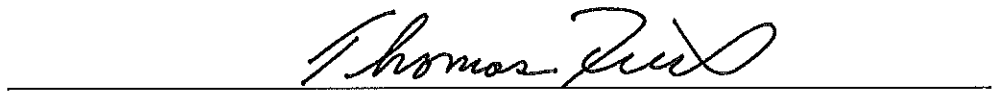
# U.S. Department of Health and Human Services

## Centers for Disease Control and Prevention

# Report to Congress on the Epidemiological Study on Inflammatory Bowel Disease



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In its report on the fiscal year (FY) 2014 budget for the Department of Health and Human Services, the Senate Appropriations Committee stated

> *The Committee continues to prioritize CDC's inflammatory bowel disease epidemiology study, and requests a report on the ongoing activities in this important area.* (Senate Report113-71, page 68)

In response to this request, the following report has been prepared by the National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC), Department of Health and Human Services.

## Background

Crohn's disease and ulcerative colitis are chronic inflammatory diseases of the gastrointestinal tract, and are collectively known as inflammatory bowel disease (IBD). Inflammation affects the entire digestive tract in Crohn's disease and only the large intestine in ulcerative colitis. IBD is a chronic progressive disease that causes severe ongoing gastrointestinal symptoms that can dramatically affect quality of life. IBD can be resistant to medical treatments and often results in surgical intervention, thereby making it a costly condition as well. In 2008, direct treatment costs alone for patients with IBD were estimated to be more than $6.3 billion.[1] When considering indirect costs such as missed work opportunities, IBD has been estimated to cost an additional $5.5 billion (in 2009 US dollars).[2]

In the United States, as many as 1 million to 1.3 million people suffer from IBD.[3,4] A 2004 review showed that the prevalence in North America ranged from 26 to 199 cases per 100,000 persons for Crohn's disease and from 37 to 246 cases per 100,000 persons for ulcerative colitis.[4] A 2007 study of insurance claims for 9 million Americans reported the prevalence of Crohn's disease to be 201 per 100,000 adults and the prevalence of ulcerative colitis to be 238 per 100,000 adults.[3] In the 2004 review, the incidence rate of newly diagnosed cases in North

America ranged from 3.1 to 14.6 cases per 100,000 person-years (number of persons times the number of years of illness) for Crohn's disease and from 2.2 to 14.3 cases per 100,000 person-years for ulcerative colitis.[4]

IBD also affects children, who may have impaired growth with lifelong consequences as a result.[5] The study of insurance claims reported that the prevalence was 43 per 100,000 children for Crohn's disease and 28 per 100,000 children for ulcerative colitis.[3] There are three studies on the incidence of pediatric IBD in the United States, each using different data obtained mostly from a single research study or geographic area, but with similar overall estimates. In these studies, researchers estimated the incidence of pediatric Crohn's disease at 3.4 per 100,000 person-years during 1940–2000 in Olmstead County, Minnesota,[6] 2.8 per 100,000 person-years during 1996–2006 in northern California,[7] and 6.6 per 100,000 person-years during 2000–2007 in Wisconsin.[8] The incidence of pediatric ulcerative colitis was estimated as 2.4 per 100,000 person-years during 1940–2000 in Olmstead County, Minnesota,[6] 3.4 per 100,000 person-years during 1996–2006 in north California,[7] and 2.4 per 100,000 person-years during 2000–2007 in Wisconsin.[8]

There are a number of challenges that make it difficult to determine accurate national prevalence and incidence estimates for IBD, including the lack of definitive easily measured outcomes like mortality; the fact that IBD is not a "reportable condition" for any local, state, or national agency; the lack of a gold standard for diagnosis; and wide variations in disease severity and outcomes. In addition, there are limitations within the existing data such as incomplete statistics on certain subgroups including racial and ethnic minorities and geographic regions. In spite of these challenges, reported rates remain in similar ranges. There are also limitations to our knowledge concerning IBD causation and disease progression. While the cause of IBD is unknown, it is thought to arise from an interaction between genes, the immune system, and environmental factors.

## CDC Activities

CDC first began addressing IBD in 2005. Since this time, CDC has worked in conjunction with the Crohn's & Colitis Foundation of America (CCFA) and various subcontracted academic and medical collaborative partners to address gaps in epidemiologic data and information about treatment for IBD.

During 2005–2013, activities focused on addressing the challenges and limitations of current IBD surveillance and epidemiology data, including

- Supporting publications describing the incidence and prevalence of IBD in a quasi-population-based cohort consisting of Kaiser-Permanente Northern California HMO members[9,7] and patterns of care for patients with IBD in this population, including a description of mortality rates and cause of death, and use of immune modulators and biologics.[10,11,12, 13]
- Supporting the Ocean State Crohn's & Colitis Area Registry (OSCCAR), a prospective, state-based cohort that assesses the prevalence and incidence of IBD in Rhode Island, particularly among children, with goals of gaining insight into the etiology of IBD, learning why the course of illness varies among individuals, and determining what factors (including physician attitudes and knowledge) may improve outcomes.[14,15]
- Seeking expert recommendations on methods of ascertaining the incidence and prevalence of IBD in the United States. The expert consensus recommendation was to employ a multifaceted model of surveillance of the burden of disease that ideally would move beyond incidence and prevalence to incorporate factors associated with the burden of disease, such as costs, loss of work productivity, and morbidity.[16]

### *Epidemiology*

Through a competitively awarded, 5-year cooperative agreement initiated in FY 2013, CDC has partnered with CCFA to support an epidemiological research study to obtain surveillance data about children and adults through OSCCAR. Investigators at Harvard Medical School and the Warren Alpert Medical School of Brown University are conducting the study and also will define the demographic and clinical characteristics of IBD and its effects on the health of

affected persons. The results from the study will provide a better understanding of the epidemiology of the disease and can be used to target interventions for groups at high risk for IBD and to inform best clinical practices. Findings are expected to add to the understanding of

- Burden of IBD in the United States, by describing prevalence and incidence in a state or regional population.
- Health effects of IBD, including well-being, quality of life, and perception of disability of affected persons.
- Variations in practices in the evaluation and management of IBD.
- Effectiveness of various clinical practices on the outcome of the disease.

The funding also leverages CCFA's existing organizational and communications structure to provide research, education, and support for IBD; to expand descriptions of disease symptoms and outcomes; and to communicate important information to patients and their providers, improving outcomes. A number of outcomes are being addressed through current CDC and CCFA activities; each activity is explained below.

***IBD Surveillance***

To date, a measure of IBD (defined as having either Crohn's disease or ulcerative colitis) has been surveyed in only one nationally representative US population sample.[17] The 1999 survey results revealed that the prevalence of persons reporting that they had IBD was 0.8%, or about 790.7 per 100,000 among adults aged 20–64 years.[17] In order to monitor the national prevalence of IBD, CDC currently is exploring the addition of two questions on ulcerative colitis and Crohn's disease to the 2016 National Health Interview Survey.

***Impact of IBD on Affected Persons***

Through the CCFA cooperative agreement, researchers continue to conduct long-term follow-up surveillance with the approximately 400 registrants enrolled in OSCCAR. They intend to describe the variability and progression of patient-reported outcomes, including quality of life and work productivity, outcomes specific to women and children, description of medical outcomes, and reported health care utilization by individuals. The OSCCAR cohort presents a

unique opportunity to measure patient-reported outcomes longitudinally from close to the time of diagnosis through the evolution of the disease over time. Follow-up allows for the development of descriptive and predictive models of disease outcomes based upon three main components: 1) *clinical predictors* (demographic, psychosocial, or clinical characteristics) present at baseline, 2) *modifying factors* (disease activity, exposures, such as medications, and behaviors, such as smoking) measured during the course of disease that could affect outcomes, and 3) *disease outcomes*.

Follow-up data collection also addresses a variety of outcomes , such as those pertaining to sexual health, fatigue, and generic and health-related quality of life that result from IBD. Current progress on the following subprojects includes

- *Issues related to gender and sexuality such as body image, menstruation, and fertility.* Activities include exploring the relationship between body image dissatisfaction and quality of life, an area that is largely unrecognized by diagnosing and treating physicians, and which could help to determine appropriate interventions, including avoidance of steroid treatment. In addition, researchers continue to identify disease characteristics associated with menstrual changes, which some previously had found to be highly prevalent among women in the OSCCAR incidence cohort.

- *Fatigue and quality of life.* Researchers plan to finalize and disseminate their analyses concerning the issue of fatigue in IBD, including the scope of the problem and contributing factors. Researchers are also exploring whether a measure of clinical screening for fatigue can serve as a marker for other aspects of diminished quality of life.

In addition, OSCCAR enrollees are being asked to join the CCFA Partners in IBD research registry, an online cohort with more than 13,000 subjects enrolled nationwide, through a linkage between both studies. CCFA Partners collect information in the following areas: demographics, IBD disease information (characteristics, family history, recent disease activity, etc.), diet and exercise, health status, and adherence. The CCFA Partners registry will benefit from details learned from the OSCCAR cohort and from clinical data that can validate self-reported

outcomes. The linkage between these cohorts offers an opportunity to cross-validate patient self-reported data, confirming the self-report elements that are accurate and producing data that can be applied to a much larger cohort. The potential applications of this work to epidemiological research are substantial.

***Variables Associated with Disparate Outcomes in IBD***

Cooperative agreement activities also focus on identifying independent variables (e.g., psychosocial, economic, demographic, clinical, and biological) associated with disparate outcomes in IBD, and identifying variations in the use of medical therapies that independently affect outcomes. Goals of this work include

- Creating models to determine independent factors associated with variations in disease outcomes and symptoms such as the short-, medium-, and long-term outcomes of corticosteroid resistance, the time to development of penetrating or stricturing disease (Crohn's disease) or extension of disease (ulcerative colitis), and the time to surgery.

- Identifying variations in the use of medical therapies that independently affect outcomes. Researchers are testing the hypotheses that the use of corticosteroids, use of immune modulators, and use of biologic agents are independently associated with distinct disease outcomes. In addition, researchers plan to explore the timing of initiation of steroids in relation to diagnosis and the duration of therapy in relation to disease outcomes. They also plan to explore other practice patterns, including variations in the timing and use of immune modulators and biologics, imaging (CT or MR), and endoscopy to determine if specific patterns of use are associated with better or worse outcomes, while controlling for disease activity or inflammation.

***Variations in Clinical Practice and Programs to Address Them***

The models described above can help to explain how variations in medical practice affect disease, thereby making it possible to determine whether specific patient characteristics—demographic factors, disease activity, and disease location—can play a role, and to what degree physician characteristics account for variations in practice. Understanding the patient and

provider characteristics associated with variations in practice will inform the design of educational or other interventions to improve disease outcomes. For example, cooperative agreement subprojects under this aim include

- *Steroid use.* Ongoing work has focused on analyzing demographic, clinical, and provider characteristics associated with use of steroids. Results from these analyses will serve as the basis for models of disease outcomes in association with steroid use. Identifying risk factors for steroid use, as well as factors associated with appropriate use of steroid-sparing strategies, will inform clinical practice in minimizing the use of these agents, with consequent health benefits to IBD patients.

- *Testing for C. difficile infection. Clostridium difficile* infection (CDI) occurs frequently among patients with IBD, and has been associated with a variety of adverse outcomes in IBD, including colectomy (in ulcerative colitis), hospitalization, and mortality.[18-22] Testing for CDI is inconsistent, and delayed diagnosis of CDI in newly diagnosed IBD patients may be a significant quality issue. Current work is focused on identifying patient and provider factors associated with appropriate CDI testing, in order to design interventions that may increase the rate of appropriate testing.

- *Nutrition and dietary behaviors.* Under previously funded work, researchers concluded that nutrient intake in pediatric IBD appears to fall below recommended intakes due to unhealthy dietary behaviors. Building on this work, current cooperative agreement research is focused on 1) examining factors associated with healthy dietary behaviors and adherence to dietary recommendations, and 2) examining the relationship between dietary behaviors and IBD health outcomes in order to recommend how best to develop behavioral interventions to maximize nutrition.

- *Radiation exposure.* Efforts continue on characterizing radiation exposure during treatment and identifying IBD-related risk factors for increased radiation exposure. Study results could lead to effective measures to minimize radiation exposure during the identification and treatment of IBD to minimize the risk of cancer.

## Summary

CDC continues to partner with CCFA to support research activities to determine prevalence and incidence rates of IBD in the United States, to identify how IBD affects the health of persons with these conditions, and to develop and disseminate science-based interventions to improve disease outcomes.

Progress made on key activities includes increasing surveillance, epidemiology, and applied research by

- Analyzing surveillance data and enhancing existing data systems to capture IBD data.
- Publishing and increasing the base of scientific evidence on IBD. As a result of CDC's epidemiologic study of IBD projects, 38 journal articles have been published and 9 journal articles are under development (see appendices).
- Increasing applied research capacity through the creation of a cohort of IBD patients in the Ocean State Crohn's and Colitis Area Registry.
- Increasing development and advancement of interventions to address variations in practice.
- Maintaining online scientific information and resources.

In FY 2014, CDC continues to support IBD studies to improve the understanding of the epidemiology of the disease, to inform best clinical practices, and to improve the lives of those affected by IBD.

## Appendix A: Articles Resulting from CCFA's Subcontract with Kaiser-Permanente of Northern California (in Chronological Order)


Allison J, Herrinton LJ, Yu J, Liu L, Lowderu J. Natural history of severe ulcerative colitis in a community-based health plan. *Clin Gastroenterol Hepatol.* 2008;6(9):999–1003.

Herrinton LJ, Liu L, Lewis JD, Griffin PM, Allison J. Incidence and prevalence of inflammatory bowel disease among members of Kaiser Permanente, Northern California, 1996–2002. *Am J Gastroenterol.* 2008;103(8):1998–2006.

Herrinton LJ, Liu L, Fireman B, et al. Time trends in therapy and outcomes for adult inflammatory bowel disease, Northern California, 1998–2005. *Gastroenterology.* 2009;137(2):502–511.

Lewis JD, Abramson O, Pascua M, et al. Incidence and outcomes of myelosuppression during thiopurine therapy for inflammatory bowel disease: implications for monitoring recommendations. *Clin Gastroenterol Hepatol.* 2009;7(11):1195–1201.

Liu L, Lewis JD, Griffin PM, Allison JA, Herrinton LJ. The positive predictive value of diagnoses for Crohn's disease, ulcerative colitis, and overall inflammatory bowel disease in computerized data among members of Kaiser Permanente, Northern California, 1996–2002. *Pharmacoepidemiol Drug Saf.* 2009;18(11):1086–1093.

Abramson O, Durant M, Mow W, et al. Incidence, prevalence and time trends of pediatric inflammatory bowel disease in Northern California, 1996–2006. *J Pediatr.* 2010;157(2):233–239.e1.

Velayos FS, Liu L, Lewis JD, et al. Prevalence of colorectal cancer surveillance in ulcerative colitis patients in an integrated health-care delivery system. *Gastroenterology.* 2010;139(5):1511–1518. *Second most frequent article cited in* Gastroenterology *during 2010, and awarded Editor's Pick for 2010.*

Herrinton LJ, Liu L, Weng X, Lewis J, Hutfless S, Allison JE. Role of thiopurine and Anti-TNF therapy in lymphoma in inflammatory bowel disease. *Am J Gastroenterol.* 2011;106(12):2146–2153.

Herrinton LJ, Liu L, Mitchel EF, Jr, Stein CM, Griffin MR. Changes in co-therapies after initiation of disease-modifying anti-rheumatic drug therapy in patients with rheumatoid arthritis. *Arthritis Care Res* (Hoboken). 2011;63(10):1415–1424.

Grijalva CG, Chen L, Delzell E, et al. Initiation of biologic DMARDs and the risk of hospitalization for infection in patients with autoimmune disease. *JAMA.* 2011;306(21):2331–2339.

Herrinton LJ, Curtis JR, Chen L, et al. Study design for a comprehensive assessment of biologic safety using multiple healthcare data systems. *Pharmacoepidemiol Drug Saf.* 2011;20(11):1199–1209.

Herrinton LJ, Liu, L, Abramson O, Jaffe E. The incidence of hepatosplenic T-cell lymphoma in a large managed care organization, with reference to anti-tumor necrosis factor therapy, Northern California, 2000–2006. *Pharmacoepidemiol Drug Saf.* 2012;21(1):49–52.

Herrinton LJ, Liu L, Allison JE, Lewis JD, Hutfless SM, Velayos FS. Incidence and mortality of colorectal cancer in inflammatory bowel disease, 1996–2006. *Gastroenterology.* 2012;143(2):382–389.

Hutfless S, Li DK, Heyman MB, Bayless TM, Abramson O, Herrinton LJ. Prenatal and birth characteristics and risk of pediatric-onset inflammatory bowel disease. *Digestive Diseases and Sciences.* 2012:57(8):2149–2156.

Beukelman T, Haynes K, Curtis JR, et al.; Safety Assessment of Biological Therapeutics Collaboration. Rates of malignancy associated with juvenile idiopathic arthritis and its treatment. *Arthritis Rheum.* 2012;64(4):1263–1271.

Beukelman T, Xie F, Chen L, et al.; SABER Collaboration. Rates of hospitalized bacterial infection associated with juvenile idiopathic arthritis and its treatment. *Arthritis Rheum.* 2012;64(8):2773–2780.

Toh S, Li L, Harrold L, et al. Comparative safety of infliximab and etanercept on the risk of serious infections: does the association vary by patient characteristics? *Pharmacoepidemiol Drug Saf.* 2012;21(5):524–534.

Toh D, Li L, Harrold L, et al. Comparative safety of infliximab and etanercept on the risk of serious infections—does the association vary by patient characteristics? [abstract] *Clin Med Res.* 2012;10(3):188.

Grant M, McMullen CK, Altschuler A, et al. Irrigation practices in long-term survivors of colorectal cancer with colostomies. *Clin J Oncol Nurs.* 2012;16(5):514–519.

Wu JJ, Nguyen T, Herrinton LJ, Poon KYT. The association of psoriasis with other autoimmune diseases. *Journal of Allergy and Autoimmune Disease.* 2012;67(5):924–930.

Herrinton LJ, Liu L, Chen L, et al. Association between anti-TNF-α therapy and all-cause mortality. *Pharmacoepidemiol Drug Saf.* 2012;21(12):1311–1320.

Kawatkar AA, Jacobsen SJ, Levy GD, Medhekar S, Venkatasubramaniam KV, Herrinton LJ. Direct medical expenditure associated with rheumatoid arthritis in a nationally representative sample from the medical expenditure panel survey. *Arthritis Care Res* (Hoboken). 2012;64(11):1649–1656.

Winthrop KL, Baxter R, Liu L, et al. Mycobacterial diseases and antitumour necrosis factor therapy in the USA. *Ann Rheum Dis*. 2013;72(1):37–42.

Haynes K, Beukelman T, Curtis JR, et al. Tumor necrosis factor alpha inhibitor therapy and cancer risk in chronic immune mediated diseases. *Arthritis Rheum.* 2013;65(1):48–58.

Winthrop KL, Chen L, Fraunfelder FW, et al. Initiation of anti-TNF therapy and the risk of optic neuritis: from the Safety Assessment of Biologic thERapy (SABER) study. *Am J Ophthalmol.* 2013;155(1):183–189.

Winthrop KL, Baddley JW, Chen L, et al. Initiation of anti-TNF therapy is not associated with an increased risk of herpes zoster: from the Safety Assessment of Biologic thERapy (SABER) study. *JAMA.* 2013;309(9):887–895.

Herrinton LJ, Liu L, Ouellet-Hellstrom R, et al. Association between anti-TNF-α therapy and risk of interstitial lung disease and pulmonary fibrosis. *Pharmacoepidemiol Drug Saf.* 2013;22(4):394–402.

Baddley JW, Winthrop KL, Chen L, et al. Non-viral opportunistic infections in new users of TNF inhibitor therapy: results of the Safety Assessment of Biologic thERapy (SABER) study. *Ann Rheum Dis.* Published online first: 13 July 2013 doi:10.1136/annrheumdis-2013-203407.

Solomon DH, Curtis JR, Saag KG, et al. Cardiovascular risk in rheumatoid arthritis: comparing TNFa blockade with nonbiologic DMARDs. *Am J Med.* 2013;126(8):730.e9–730.e17. doi: 10.1016/j.amjmed.2013.02.016.

Herrinton LJ. Regarding: a tale of two cohorts. *Gastroenterology.* 2013;144(3):e21–e22.

Li D, Collins B, Velayos FS, et al. Racial and ethnic differences in health care utilization and outcomes among ulcerative colitis patients in an integrated health care organization. *Digestive Diseases and Sciences.* 2014;59(2):287–294.

## Appendix B: Articles Resulting from CCFA's Subcontract with the Ocean State Crohn's and Colitis Area Registry

Mount Sinai School of Medicine
Rhode Island Hospital

***Published Manuscripts***

Shah SA, Feller ER. Inflammatory bowel disease. *Medicine and Health Rhode Island.* 2009;92(3):72–77.

Lam MY, Lee H, Bright R, Korzenik JR, Sands BE. Validation of interactive voice response system administration of the Short Inflammatory Bowel Disease Questionnaire. *Inflamm Bowel Dis.* 2009;15(4):599–607.

Saha S, Lam M, Roberson E, et al. Inflammatory bowel disease: a survey of Rhode Island physicians. *Medicine and Health Rhode Island.* 2012;95(1):4–8.
Long MD, Hutfless S, Kappelman MD, et al. Challenges in designing a national surveillance program for inflammatory bowel disease in the United States. *Inflamm Bowel Dis.* 2014;20(2):398–415.

Saha S, Zhao YQ, Shah SA, et al. menstrual cycle changes in women with inflammatory bowel disease: a study from the Ocean State Crohn's & Colitis Area Registry. *Inflamm Bowel Dis.* 2014;20(3):534–540.

Cohen BL, Zoëga H, Shah SA, et al. Fatigue is highly associated with poor health-related quality of life, disability and depression in newly-diagnosed patients with inflammatory bowel disease, independent of disease activity. *Aliment Pharmacol Ther.* 2014;39(8):811–822.

***Manuscripts in Progress***

**Title**: Incidence of Crohn's disease and ulcerative colitis in Rhode Island, 2008–2010
**Brief description:** A manuscript on the incidence of Crohn's disease and ulcerative colitis among the total population of Rhode Island.
**Key goals/objectives:** To determine the incidence rate of IBD in a state-based cohort, representing the entire state population.
**Journal or Intended Journal:** Clinical Gastroenterology and Hepatology
**Authors:** Sands BE, Shah SA, LeLeiko NS, Bright RM, Zoega H, Lidofsky S, Law M, Moniz H, Grabert SA, Bancroft B, Merrick M, Flowers NT
**How supports state or national public health programs:** Demonstrates and validates methodology to provide accurate incidence rates for IBD in a state, and also provides the most updated measure of incidence rates—found to be higher in RI than has been reported in other US locations—and allows projection of accurate incidence rates in the United States, adjusted by age and sex.

**Title**: Testing for *Clostridium difficile* in patients newly diagnosed with IBD in a community setting

**Brief description:** A manuscript on the rate of CDI testing at the time of diagnosis of IBD
**Key goals/objectives:** To determine how CDI affects the course of IBD.
**Journal or Intended Journal:** Inflammatory Bowel Diseases
**Authors:** Krishnarao A, de Leon L, Bright R, Moniz H, Law M, Leleiko N, Sands BE, Merrick M, Flowers N, Shapiro J, Giacalone J, Shah SA
**How supports state or national public health programs:** Documents critical under-testing for C. difficile, an important precipitant of flare in IBD, and associated with worse outcomes in patients with IBD.

**Title**: Nutritional behavior in newly diagnosed pediatric IBD patients
**Brief description:** A manuscript on the dietary behaviors of children with IBD.
**Key goals/objectives:** To demonstrate the important role of assessing dietary behaviors in children with IBD in response to the demands brought about by their chronic illness.
**Journal or Intended Journal:** Journal of Pediatric Gastroenterology and Nutrition
**Authors:** Hagin S, Lobato DJ, Sands BE, Korzenik JR, Flowers N, Merrick M, Shah SA, Bancroft B, Bright R, Law M, Moniz H, Shapiro J, LeLeiko NS
**How supports state or national public health programs:** Identifies suboptimal eating behaviors, with possible implications for under-nutrition of children with IBD.

**Title**: Corticosteroid use in a prospective, community-based cohort of newly diagnosed inflammatory bowel disease patients
**Brief description:** A manuscript examining corticosteroid use during the first year of IBD diagnosis in a prospective, community-based inception cohort in the state of Rhode Island.
**Key goals/objectives:** To describe the rates of corticosteroid exposure during the first year of IBD diagnosis and to understand whether clinical features or characteristics of the treating gastroenterologist may be associated with steroid use.
**Journal or Intended Journal:** American Journal of Gastroenterology
**Authors:** Shapiro JM, Hagin SE, Sands BE, Leleiko NS, Bright R, Law M, Moniz H, Giacalone J, Merick M, Shah SA
**How supports state or national public health programs:** Shows that corticosteroids—well known to be associated with numerous harmful effects—are still widely used in the community to treat patients with IBD, and shows associations with worse disease outcomes.

**Title**: Radiation exposure to the abdomen and pelvis in IBD patients enrolled in the Ocean State Crohn's and Colitis Area Registry (OSCCAR)
**Brief description:** A manuscript on type and quantity of diagnostic imaging exams in patients with newly diagnosed IBD.
**Key goals/objectives:** To identify specific subsets of patients newly diagnosed with IBD at risk for significant radiation exposure early in the disease course.
**Journal or Intended Journal:** Inflammatory Bowel Diseases
**Authors:** Wu E, Engels M, Grand D, Harris A, Giacalone J, Shah SA, Shapiro J, Leleiko NS, Bright R, Law M, Moniz H, Merrick M, Sands BE
**How supports state or national public health programs:** Demonstrates significant radiation exposure among patients with IBD—greater among those with Crohn's disease and adults with IBD—with implications for developing programs to avoid excessive radiation exposure in IBD patients.

**Title**: Body image dissatisfaction in an incident cohort of inflammatory bowel disease: a longitudinal study from the Ocean State Crohn's and Colitis Area Registry
**Brief description:** A manuscript on the burden of body image dissatisfaction in individuals with IBD.
**Key goals/objectives:** To determine the changes in body image dissatisfaction which occur over time in a prospective cohort of adults with IBD.
**Journal or Intended Journal:** Inflammatory Bowel Diseases
**Authors:** Saha S, Zhao Y, Shah S, Bright R, Lidofsky S, Esposti SD, LeLeiko N, Law M, Moniz H, Flowers N, Merrick M, Sands BE
**How supports state or national public health programs:** Demonstrates that women, more than men, with IBD may have altered body image and that this dissatisfaction may be greater if they are treated with corticosteroids. This has implications for the psychosocial well-being of women with IBD.

**Title**: Sensitivity, specificity, and stability of seromarkers in a prospective, population-based inception cohort of newly-diagnosed inflammatory bowel disease (IBD)
**Brief description:** A manuscript on the use of seromarkers in the diagnosis and prognosis of IBD.
**Key goals/objectives:** To assess the accuracy of seromarkers in patients with newly-diagnosed, community-based IBD and to assess the stability of seromarkers over time.
**Journal or Intended Journal:** American Journal of Gastroenterology
**Authors:** Mao E, Giacalone J, Sands BE, Leleiko N, Wallenstein S, Princen F, Singh S, Lockton S, Bright R, Law M, Moniz H, Shapiro J, Merrick M, Shah SA
**How supports state or national public health programs:** Shows that a panel of serologic markers used in the diagnosis of patients with IBD has less sensitivity for the diagnosis when used soon after the diagnosis is made. In addition, patients without disease complications are more likely to test falsely negatively for these serologic tests, with implications for physicians who order such tests.

## References


1. Kappelman MD, Rifas-Shiman SL, Porter CQ, et al. Direct health care costs of Crohn's disease and ulcerative colitis in US children and adults. *Gastroenterology.* 2008;135(6):1907–1913.
2. Park KT, Bass D. Inflammatory bowel disease-attributable costs and cost-effective strategies in the United States: a review. *Inflamm Bowel Dis.* 2011;17(7):1603–1609.
3. Kappelman MD, Rifas-Shiman SL, Kleinman K, et al. The prevalence and geographic distribution of Crohn's disease and ulcerative colitis in the United States. *Clin Gastroenterol Hepatol.* 2007;5(12):1424–1429.
4. Loftus EV Jr. Clinical epidemiology of inflammatory bowel disease: incidence, prevalence, and environmental influences. *Gastroenterology.* 2004;126(6):1504–1517.
5. Newby EA, Croft NM, Green M, et al. Natural history of pediatric inflammatory bowel diseases over a 5-year follow-up: a retrospective review of data from the register of pediatric inflammatory bowel diseases. *J Pediatr Gastroenterol Nutr.* 2008;46(5):539–545.
6. Loftus CG, Loftus EV Jr, Harmsen WS, et al. Update on the incidence and prevalence of Crohn's disease and ulcerative colitis in Olmsted County, Minnesota, 1940–2000. *Inflamm Bowel Dis.* 2007;13(3):254–261.
7. Abramson O, Durant M, Mow W, et al. Incidence, prevalence, and time trends of pediatric inflammatory bowel disease in Northern California, 1996 to 2006. *J Pediatr.* 2010;157(2):233. e1–239. e1.
8. Adamiak T, Walkiewicz-Jedrzejczak D, Fish D, et al. Incidence, clinical characteristics, and natural history of pediatric IBD in Wisconsin: a population-based epidemiological study. *Inflamm Bowel Dis.* 2013;19(6):1218–1223.
9. Herrinton LJ, Liu L, Lewis JD, Griffin PM, Allison J. Incidence and prevalence of inflammatory bowel disease in a Northern California managed care organization, 1996–2002. *Am J Gastroenterol.* 2008;103(8):1998–2006.
10. Herrinton LJ, Liu L, Fireman B, et al. Time trends in therapy and outcomes for adult inflammatory bowel disease, Northern California, 1998–2005. *Gastroenterology.* 2009;137(2):502–511.
11. Velayos FS, Liu L, Lewis JD, et al. Prevalence of colorectal cancer surveillance in ulcerative colitis patients in an integrated health-care delivery system. *Gastroenterology.* 2010;139(5):1511–1518.
12. Herrinton LJ, Liu L, Weng X, Lewis JD, Hutfless S, Allison JE. Role of thiopurine and anti-TNF therapy in lymphoma in inflammatory bowel disease. *Am J Gastroenterol.* 2011;106(12):2146–2153.
13. Herrinton LJ, Liu L, Levin TR, Allison JE, Lewis JD, Velayos FS. Incidence and mortality of colorectal adenocarcinoma in persons with inflammatory bowel disease from 1998 to 2010. *Gastroenterology.* 2012;143(2):382–389.

14. Sands BE, LeLeiko N, Shah SA, Bright R, Grabert S. OSCCAR: Ocean State Crohn's and Colitis Area Registry. *Medicine and Health Rhode Island.* 2009;92(3):82–88.

15. Saha S, Lam M, Roberson E, et al. Evaluation of possible inflammatory bowel disease: a survey of Rhode Island physicians. *Medicine and Health Rhode Island.* 2012;95(1):4–8.

16. Long MD, Hutfless S, Kappelman MD, et al. Challenges in designing a national surveillance program for inflammatory bowel disease in the United States. *Inflamm Bowel Dis.* 2013;20(2):398–415.

17. Longobardi T, Jacobs P, Bernstein CN. Work losses related to inflammatory bowel disease in the United States: results from the National Health Interview Survey. *Am J Gastroenterology.* 2003;98(5):1064–1072.

18. Rodemann J, Dubberke E, Reske K, et al. Incidence of *Clostridium difficile* infection in inflammatory bowel disease. *Clin Gastro Hepatol* 2007; 5: 339-344.

19. Ananthakrishnan AN, McGinley EL, Binion DG. Excess hospitalization burden associated with *Clostridium difficile* in patients with inflammatory bowel disease. *Gut* 2008; 57: 205-210.

20. Chiplunker A, Ananthakrishnan AN, Beaulieu DB, et al. Long-term impact of *Clostridium difficile* on inflammatory bowel disease. *Gastroenterology* 2009; 136.

21. Jodorkovsky D, Young Y, Abreu MT. Clinical outcomes of patients with ulcerative colitis and co-existing *Clostridium difficile* infection. *Dig Dis Sci* 2010; 55: 415-420.

22. Jen MH, Saxena S, Bottle A, et al. Increased health burden associated with *Clostridium difficile* diarrhoea in patients with inflammatory bowel disease. *Aliment Pharmacol Ther* 2011; 33: 1322-1331.