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Prevalence of Pediatric Inflammatory Bowel Disease in the United States: Pooled Estimates from Three Administrative Claims Data Sources

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The worldwide prevalence of Crohn's disease (CD) and ulcerative colitis (UC), collectively known as inflammatory bowel diseases (IBD), has increased throughout the last several decades.^{1,2} Pediatric IBD (PIBD), a distinct clinical entity with a more extensive anatomic distribution and more aggressive natural history than adult IBD, has historically been

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Author contributions

Author	Study concept and design	Acquisition of data	Analysis and interpretation	Drafting manuscript	Critical revisions	Statistical analysis
Kappelman	X		X		X	
Brensinger	X		X		X	X
Parlett	X	X	X		X	X
Hurtado-Lorenzo			X		X	
Lewis	X	X	X	X	X	

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considered a rare disease. The prevalence of PIBD in North America is high compared to other continents, yet nationally representative United States (U.S.) estimates are few³ with even fewer estimates of the racial and geographic distribution of disease.⁴ We recently defined the prevalence of physician-diagnosed IBD in the United States in a nationally representative population by pooling data from public and private health plans.⁵ In this report, we further describe the prevalence of PIBD and distribution across age, sex, region, and race.

We analyzed two commercial insurance claims datasets [Optum's de-identified Clinformatics® Data Mart Database (CDM) and Carelon Research's Healthcare Integrated Research Database (HIRD®)] along with data from 5 of the largest state Medicaid plans (Florida, New York, Pennsylvania, Ohio and California). Each data set contains physician encounters, prescription drug claims, hospitalizations, and procedures (including infused medications). Among plan enrollees < 20 years of age, we used a validated combination of medical diagnoses and prescription medications to identify cases of prevalent IBD (PPV 78–94%).⁶ We computed age- and sex-specific estimates within each dataset and used direct standardization to 2020 U.S. census data to generate national prevalence estimates. See Supplemental Methods for further detail.

Our study population included 2,741,204 individuals <20 years of age with ≥4 years of continuous insurance of whom 4,100 met the definition of IBD requiring two or more diagnoses or one diagnosis and a prescription for an IBD medication. The age-, sex- and insurance status standardized prevalence per 100,000 population was 122 per 100,000 (95% CI 117–127) for IBD, 71 per 100,000 (95% CI 68 – 75) for CD and 44 per 100,000 for UC (95% CI 41 – 47). Based on a 2020 U.S. census population of 82,194,564 persons < 20 years of age, we estimate that approximately 100,429 American youth are living with IBD (58,733 CD and 36,270 UC). In a sensitivity analysis assuming the Medicaid prevalence growth between 2011 and 2018 was the same as in the commercially-insured population, we estimate that 106,277 youth may be living with IBD (61,877 CD and 38,517 UC; prevalence per 100,000 75 for CD, 47 for UC, and 129 for IBD).

All prevalences increased with age (Figure 1). Estimates of the prevalence and number of individuals affected by CD, UC, and total IBD using an age threshold of < 18 years to define pediatric IBD are provided in Supplemental Table 1.

The prevalence of CD, but not UC, was higher among males than females. The prevalence of pediatric IBD varied by race and ethnicity (Supplemental Figure 1). The prevalence of IBD per 100,000 population was 145 (95% CI 135–155) in White, 91 (71–111) in Black, 52 (30–74) in Asian and 88 (73–102) in Hispanic Americans. The CD to UC ratio was higher in White (1.8) and Asian Americans (2.1) than in Black (1.1) and Hispanic Americans (1.2). The prevalences of IBD, CD, and UC were all higher in the northeast than in other regions. (Supplemental Figure 2).

The prevalence of PIBD slightly increased over time [110 per 100,000 (95% CI 106–113) in 2011, 119 (115–123) per 100,000 in 2014, 126 (122–130) per 100,000 in 2017, and 125 (121–129) per 100,000 in 2020].

By pooling data from two commercial insurance plans and five states' Medicaid claims, we estimate that over 100,000 U.S. youth are living with IBD. Although cross-country comparisons are limited by differing methodology and inconsistent age-cutoffs to define the pediatric age group, these data suggest that the prevalence of PIBD in the U.S. is amongst the highest worldwide³ and consistent with data from Northern Europe and Canada. Prior prevalence data in the U.S. are sparse; however, this report is consistent with our prior study which estimated the 2009 prevalence of pediatric CD and UC as 58 and 34 respectively.⁷ Taken together, these data suggest that prevalence of pediatric IBD in the U.S. continues to rise, consistent with the epidemiological stage of compounding prevalence. The higher prevalence of PIBD in the Northeast⁷ and among Whites⁴ is also consistent with prior studies and warrants additional research regarding etiology and/or referral and diagnostic patterns. The higher predominance of pediatric CD among males is also consistent with prior literature.⁸

This study is unique in having pooled data that are representative of nearly the entire U.S. population with commercial and Medicaid health insurance. However, we recognize our study did not capture uninsured Americans, a population overrepresented by people of color and non-citizens⁹. However, as the uninsured rate among children (5.1%) is half that of nonelderly adults (11.3%)⁹, the impact of this omission on our overall prevalence estimate is likely to be small. We also acknowledge that algorithms for imputation of race/ethnicity within CDM are imperfect¹⁰ and, along with our assumptions about insurance weighting, creates some degree of uncertainty around our prevalence estimates. Additionally, the administrative case definition used in this study is subject to misclassification. To the extent that the underestimation of prevalence due to imperfect sensitivity roughly matches the overestimation due to imperfect specificity, we believe that our study provides a reasonable estimate of PIBD prevalence in the U.S. We also did not have access to data on social determinants of health and could not incorporate this in our analyses.

In summary, we believe this to be the most comprehensive assessment of physician-diagnosed PIBD in the U.S. to date. When taken in the context of existing literature, the U.S. burden of PIBD is amongst the highest worldwide and the prevalence continues to increase. These data can be used to inform health policy and resource allocation and suggest the need for future investigation to better understand the causes and consequences of observed differences based on geography, race and ethnicity.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Transparency Statement

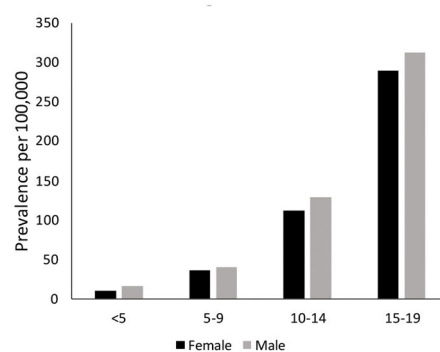
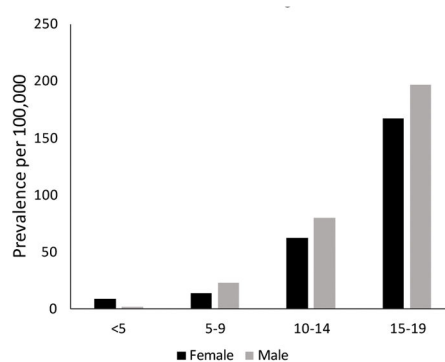
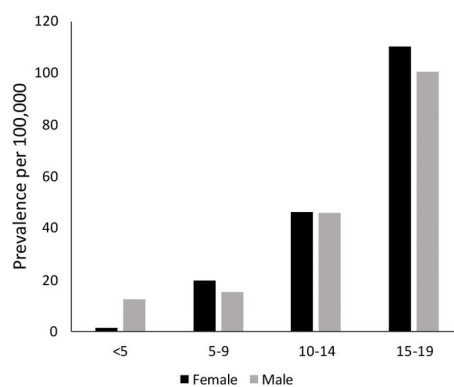
“Data requests can be made directly to each data source used in this project.”

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A.**B.****C.****Figure 1.**

Age- and sex-specific prevalence per 100,000 population of (A) pediatric IBD, (B) pediatric Crohn's disease and (C) pediatric ulcerative colitis in the United States.