that we understand the role of shifting environmental landscapes in regions currently in the *Emergence and Acceleration in Incidence* phases of their epidemiologic evolution. These regions could provide an opportunity to identify important risk factors as their environments are rapidly evolving, often due to policy changes that are made quickly in the face of developing economies. However, countries in the *Compounding Prevalence* phase (i.e., high incidence developed nations such as Canada) could also be highly amenable to environmental policy interventions or public health measures to improve behavioural determinants.[13] This understanding will be critical in any intervention aiming to decrease IBD incidence by minimizing harmful exposures and maximizing beneficial exposures. Preclinical cohorts, such as the Crohn's and Colitis Canada GEM Project, are helping to identify at-risk individuals who are amenable to preventive interventions.[14]

Implications of a Growing and Aging IBD Population

The rapidly rising prevalence of IBD in Canada will drastically increase the number of people requiring care for their IBD – with implications for both health human resources and healthcare spending. Furthermore, the IBD population is aging – the prevalence of IBD is growing faster among seniors than in any other age group.[4,5] This group is comprised both of individuals diagnosed with IBD earlier in life who are aging and individuals newly diagnosed among a rapidly growing Canadian senior population. Although the life expectancy of individuals with IBD is increasing, older adults with IBD are at an increased risk of age-related comorbidities,[15] and have a lower health-related quality of life, resulting in a substantially reduced health-adjusted life expectancy.[16] The combination of managing long-standing IBD and age-related comorbidities implies that the clinical management of people living with IBD will become increasingly complex.

Patients with timely access to gastroenterologist care have better outcomes.[17,18] The ratio of gastroenterologists to the general population in Canada is approximately 2 per 100,000, and this number has remained relatively stable over the past decade[19,20] despite the growing prevalence of IBD. As the prevalence of IBD continues to grow and the IBD population ages, the demands on gastroenterology clinics will only increase and models of care will need to evolve to meet this growing demand.

Furthermore, our healthcare system needs to prepare for the increasing costs of treating people living with IBD. In 2018, the direct healthcare costs of IBD were conservatively estimated at $1.28 billion.[21] Over the past decade, the costs of medical care for IBD have risen rapidly and were estimated to be $3.33 billion in 2023.[22] This substantial increase in healthcare costs is largely driven by the costs of expensive biologic therapies that have not been offset by reductions in costs related to hospitalizations and surgeries. These costs do not account for the substantial indirect and out-of-pocket costs incurred by people living with IBD and their caregivers, which exceeded $2 billion in 2023.[23] Furthermore, indirect costs related to presenteeism (reduced productivity while at work) and absenteeism (time off work) can be reduced by effectively treating a person's IBD. A healthier IBD population will reduce the overall economic burden of IBD. These rising costs are not indefinitely sustainable and need to be addressed without compromising the quality of care provided to people living with IBD.

Conclusions

The number of Canadians living with IBD is rising. Without changes in the approach to how we manage the increasing needs of the growing IBD population, the demand for gastroenterologists and the cost of caring for people living with IBD will exceed our current capacity to provide high quality care to these patients. We need to bring awareness of the growing costs of caring for the growing IBD population to government, policy makers, and other healthcare payers (e.g., the private healthcare insurance industry). Furthermore, it is crucial to understand why IBD is becoming increasingly common in some populations (e.g., First Nations individuals, children, and younger immigrants from certain regions). We will require better research funding to fully understand the environmental factors that are contributing to the rise of IBD in these populations. Only by better understanding the complex etiology of IBD will we be able to develop strategies that will minimize the future burden of IBD in Canada.

Key Takeaways:

1. Trends in IBD incidence in Canada vary across provinces, age groups, and by type of IBD; incidence rates and trends over time are similar for males and females.
2. The incidence of pediatric IBD was increasing the fastest among children diagnosed at <6 years of age. The prevalence of IBD was increasing the fastest among seniors ≥65 years of age.
3. Although the prevalence of IBD among First Nations individuals remains lower than that of the general population, it is increasing faster than in the general population.
4. As the prevalence of IBD continues to grow and the IBD population ages, the demands on gastroenterology clinics will only increase and models of care will need to evolve to meet this growing demand.
5. The rising costs of treating and managing IBD are not sustainable in the long-term and need to be addressed without compromising the quality of care provided to people living with IBD.

Correspondence:

Ellen Kuenzig, PhD
Email: ellen.kuenzig@sickkids.ca

Financial Disclosures:

Ellen Kuenzig: None declared.

Gilaad Kaplan: **Honoraria for Speaking/Consulting:** AbbVie, Amgen, Janssen, Pfizer, Sandoz, and Pendophram; **Research Grants:** Ferring; **Educational Activities:** AbbVie, Bristol Myers Squibb, Ferring, Fresenius- Kabi, Janssen, Pfizer, Takeda; **Shared Patent Ownership:** TREATMENT OF INFLAMMATORY DISORDERS, AUTOIMMUNE DISEASE, AND PBC. UTI Limited Partnership, assignee. Patent WO2019046959A1. PCT/ CA2018/051098. 7 Sept. 2018.

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. **Consulting:** Dairy Farmers of Ontario, McKesson Canada (unrelated to medications used to treat inflammatory bowel disease), Canadian Agency for Drugs and Technology in Health.

References:

1. Rose KL, Sherman PM, Cooke-Lauder J, Mawani M, Benchimol EI, Kaplan GG, et al. The Impact of Inflammatory Bowel Disease in Canada 2018: IBD Research Landscape in Canada. Journal of the Canadian Association of Gastroenterology. 2018;390(10114):2769 - 11.
2. Windsor JW, Kuenzig ME, Murthy SK, Bitton A, Bernstein CN, Jones JL, et al. The 2023 Impact of Inflammatory Bowel Disease in Canada: Executive Summary. Journal of the Canadian Association of Gastroenterology. 2023;6(Supplement_2):S1-S8.
3. Benchimol EI, Kaplan GG, Bernstein CN, Bitton A, Jones JL, Kuenzig ME, et al. 2023 Impact of Inflammatory Bowel Disease in Canada2023. Available from: https://crohnsandcolitis.ca/Crohns_and_Colitis/documents/reports/2023-IBD-Report-English-LR.pdf?ext=.pdf.
4. Coward S, Benchimol EI, Bernstein CN, Avina-Zubieta A, Bitton A, Carroll MW, et al. Forecasting the incidence and prevalence of inflammatory bowel disease: a Canadian nationwide analysis. Am J Gastroenterol. 2024.
5. Coward S, Benchimol EI, Kuenzig ME, Windsor JW, Bernstein CN, Bitton A, et al. The 2023 Impact of Inflammatory Bowel Disease in Canada: Epidemiology of IBD. Journal of the Canadian Association of Gastroenterology. 2023;6(Supplement_2):S9-S15.
6. Benchimol EI, Bernstein CN, Bitton A, Carroll MW, Singh H, Otley AR, et al. Trends in epidemiology of pediatric inflammatory bowel disease in Canada: distributed network analysis of multiple population-based provincial health administrative databases. The American Journal of Gastroenterology. 2017;112:1120 - 34.
7. Pena-Sanchez JN, Osei JA, Marques Santos JD, Jennings D, Andkhoie M, Brass C, et al. Increasing Prevalence and Stable Incidence Rates of Inflammatory Bowel Disease Among First Nations: Population-Based Evidence From a Western Canadian Province. Inflamm Bowel Dis. 2022;28(4):514-22.
8. Benchimol EI, Mack DR, Guttmann A, Nguyen GC, To T, Mojaverian N, et al. Inflammatory Bowel Disease in Immigrants to Canada And Their Children: A Population-Based Cohort Study. The American Journal of Gastroenterology. 2015;110(4):553 - 63.
9. Dhaliwal J, Tuna M, Shah BR, Murthy S, Herrett E, Griffiths AM, et al. Incidence of Inflammatory Bowel Disease in South Asian and Chinese People: A Population-Based Cohort Study from Ontario, Canada. Clin Epidemiol. 2021;13:1109-18.
10. Hracs L, Windsor J, Gorospe J, Cummings M, Coward S, Buie M, et al. [Pre-print] The global evolution of inflammatory bowel disease across four epidemiologic stages2024 January 30, 2024. Available from: https://www.researchsquare.com/article/rs-3846147/v1.
11. Ng SC, Shi HY, Hamidi N, Underwood FE, Mphil WT, Benchimol EI, et al. Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. The Lancet. 2018;390(10114):2769 - 78.
12. Kaplan GG, Windsor JW. The four epidemiological stages in the global evolution of inflammatory bowel disease. Nature Reviews Gastroenterology & Hepatology. 2021;18(1):56-66.
13. Herauf M, Coward S, Pena-Sanchez JN, Bernstein CN, Benchimol EI, Kaplan GG, et al. Commentary on the Epidemiology of Inflammatory Bowel Disease in Compounding Prevalence Nations: Toward Sustaining Healthcare Delivery. Gastroenterology. 2024.
14. Raygoza Garay JA, Turpin W, Lee SH, Smith MI, Goethel A, Griffiths AM, et al. Gut Microbiome Composition Is Associated With Future Onset of Crohn's Disease in Healthy First-Degree Relatives. Gastroenterology. 2023;165(3):670-81.
15. Shaffer SR, Kuenzig ME, Windsor JW, Bitton A, Jones JL, Lee K, et al. The 2023 Impact of Inflammatory Bowel Disease in Canada: Special Populations—IBD in Seniors. Journal of the Canadian Association of Gastroenterology. 2023;6(Supplement_2):S45-S54.
16. Kuenzig ME, Manuel DG, Donelle J, Benchimol EI. Life expectancy and health-adjusted life expectancy in people with inflammatory bowel disease. Cmaj. 2020;192(45):E1394-E402.
17. Nguyen GC, Bouchard S, Diong C, and PA, Care through Centres of Excellence (PACE) Network. Access to Specialists and Emergency Department Visits in Inflammatory Bowel Disease: A Population-Based Study. J Crohn's Colitis. 2018;13(3):330-6.
18. Kuenzig ME, Stukel TA, Kaplan GG, Murthy SK, Nguyen GC, Talarico R, et al. Variation in care of patients with elderly-onset inflammatory bowel disease in Ontario, Canada: A population-based cohort study. Journal of the Canadian Association of Gastroenterology. 2020;4(2):e16-e30.
19. Leddin D, Carroll M, Gillis C, Cehovin A. Gastroenterology Practitioner and Trainee Numbers in Canada 2018: Annual Report From the Canadian Association of Gastroenterology. J Can Assoc Gastroenterol. 2021;4(2):52-6.
20. Statistics Canada. Table 17-10-0009-01 Population estimates, quarterly. 2023.
21. Kuenzig ME, Benchimol EI, Lee L, Targownik LE, Singh H, Kaplan GG, et al. The Impact of Inflammatory Bowel Disease in Canada 2018: Direct Costs and Health Services Utilization. Journal of the Canadian Association of Gastroenterology. 2018;110(9):1324 - 17.
22. Kuenzig ME, Coward S, Targownik LE, Murthy SK, Benchimol EI, Windsor JW, et al. The 2023 Impact of Inflammatory Bowel Disease in Canada: Direct Health System and Medication Costs. Journal of the Canadian Association of Gastroenterology. 2023;6(Supplement_2):S23-S34.
23. Kuenzig ME, Im JHB, Coward S, Windsor JW, Kaplan GG, Murthy SK, et al. The 2023 Impact of Inflammatory Bowel Disease in Canada: Indirect (Individual and Societal) and Direct Out-of-Pocket Costs. Journal of the Canadian Association of Gastroenterology. 2023;6(Supplement_2):S16-S22.