Final Report of
The Epidemiologic Study on
Crohn’s Disease and Ulcerative Colitis

HB 869 ER (Section 2)

Prepared by

Bureau of Epidemiology
Florida Department of Health

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EXECUTIVE SUMMARY

Crohn’s disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD), are serious chronic disorders of the gastrointestinal tract. On June 10, 2005, Governor Jeb Bush signed House Bill 869 entitled “Crohn’s and Colitis Disease Research Act” that requires the Florida Department of Health (DOH) to conduct an epidemiologic study on IBD. The goal of this epidemiologic study is to determine: (1) the prevalence of Crohn’s disease and ulcerative colitis in Florida; (2) the demographic characteristics of patients with Crohn’s disease and ulcerative colitis; and (3) the role of environmental and genetic risk factors in the development of Crohn’s disease and ulcerative colitis. The act became effective on July 1, 2005, and the final report is due on February 1, 2006.

An advisory committee was developed for the epidemiologic study. The committee members consisted of representatives and researchers at DOH, the University of Florida, Agency for Health Care Administration (AHCA), Blue Cross Blue Shield (BCBS), Crohn’s and Colitis Foundation of America (CCFA), members of the House of Representatives and the Senate, physicians, other medical providers, and other interested groups. Monthly conference calls and an in-person conference were held for the committee members to guide the study.

The study was designed based on an extensive literature review of previous epidemiologic studies and recommendations from national experts. This study received support from the Secretary of the Department of Health, medical providers, and IBD patients throughout the state.

BCBS and AHCA provided large healthcare claim datasets, including BCBS data, Medicaid data, hospital discharge data, and ambulatory patient data. The DOH team conducted gastroenterology physician surveys, an IBD patient survey, and a statewide survey of general population through the Behavioral Risk Factor Surveillance System (BRFSS). The definition of IBD was based on a set of International Classification of Disease Version 9 (ICD-9) codes.

The study collected healthcare claim data with more than 42 million unduplicated records in up to 10 years, and surveyed more than 2,000 households, medical providers, and IBD patients statewide during the study period. The data were analyzed by patient’s gender, race/ethnicity, age, residential county, household income, and type of health insurance. Statewide prevalence and number of IBD patients were estimated based on the data of this study and make-up of Florida population.

It is estimated that the prevalence of Crohn’s disease is 222 per 100,000 persons and the prevalence of ulcerative colitis is 307 per 100,000 persons in Florida. It is also estimated that there are approximately 35,500 Crohn’s disease patients and 49,000 ulcerative colitis patients in Florida. Approximately 11 percent of IBD patients are hospitalized and 12 percent of IBD patients are treated as ambulatory patients every year. The prevalence of IBD was higher among people ages 30 to 80 years old than among other age groups, higher among non-Hispanic Whites than among other race/ethnicity groups, and higher among females than among males. Medicaid recipients had the lowest prevalence rates in either inpatients or ambulatory patients. Sarasota and Palm Beach counties were the only two counties that had a high prevalence of both Crohn’s disease and ulcerative colitis in all hospital discharge data, ambulatory patient data, and BCBS data.

This study surveyed 27 IBD patients and found a high percent of non-Hispanic Whites, a high percent of patients with a family history, and a high percent of Jewish descents, which may
suggest an association between genetic factors and IBD. The survey examined several environmental factors based on literature reviews, including exposures to cigarette smoking, history of living near cattle and history of tonsillectomy or appendectomy. However, no causal relationship could be established between these risk factors and IBD due to the nature of the small survey of a convenient sample.

Future studies are recommended based on this study. These studies include: (1) a BRFSS survey with increased sample size to better estimate the population-based prevalence of IBD; (2) a case-control study to identify risk factors of IBD; and (3) an IBD patient voluntary registry through their providers. This registry will provide data for a longitudinal follow-up study of IBD patients on treatment, outcome, and quality of life.
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BACKGROUND

Crohn’s disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD), are serious chronic disorders of the gastrointestinal tract. Approximately 1.4 million Americans are afflicted with these illnesses, 30 percent of whom are diagnosed during childhood. IBD represents a major cause of morbidity from digestive illness, and ulcerative colitis patients are at high risk for developing colorectal cancer. Although IBD is rarely fatal, it is often devastating.

On November 30, 2004, President George W. Bush signed into law the first piece of legislation focused on Crohn’s disease and ulcerative colitis, entitled the “Research Review Act.” During the 108th Congress, the Crohn’s and Colitis Foundation of America and its National IBD Advocacy Network advanced this legislation with three provisions for advancing research on IBD. Provisions were taken directly from legislation, entitled the “Inflammatory Bowel Disease Research Act.” Within 12 months after the date of the enactment, the director of the Centers for Disease Control and Prevention was responsible for submitting a comprehensive plan to address the burden of inflammatory bowel disease, in both adult and pediatric populations, to the Senate Health, Education, Labor and Pensions Committee, the House Energy and Commerce Committee, and the House and Senate Appropriations Committee.

There is a perceived increase of IBD in Florida; however, no previous research has been conducted to reveal the prevalence of these illnesses among Florida residents. Therefore, the Florida State Legislature enacted the “Crohn’s and Colitis Disease Research Act.”

On June 10, 2005, Florida House Bill 869 was approved by Governor Jeb Bush. House Bill 869 is referred to as the “Crohn’s and Colitis Disease Research Act.” The act requires the Florida Department of Health (DOH) to conduct an epidemiologic study on inflammatory bowel disease in collaboration with the University of Florida College of Public Health and Health Professions, and requires the establishment of an IBD study group that must consist of representatives from the DOH, the Agency for Health Care Administration (AHCA), Crohn’s and Colitis Foundation of America (CCFA), the House of Representatives, the Senate, medical providers, and other interested groups. The effective start date is July 1, 2005, and the final report is due to the Governor and the Florida Legislature by February 1, 2006.

PURPOSE OF THE STUDY

The purpose of this study is to work with the University of Florida and other agencies and organizations to conduct an epidemiologic investigation. The goal of this epidemiologic study is to determine the:

2. Demographic characteristics of patients with Crohn’s disease and ulcerative colitis.
3. Role of environmental and genetic risk factors in the development of Crohn’s disease and ulcerative colitis.
IMPLEMENTATION OF THE STUDY

Literature Review

As the first step of study design, DOH conducted an extensive literature review for studies on IBD. The project coordinator searched the Internet and journals to identify previous epidemiologic studies on both adult and childhood IBD. Through the literature review, DOH gathered information regarding potential and known IBD risk factors, epidemiologic and clinical characteristics of patients with IBD, and potential environmental exposures for IBD.

Drs. Robert Sandler and Edward Loftus (Sartor RB, Sandborn WJ, eds., Kirsner's Inflammatory Bowel Diseases, 6th ed., New York: Saunders, 2004) reviewed risk factors for IBD, including demographic characteristics of patients, diet, breast feeding and perinatal events, marital status, occupation and social class, oral contraceptives, cigarette smoking, non steroidal anti-inflammatory drugs, appendectomy, measles, and other miscellaneous factors. Sandler and Loftus conclude that there is undisputable evidence of heritable factors in the genesis of IBD, and environmental influence may attribute to 85-90 percent in ulcerative colitis and 50-55 percent in Crohn's disease. Smoking is highly associated with Crohn's disease, as is nonsmoking with ulcerative colitis. Truelove (Br Med J 1961:1:61) noted cow's milk might exacerbate symptoms of ulcerative colitis.

Dr. Edward Loftus (Gastroenterology, 2004:126:1504-17) states that previous studies have provided insight into the differences in incidence of IBD across age, time, and geographic region, suggesting that environmental factors can significantly modify the expression of these conditions. They suggest the strongest risk factors to be identified at this time are family history of IBD, cigarette smoking, and appendectomy. Research also suggests variation in the demographics of IBD patients:

- Gender: Females tend to have a predominance of Crohn's disease, whereas men tend to have a higher incidence of ulcerative colitis.
- Age: Both Crohn's disease and ulcerative colitis are most commonly diagnosed in late adolescence and early adulthood, however, the diagnosis may occur at any age.
- Race/Ethnicity: Although Whites have a higher incidence of IBD, the incidence among African Americans is approaching that of Whites. Asian Americans, Hispanic Americans, and aboriginal North Americans are less likely to develop IBD, especially Crohn's disease. Ethnic and racial differences may be more related to lifestyle and environmental influences than genetic differences.

Consultations from Experts

In addition to the literature search, DOH sought national and local experts to provide insights for developing Florida's IBD research plan. The project coordinator and the team consulted with many researchers nationwide for research methodology. The information received from these experts helped the Florida researchers refine the methodology of the IBD study. From August through December of 2005, DOH communicated with the following individuals and organizations for their suggestions and advice:
- Mr. Sean Cucchi and Dr. Siobhán O’Connor, Centers for Disease Control and Prevention (CDC), discussed the “Inflammatory Bowel Disease Research Act,” which requires the CDC, in conjunction with CCFA, to conduct a national IBD epidemiology study. DOH requested information regarding CDC’s research approach and methodology for data collection at the national level.

- Ms. Suzanne Rosenthal, CCFA Co-Founder, and Chairman of the Board Emeritus, and Marjorie Merrick, CCFA Vice President of Research and Scientific Programs provided contact information for national IBD experts, potential funding sources, and guidance in developing methodology.

- Florida CCFA representatives provided contact information for Florida physicians, IBD support group facilitators, and IBD awareness activities.

- Dr. Robert Sandler, Chief, Division of Gastroenterology and Hepatology at the University of North Carolina, and member of CCFA’s National Scientific Committee, provided information on IBD epidemiological literature, former IBD study group activities, survey development, and future research development.

- Dr. Amy Trachter, Assistant Professor of Clinical Medicine, Department of Medicine Division of Gastroenterology, Miller School of Medicine University of Miami, provided revisions to patient survey and disseminated surveys to IBD patients. Dr. Trachter also offered additional support for developing grant proposals and future IBD research.

- Dr. Subra Kugathasan, Associate professor, Pediatrics, Medical College of Wisconsin, discussed resources imperative for the development and maintenance of a pediatric IBD registry.

- Dr. Ira Shafran, Shafran Gastroenterology Center, provided the “Inflammatory Bowel Disease Questionnaire Treatment Evaluation Form,” a survey administered to patients at his Gastroenterology Center.

- Dr. Lisa Herrinton (Co-PI of IBD study funded by CCFA) of Kaiser Permanente Division of Research, provided information regarding research approach and methodology of two CCFA-funded epidemiological studies. She also shared with DOH the prevalence of IBD among nine health plans across the United States (U.S.), and incidence and prevalence of IBD at Kaiser Permanente, Northern California.

- Mr. David Wolff, Crohn’s and Colitis support group facilitator, provided information about IBD patients and the daily implications of living with these illnesses. Mr. Wolff gave insight for the development of a pilot patient survey and assisted in the distribution of surveys to support group members.

**Advisory Committee**

The study advisory group (a.k.a. Advisory Committee) consisted of epidemiologists at DOH, analysts at AHCA and Blue Cross Blue Shield, physicians and researchers at the University of Florida, members of the House of Representatives and the Senate, representatives from CCFA, medical providers, and other interested groups. The group welcomed any interested organization or individual to participate in the study group.
The first Advisory Committee conference call was held on June 14, 2005. Representatives from the DOH and the University of Florida (UF) participated in the conference call. The group decided to appoint a coordinator, develop an advisory committee, conduct monthly conference calls, and schedule an in-person meeting for advisory members. The group also approved the data collection methodology proposed by the DOH.

Regan Glover of the DOH was appointed as the project coordinator on July 18, 2005.

A letter of invitation to join the Advisory Committee was sent to medical providers, the legislature, representatives from Blue Cross Blue Shield of Florida, state and national Crohn’s and Colitis Foundation of America representatives, and the Agency for Health Care Administration. Those interested in joining the committee and/or following the study were placed in a contact database.

Members of the Advisory Committee, consultants, and analysts for this study are:
- AHCA: Gloria Barker, Mel Chang, Susan Chen, Beth Eastman, Adrienne Henderson, Lisa Rawlins, and Cliff Schmidt
- BCBS: John Bookstaver, Randy Kammer, John Montgomery, David Pizzi, and John Williams
- CDC: Sean Cucchi and Siobhan O’Connor
- CCFA: Kiren Annigeri, Marlene Bluestein, Toby Gordon, Marjorie Merrick, Suzanne Rosenthal, Allison Silver, Ellen Shapiro, Kelly Stouten, and Dave Wolff
- DOH: Lisa Fisher, Regan Glover, Youjie Huang, Curt Miller, Heather Murphy, Mike Paredes, and Dian Sharma
- Florida House Representative: Eleanor Sobel
- Florida Senate: Gwen Margolis
- Kaiser Permanente: Lisa Herrinton
- Tidewater Consulting, Inc.: Frank Mayernick
- Physician: Lawrence Adams
- Psychologist: Amy Trachter
- UF: Paul Duncan, Chris Jolley, Robert Frank, and John Valentine

Conference calls were held on August 11, September 1, October 6, November 3, 2005, and January 18, 2006. Representatives from a number of agencies, universities, and organizations, as well as interested individuals, participated in the conference calls. The Advisory Committee provided recommendations for the following issues:
- Requirements of House Bill 869.
- Identification of additional members for the study advisory group.
- Plan of study, including overall approach and timeline.
- Diagnoses and procedure codes (ICD-9) for identifying IBD cases in claim data.
- Methods of conducting a survey of GI physicians and IBD patients.
- Development of the pediatric survey and cover letter.
- Survey questions to be added to statewide Behavioral Risk Factor Surveillance System (BRFSS).
- Progress of the study, including data analyses and survey response.
- Preliminary findings of the study.

On November 15, 2005, the Advisory Committee had an in-person meeting in Gainesville, Florida. The participants reviewed preliminary findings and discussed strengths/limitations of study methods and potential sources of data dissemination.
**Information Dissemination**

The DOH Bureau of Epidemiology made great efforts to disseminate the information regarding the study, including the purpose, methods, and preliminary results to public health professionals, medical providers, Advisory Committee members, and the general public during the entire study period.

- To public health professionals:
  - The Bureau published an article introducing the new research in *Epi Update* in July 2005. *Epi Update* is a web-based weekly journal published by the Bureau of Epidemiology. A follow-up article to update the progress of the study was published in *Epi Update* in September 2005.
  - The study was introduced to county health departments on a bi-weekly conference call in August 2005.
  - An overview of the IBD study was submitted to *The Health Advisor*, which is the forum to spotlight Department of Health special events, people, programs, and statistics. The newsletter is sent to county health departments, Department of Health units, legislators, and others involved in health around the state and country. The article will appear in the January/February 2006 issue.

- To Advisory Committee members:
  - Plans, progress of the implementation of the study, and preliminary results were provided to, and reviewed by, the Advisory Committee at monthly conference calls and the in-person meeting in November.

- To Medical providers:
  - The study was introduced to gastroenterologists at the 40th Annual Meeting of the Florida Gastroenterological Society and the American College of Gastroenterology in Naples, Florida, on September 9-11, 2005.

- To interested groups and individuals:
  - The project coordinator presented preliminary findings for Crohn’s Disease at the CCFA Fourth Annual Advances in IBD Research in Miami Beach, Florida, in December 2005.
  - Per suggestion from a spokesperson for the national chapter of CCFA, a letter was sent to former first lady, Barbara Bush, introducing the Florida IBD study and inviting her to attend a meeting where the findings from this study will be presented.
  - Frequent conversations were maintained via e-mails and phone calls between the project coordinator and IBD support groups in the state.

**METHODS**

**Sources of Data**

When sources of population-based data were identified, the DOH research team found that all databases available were developed for purposes other than IBD epidemiologic study, and not a single database was available that would meet the specific needs for this study. Therefore, the
research team decided to collect a number of large databases that each covers part of the IBD population and then combine the information from these databases for a comprehensive result.

The data included in this study consisted of healthcare claim data (hospital discharge data, ambulatory care data, Blue Cross Blue Shield data, and Medicaid data), and survey data (physician survey, patient survey, and BRFSS survey). Collectively, these data covered a majority of the Florida population and provided a well-represented prevalence of IBD in Florida.

**Blue Cross Blue Shield (BCBS) claim data**

BCBS of Florida provided claim data for their members from calendar years 2001 to 2005. BCBS is one of the major private health insurance carriers, with approximately 30 percent of Florida’s commercial market share. More than 2.5 million BCBS members in Florida receive medical services every year. BCBS members consist of males and females of all ages and races. A majority (more than 80 percent) of members who had a claim record are under the age of 65. Claim data capture information on hospitalizations and clinic visits.

The data were unduplicated to provide the number of patients, instead of the number of medical services. Therefore, if a patient with IBD had more than one visit, he or she was only counted once during the data collection timeframe. Disease diagnoses were grouped into several categories: Crohn’s disease (ICD-9 code: 555.9), chronic proctitis (556.2), chronic sigmoiditis (556.3), colitis (556.8, 556.9), enteritis (555.0, 555.1), ileitis (555.2), and other and unspecific colitis (558.9). Data were broken down by patient’s age, sex, and residential county.

The DOH included data in four years (2001-2004) in this study, with 10,970,547 person-years. On average, 2,742,637 BCBS members were included in the data each year during 2001-2004.

**Medicaid data**

Medicaid claim data in fiscal years (FYs) 2000-2004 were provided by AHCA. Medicaid data included all claims, both hospitalizations and clinic visits, for more than one million Medicaid recipients in Florida. Medicaid recipients consist of people of all ages, with more than 50 percent of recipients who are under age 20.

The data were unduplicated to count only the number of patients who received medical care. Disease diagnoses were grouped into several categories: Crohn’s disease (ICD-9 code: 555), ulcerative colitis (ICD-9 code: 556), and other IBD (ICD-9 code: 558). Data were broken down by patient’s age, sex, and residential county.

Data in all five years (FYs 2000-2004) were included in the study. The data contain 5,922,697 person-years of records, with an average of 1,184,539 recipients each year.

**Ambulatory patient data**

AHCA provided ambulatory patient data for fiscal years 1997-2004. The ambulatory patient data are collected from freestanding ambulatory surgical centers, lithotripsy centers, cardiac catheterization laboratories, and short-term acute care hospitals. Ambulatory patients are those who have a face-to-face encounter with a provider, and who are not formally admitted
as an inpatient in an acute care hospital setting, and not treated in the emergency room. The ambulatory patient data include patients of all ages and races, regardless of the type of a patient’s medical insurance.

Disease diagnoses were grouped into several categories based on either primary diagnosis or any of the secondary diagnoses. These categories are Crohn’s disease, ulcerative colitis, and other colitis.

Data in all eight years were included in the analysis. There were 12,710,291 patient records analyzed, with an average of approximately 1.6 million patients every year. Patients might have more than one ambulatory visit either in a single year or in different years. The DOH unduplicated multiple visits in two ways: 1) to count each patient only once for the entire 8-year period for number of “new” IBD patients among ambulatory patients; and 2) to count each patient once in a single year for an annual prevalence of IBD patients among ambulatory patients. Data were analyzed by race, age, residential county, and type of medical insurance.

**Hospital discharge data**
AHCA also provided hospital discharge data for 1995-2004. The hospital discharge data include all inpatients of all ages and types of medical insurance.

Disease diagnoses were grouped into several categories based on either primary or secondary diagnoses. These categories are Crohn’s disease, ulcerative colitis, and other colitis.

Data in all 10 years were included in the analysis. There were 12,769,086 inpatient records analyzed, with an average of approximately 1.2 million patients every year. Many patients had more than one hospitalization either in a single year or in different years. The DOH unduplicated multiple hospitalizations in two ways: 1) to count each patient once in the entire 10-year period for number of “new” IBD patients among inpatients; and 2) to count each patient once in a single year for an annual prevalence of IBD patients among inpatients.

IBD inpatients who had ambulatory visit(s) were excluded from the analyses to avoid duplication for patients receiving medical care in hospitals. Data were analyzed by race, age, residential county, and type of medical insurance.

**Gastroenterology (GI) Physician survey**
DOH Bureau of Epidemiology developed a gastroenterology (GI) physician survey in August 2005. (See attachment 1 for the survey questionnaire.) The survey was designed to estimate:
- Patient demographics
- Number of newly diagnosed IBD cases within past 12 months
- Severity of illness measured by hospitalizations due to IBD
- Role of family history
- Patient’s enrollment for colon cancer surveillance
The survey questionnaire was sent to 660 gastroenterologists in Florida by mail. The DOH research team received 132 returned survey questionnaires, among which 113 were completed.

Regan Glover, the project coordinator, distributed the survey questionnaires at the general sessions of the 40th Annual Meeting of the Florida Gastroenterological Society and the American College of Gastroenterology in Naples Florida on September 9-11, 2005. Ten completed surveys were received from the conference attendees.

**Pediatric GI physician survey**

The Bureau of Epidemiology revised the GI-physician survey questionnaire to address pediatric IBD patients seen by pediatric specialists. Data collected were similar to that collected from the GI physician survey. Survey questionnaires were distributed to 41 Florida members of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) via mail. A cover letter and pre-paid return envelope were included with the mailed survey. Collection period began September 26, 2005, and ended on October 26, 2005. Eight (20 percent) of 41 physicians returned completed survey questionnaires.

**IBD patient survey**

The DOH team developed a short anonymous survey of IBD patients. (See attachment 2 for the questionnaire.) Dr. Amy Trachter and GI physicians assisted with the design of questionnaire. The purpose of this survey was to obtain information on risk factors of IBD, particularly environmental factors and genetic factors.

The survey was implemented from December 23, 2005, to January 10, 2006. To keep responses anonymous, the DOH did not disseminate directly surveys to IBD patients. Instead, the survey questionnaire was emailed to facilitators of eight CCFA support groups. The facilitators were asked to distribute the survey questionnaire to their group members though e-mails. The total number of IBD patients who received the questionnaire from their support group facilitator was unknown. IBD patients who were willing to participate in the survey completed survey and returned surveys to DOH either electronically (e-mail/fax), or by U.S. Postal Service. The DOH received 27 completed survey questionnaires from IBD patients with two support groups in Miami and Sarasota.

**Behavioral Risk Factor Surveillance System survey**

The Behavioral Risk Factor Surveillance System (BRFSS) survey is a statewide random telephone survey of civilian, non-institutionalized adults (age 18 and older). The BRFSS is an ongoing collaborative survey with the CDC to monitor trends in risk behaviors related to preventable chronic diseases and conditions in Florida. Respondents are asked about health status, health behaviors, use of screening services, and access to health insurance and health care.

Three questions were designed by the Bureau of Epidemiology to survey the general population. These questions are:

- (Q1) Has anyone, including yourself, in your household, ever been told by a doctor or other health professional that you have Crohn’s disease or ulcerative colitis?
– (Q2) How many people in your household have been told that they have Crohn’s disease or ulcerative colitis?
– (Q3) How many of these people have been admitted to a hospital in the past 12 months because of Crohn’s disease or ulcerative colitis?

The purpose of these questions is to assess the prevalence of IBD (Q1), familial aggregation of IBD cases (Q2), and severity of IBD (Q3) among general population. These questions were included in the BRFSS survey from September 1, 2005, through December 15, 2005. There were 1,847 individuals surveyed, among whom 1,678 responded to these three questions.

Medicare data were requested in October 2005; however, approval to use those records was not received as of the date of this report.

**Definition of IBD**

The following are the International Classification of Disease Version 9 (ICD-9) codes that were used to define Crohn's disease, ulcerative colitis, and other IBD in healthcare claim data:

**Crohn’s disease:**
- 555.0: Ileitis (regional, segmental) and Regional enteritis or Crohn’s disease of duodenum, ileum, or jejunum
- 555.1: Colitis (granulomatous, regional, or transmural) and regional enteritis or Crohn’s disease of colon, large bowel, or rectum
- 555.2: Ileitis
- 555.9: Crohn’s disease NOS

**Ulcerative Colitis:**
- 556.0: Ulcerative (chronic) enterocolitis
- 556.1: Ulcerative (chronic) ileocolitis
- 556.2: Ulcerative (chronic) proctitis
- 556.3: Ulcerative (chronic) proctosigmoiditis
- 556.5: Left-sided ulcerative (chronic) colitis
- 556.6: Universal ulcerative (chronic) colitis
- 556.8: Other ulcerative colitis
- 556.9: Ulcerative colitis, unspecified.

**Other IBD:**
- 558.9: Other and unspecified (noninfectious gastroenteritis and colitis)

**Procedure code:**
- 45.23: Colonoscopy

**Analysis**

The primary purpose of analysis was to identify prevalence of IBD, patients’ characteristics, and IBD related risk factors. The DOH team did not attempt to make comparisons of prevalence among subpopulations. Therefore, the team did not conduct any statistical tests for difference
in prevalence among subpopulations, nor to adjust prevalence by age-distribution of the population. The methods that the DOH used for this study were:

1. Claim data
   a. Numbers of patients with IBD were tabulated.
   b. Prevalence of IBD was estimated in various populations. Prevalence is the proportion of the population with IBD in a specific year. The prevalence was calculated as follows:
      i. BCBS data and Medicaid data: by sex and age
      ii. Hospital discharge data and ambulatory patient data: by sex, age, race, and ethnicity, and type of insurance
   c. Incidence of IBD was estimated for BCBS IBD patients. Incidence is the number of new cases diagnosed per 100,000 persons in a year. Although BCBS data counted only new patients to the BCBS system in the four-year period, some of “new” patients might have been diagnosed before the study period.
   d. Proportion of IBD patients with a colonoscopy was calculated.

2. BRFSS survey data
   Prevalence of IBD was estimated by race and household income. The prevalence was not weighted by the probability of respondents being selected for the survey because the weight variable was not available during preparation of this report. Responses of “don’t know” or “unsure” were excluded from analyses.

3. Physician survey
   Percents of responses were tabulated for estimates of:
   a. Newly diagnosed cases (within past 12 months)
   b. Patient demographics
   c. Severity of illness (hospitalizations)
   d. Role of family history
   e. Colon cancer surveillance

4. Patient survey
   Percents of responses were tabulated for estimates of:
   a. Patient demographics (sex, race/ethnicity and region)
   b. Age of diagnosis/time lived with IBD
   c. Type of IBD (Crohn’s disease and ulcerative colitis)
   d. Severity of symptoms (mild, moderate, severe)
   e. Presence of family history
   f. Risk behaviors (active or passive inhalation of cigarette smoke)
   g. General assessment of health

There was a close collaboration among BCBS, AHCA, and DOH representatives and data analysts for this study. John Montgomery, John Williams, and John Bookstaver provided information on BCBS and conducted analyses of BCBS claim data. AHCA representatives Mel Chang, Beth Eastman, Susan Chen, Gloria Barker, Adrienne Henderson, and Cliff Schmidt provided support and conducted analyses on Medicaid data, hospital discharge data, and ambulatory patient data. DOH epidemiologist Youjie Huang and health data analyst Curt Miller analyzed the survey data and conducted part of the analyses of hospital discharge data and ambulatory patient data.
RESULTS

BCBS data

During 2001-2004, 6,373 BCBS members were diagnosed with Crohn’s disease and 8,658 were diagnosed with ulcerative colitis. In the BCBS claim data, an average of 2,742,637 BCBS members per year received medical services. Among those members, 1,520 members, on average, were diagnosed with Crohn’s disease and 2,061 were diagnosed with ulcerative colitis per year. (Table 1)

Table 1. Average Number of BCBS Members with IBD per Year, Florida, 2001-2004

<table>
<thead>
<tr>
<th>Age Group</th>
<th>All IBD</th>
<th>Crohn’s</th>
<th>Colitis</th>
<th>Other</th>
<th># of Members</th>
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<td>3,563</td>
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<td>287</td>
<td>381</td>
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</tr>
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<td>156</td>
<td>311</td>
<td>677</td>
<td>170,573</td>
</tr>
<tr>
<td>81+</td>
<td>430</td>
<td>59</td>
<td>102</td>
<td>269</td>
<td>122,395</td>
</tr>
<tr>
<td>By Sex</td>
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<tr>
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<td>3,006</td>
<td>684</td>
<td>956</td>
<td>1,365</td>
<td>1,296,831</td>
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<tr>
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<td>4,091</td>
<td>826</td>
<td>1,092</td>
<td>2,173</td>
<td>1,445,806</td>
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</tbody>
</table>

Number of members who were first time diagnosed with Crohn’s disease increased by 55 percent from 1,546 in 2001, to 2,395 in 2004. Similarly, the number of members diagnosed with ulcerative colitis increased by 53 percent from 1,181 in 2001, to 1,803 in 2004, and the number of patients diagnosed with other colitis increased by 45 percent from 2,820 in 2001, to 4,118 in 2004 (Figure 1).
The overall four-year prevalence was 222 per 100,000 persons for Crohn’s disease, 301 per 100,000 persons for ulcerative colitis, and 520 per 100,000 persons for other IBD.

The incidence (number of new patients among 100,000 people at risk in a year) increased during the four-year period. For Crohn’s disease, the rate increased by 92 percent from 50.4 per 100,000 to 96.9 per 100,000 person. The prevalence of ulcerative colitis increased by 90 percent. (Figure 2)
During the four-year period, the number of patients diagnosed with Crohn's disease and ulcerative colitis increased by age, and reached a peak in the 51-to-60–year-old age group (Table 1).

The four-year prevalence was the highest among people between the ages of 71 and 80 years. The prevalence increased by age, except among people age 81 years and older. (Figure 3)

The prevalence was slightly higher among females than among males for Crohn's disease (229 per 100,000 people versus 211 per 100,000 people), and ulcerative colitis (302 per 100,000 people versus 295 per 100,000 people). (Figure 3)

A colonoscopy is a medical procedure that is required to confirm the diagnosis of Crohn's disease and ulcerative colitis. Among BCBS members, a majority of new patients with Crohn's disease and ulcerative colitis had a colonoscopy. The percent of Crohn's disease patients who had a colonoscopy increased by age, from 61 percent among patients under age 11, to 87 percent among patients aged 80 years and older. The percent of patients with a colonoscopy was higher among ulcerative colitis patients than among Crohn's disease patients. Ninety percent of patients with ulcerative colitis had a colonoscopy with the exception of patients under age 11. (Figure 4)
Among Crohn’s disease patients, more females (82 percent) had a colonoscopy than did males (79 percent). Among ulcerative colitis patients, 93 percent of both males and females had a colonoscopy.

Among BCBS members, the prevalence of Crohn’s disease was greater than 400 per 100,000 in Liberty, Wakulla, Jefferson, Brevard, Glades, and Lee counties. (Figure 5) Liberty, Wakulla, Leon, Columbia, Brevard, Glades, Orange, Hillsborough, Polk, Sarasota, Palm Beach, and Broward counties had a prevalence of ulcerative colitis greater than 400 per 100,000 people. (Figure 6) Liberty, Wakulla, Brevard, and Glades counties had a high prevalence for both Crohn’s disease and ulcerative colitis.
Figure 5. Prevalence of Crohn's Disease by County Among BCBS Members, FL, 2001-2004

Figure 6. Prevalence of Ulcerative Colitis by County Among BCBS Members, FL, 2001-2004
Medicaid data

The number of Medicaid recipients receiving medical service varied greatly during FY 2000-2001 through FY 2004-2005. The average number of recipients with at least one claim for medical service was 1,184,535 per year. The average number of Medicaid recipients diagnosed with Crohn’s disease per year was 717 patients, with a prevalence of 61 per 100,000 people. On average, 304 recipients per year were diagnosed with ulcerative colitis, with a prevalence of 26 per 100,000 people. The number of recipients diagnosed with other colitis was 26,055 per year with a prevalence of 2,200 per 100,000 people. (Table 2)

Tables 2. Number of Patients with IBD among Medicaid Recipients, Florida, FY00/01-FY04/05

<table>
<thead>
<tr>
<th></th>
<th>FY00/01</th>
<th>FY01/2</th>
<th>FY02/3</th>
<th>FY03/4</th>
<th>FY04/5</th>
</tr>
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<td>1,084,413</td>
<td>895,044</td>
<td>1,170,599</td>
<td>1,730,249</td>
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<tr>
<td>Crohn's Disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>513</td>
<td>644</td>
<td>590</td>
<td>728</td>
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</tr>
<tr>
<td>Female</td>
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<td>406</td>
<td>474</td>
<td>733</td>
</tr>
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<td>Male</td>
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<td>228</td>
<td>184</td>
<td>254</td>
<td>378</td>
</tr>
<tr>
<td>Ulcerative Colitis</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
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<td>275</td>
<td>250</td>
<td>283</td>
<td>510</td>
</tr>
<tr>
<td>Female</td>
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<td>177</td>
<td>168</td>
<td>188</td>
<td>300</td>
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<td>210</td>
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<tr>
<td>Other</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
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<td>8,824</td>
<td>13,038</td>
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The prevalence of both Crohn’s disease and ulcerative colitis increased during FY2000-2001 through FY2004-2005. The prevalence of Crohn’s disease increased by 30 percent (38 percent for males and 27 percent for females), and the prevalence of ulcerative colitis increased by 52 percent (87 for males and 35 percent for females). (Figure 7)
The age-specific prevalence was the highest among people between ages 40 and 49 for both Crohn’s disease (142 per 100,000 persons) and ulcerative colitis (58 per 100,000 persons).

Females had a higher prevalence of Crohn’s disease (63 per 100,000 persons) than males (56 per 100,000 persons). However, the prevalence of ulcerative colitis was the same (26 per 100,000 persons) among both males and females. (Figure 8)
Hospital discharge data

There were 12,769,086 patients discharged from hospitals during 1995-2004. During this period, 187,700 patients were diagnosed with IBD, among whom 15,340 had Crohn’s disease and 13,820 had ulcerative colitis.

Among patients with Crohn’s disease and ulcerative colitis, there were more female patients, than there were male patients. Although most Crohn’s disease and ulcerative colitis patients were Whites, many patients of other races/ethnicities were diagnosed with IBD as well. (Table 3)

Table 3. Average Number of New Patients Hospitalized with IBD per Year, Florida, 1995-2004

<table>
<thead>
<tr>
<th></th>
<th>All IBD</th>
<th>Crohn’s</th>
<th>Colitis</th>
<th>Other</th>
<th></th>
<th>All IBD</th>
<th>Crohn’s</th>
<th>Colitis</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>By Age</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>0-</td>
<td>246</td>
<td>0</td>
<td>0</td>
<td>246</td>
<td>Black</td>
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<td>92</td>
<td>90</td>
<td>2,039</td>
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<td>3</td>
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<td>90</td>
<td>117</td>
<td>2,256</td>
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</tr>
<tr>
<td>21-30</td>
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<td>361</td>
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<tr>
<td>By Sex</td>
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<td></td>
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<td>Male</td>
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<td>662</td>
<td>600</td>
<td>6,049</td>
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</tr>
<tr>
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<td>872</td>
<td>782</td>
<td>10,265</td>
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</table>

New patients, excluding patients who were diagnosed as outpatients

The number of patients with Crohn’s disease and ulcerative colitis that were hospitalized increased by 61 percent and 51 percent, respectively, from 1995 to 2004. In 2004, 5,123 Crohn’s disease and 3,561 ulcerative colitis patients were hospitalized. (Figure 9)

The 10-year overall prevalence was 120.1 per 100,000 people for Crohn’s disease and 108.2 per 100,000 people for ulcerative colitis during the 10-year period. For calculating overall prevalence, a patient with an IBD diagnosis was counted once, regardless of how many times the patient was hospitalized in the 10-year period. Some patients were diagnosed with both Crohn’s disease and ulcerative colitis. The average prevalence of patients with either Crohn’s disease and/or ulcerative colitis was 221.0 per 100,000 people among inpatients.
The annual prevalence of Crohn’s disease increased by 26 percent, from 143 per 100,000 people in 1995 to 179 per 100,000 people in 2004. The annual prevalence of ulcerative colitis increased by 18 percent, from 106 per 100,000 persons in 1995 to 125 per 100,000 persons in 2004. (Figure 10)
The age-specific prevalence of Crohn’s disease increased by age, reached a peak of 193 per 100,000 people among the 41-to-50-year age group, then it decreased to 76 per 100,000 people among people aged 81 years and older. The prevalence of ulcerative colitis also increased by age, reached a peak of 140 per 100,000 people among 41-to-50 year age group, and decreased to 125 per 100,000 people among people aged 81 years and older. (Figure 11)

Whites had the highest prevalence of Crohn’s disease (145 per 100,000 people) and ulcerative colitis (125 per 100,000 people) among four race/ethnicity groups. Blacks had the lowest prevalence for both Crohn’s disease (61 per 100,000 people) and ulcerative colitis (51 per 100,000 people).

Patients who had a private medical insurance (147 per 100,000 people) and patients without any insurance (162 per 100,000 people) had a higher prevalence for Crohn’s disease than their counterparts did. Medicare beneficiaries had the highest prevalence (137 per 100,000 people) of ulcerative colitis. Medicaid recipients had the lowest prevalence of both Crohn’s disease (57 per 100,000 people) and ulcerative colitis (43 per 100,000 people).

Males had a higher prevalence of both Crohn’s disease (131 per 100,000 people versus 113 per 100,000 people) and ulcerative colitis (119 per 100,000 people versus 101 per 100,000 people) than females. (Figure 12)
Approximately one quarter (25.5 percent) of new Crohn’s disease patients had a colonoscopy. The percent of patients with a colonoscopy was higher among younger patients (under age 20) than among older patients, and higher among females than among males.

Among new patients with ulcerative colitis, 42.3 percent had a colonoscopy. The percent of patients with a colonoscopy was also higher among patients under age 30 and among females than among their counterparts. (Figure 13)
The percent of new Crohn’s disease patients with a colonoscopy was the highest among Hispanics. Both Medicaid recipients and patients without any medical insurance had a higher percent than their counterparts did. The percent of new ulcerative colitis patients with a colonoscopy was higher among Hispanics and Blacks than Whites and people of other races. The percent of ulcerative colitis patients with a colonoscopy was also higher among people without medical insurance and Medicaid recipients than for people with a private insurance and Medicare beneficiaries. (Figure 14)

Twelve counties had a 10-year overall prevalence of Crohn’s disease of 124 per 100,000 people or greater in Florida. These counties are Holmes, Union, Seminole, Hernando, Pasco, Pinellas, Indian River, Okeechobee, Sarasota, Charlotte, Collier, and Monroe. (Figure 15)
Figure 15. Prevalence of New Crohn’s Disease Inpatients by County of Residence, FL, 1995-2004

Twelve counties had a prevalence of ulcerative colitis of 130 per 100,000 or greater in Florida. These counties are Gulf, Suwannee, Columbia, Union, Citrus, Sumter, Lake, Hernando, Osceola, Sarasota, Charlotte, and Collier. (Figure 16)

Union, Hernando, Sarasota, Charlotte, and Collier had higher prevalence rates for both Crohn’s disease and ulcerative colitis than other counties in Florida during 1995-2004.
Ambulatory patient data

There were 12,710,291 patients who received at least one ambulatory care service during 1997-2004. Among these patients, 22,005 were diagnosed with Crohn's disease, 32,541 were diagnosed with ulcerative colitis, and 120,138 were diagnosed with other colitis.

There were more females than males among patients with Crohn's disease and ulcerative colitis. Approximately 80 percent of Crohn's disease and ulcerative colitis patients were White, and 60 percent of patients had a private health insurance. (Table 4)
Table 4. Average Number of New Outpatients with IBD per Year, Florida, 1997-2004

<table>
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<tr>
<th>By Age</th>
<th>All IBD</th>
<th>Crohn’s</th>
<th>Colitis</th>
<th>Other</th>
<th>All IBD</th>
<th>Crohn’s</th>
<th>Colitis</th>
<th>Other</th>
</tr>
</thead>
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<td>0-10</td>
<td>28</td>
<td>2</td>
<td>3</td>
<td>27</td>
<td>950</td>
<td>111</td>
<td>186</td>
<td>729</td>
</tr>
<tr>
<td>21-30</td>
<td>1,323</td>
<td>300</td>
<td>327</td>
<td>837</td>
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<td>2,207</td>
<td>3,232</td>
<td>12,085</td>
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<td>679</td>
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<td>1,726</td>
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<td>7982</td>
</tr>
<tr>
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<td>105</td>
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<td>1,064</td>
<td>568</td>
<td>101</td>
<td>142</td>
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<td>4,068</td>
<td>15,017</td>
<td>20,143</td>
<td>2,751</td>
<td>4,068</td>
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By Race

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<th>Crohn’s</th>
<th>Colitis</th>
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<td>729</td>
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By Insurance

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<tr>
<td>Medicaid</td>
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<tr>
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<td>1,726</td>
<td>2,446</td>
<td>7982</td>
</tr>
<tr>
<td>Other</td>
<td>568</td>
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<td>142</td>
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By Sex

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<tr>
<td>Total</td>
<td>20,143</td>
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</table>

New patients, including patients who were also hospitalized

The number of Crohn’s disease patients that were treated as ambulatory patients was 3,304 in 1997 and increased by 62 percent to 5,360 in 2004. The number of ulcerative colitis patients increased by 71 percent, from 4,279 in 1997 to 7,298 in 2004. (Figure 17)
The 8-year overall prevalence (each patient was counted only once) was 173.1 per 100,000 people for Crohn’s disease and 256 per 100,000 people for ulcerative colitis during 1997-2004. Some patients were diagnosed with both Crohn’s disease and ulcerative colitis. The average prevalence of patients with Crohn’s disease and/or ulcerative colitis was 412.4 per 100,000 people.

The annual prevalence of ambulatory patients increased for both Crohn’s disease and ulcerative colitis in the 8-year period. The prevalence of Crohn’s disease increased by 11 percent, from 260 per 100,000 persons in 1997 to 289 per 100,000 persons in 2004. The prevalence of ulcerative colitis increased by 17 percent, from 337 per 100,000 persons in 1997 to 395 per 100,000 persons in 2004. (Figure 18)

![Figure 18. Prevalence of Outpatients with Crohn’s Disease and Ulcerative Colitis, Florida, 1997-2004](image)

The age-specific prevalence of Crohn’s disease increased dramatically in teenagers and peaked in the 21- to 30-year-old age group. Age-specific prevalence decreased among patients aged 30 years and older, with an exception of an increase in the 41- to 50-year-old age group.

The age-specific prevalence of ulcerative colitis increased among patients between ages 11 and 30 years, and then reached a peak of 358 per 100,000 persons among the 41- to 50-year–old age group. The prevalence then decreased by age among people aged 50 years and older. (Figure 19)
Patients of other races had the highest prevalence of Crohn’s disease at 200 per 100,000 people. The prevalence of Crohn’s disease among Whites was the second highest at 150 per 100,000 people. The prevalence of Crohn’s disease was the highest among patients with a private health insurance (193 per 100,000 people). The prevalence was the lowest among Medicaid recipients (75 per 100,000 people). The prevalence of Crohn’s disease was slightly higher among males (143 per 100,000 people) than among females (141 per 100,000 people). (Figure 20)
The prevalence of ulcerative colitis was the highest among Whites (125 per 100,000 people), and among Medicare beneficiaries (137 per 100,000 people). The prevalence was the lowest among Medicaid recipients (43 per 100,000 people). Males had a higher prevalence of ulcerative colitis (265 per 100,000 people) than females (224 per 100,000 people). (Figure 22)

Approximately 82 percent of Crohn's disease patients had a colonoscopy. The percent of Crohn's disease patients with a colonoscopy was lower among patients under age 20 than among older patients. The percent was the same among both males and females.

A majority (94 percent) of ulcerative colitis patients had a colonoscopy. The percent of ulcerative colitis patients with a colonoscopy was higher among patients aged 20 years and older. There was no difference in the percentage between males and females. (Figure 21)

The percent of Crohn’s disease patients with a colonoscopy was the highest among patients of other races (96 percent), and among patients with a private health insurance (95 percent). The percent of ulcerative colitis patients who had a colonoscopy was the lowest among Medicaid recipients (90 percent). (Figure 22)
Twelve counties had an eight-year overall prevalence of Crohn’s disease of 140 per 100,000 persons or greater in Florida. These counties are Columbia, Union, Clay, Alachua, Flagler, Seminole, Pinellas, Manatee, Sarasota, Lee, Hendry, and Broward. (Figure 23) It is noteworthy that Union, Seminole, Pinellas, and Sarasota also had a high prevalence of Crohn’s disease among inpatients. (Figure 15)
Thirteen counties had an overall prevalence of ulcerative colitis of 300 per 100,000 people or greater in Florida. These counties are Gulf, Leon, Jefferson, Citrus, Lake, Hernando, Seminole, Pinellas, Sarasota, Collier, Palm Beach, Broward, and Monroe. (Figure 24) Among these counties, Gulf, Citrus, Lake, Hernando, Sarasota, and Collier also had a high prevalence of hospitalization for ulcerative colitis.

Seminole, Pinellas, Sarasota, and Broward counties had high prevalence rates for both Crohn’s disease and ulcerative colitis among ambulatory patients.

Sarasota was the only county that had a high prevalence for both Crohn’s disease and ulcerative colitis among both inpatients and ambulatory patients.

**BRFSS Survey**

A total of 1,678 respondents answered the survey questions in the IBD module. Excluded from the analysis were 19 respondents who answered “don’t know” or “not sure.” Among the 1,659 respondents included in the final analysis, 63 reported that someone in their household was diagnosed with IBD. Three (4.8 percent) of 63 households had more than one person diagnosed with IBD.

BRFSS data suggested that 3.2 percent of all households have IBD patient(s), with 4.2 percent of households among Whites, 3.4 percent of households among Hispanics, 1.6 percent of households among Blacks, and 1.7 percent of households among other races.
There was no difference in the percent of having somebody with IBD between households with annual income less than $50,000 and household with annual income of $50,000 or more.

Among the 3,066 adults and 916 children within the 1,659 households, 66 persons were reported being diagnosed with IBD. Because the BRFSS survey did not ask for the age of individuals with IBD, the DOH team estimated that two of the people with IBD were children (under age 20), based on the age distribution of hospital discharge, and ambulatory care, data. The prevalence of IBD was estimated as 2.1 percent for adults and 0.22 percent for children. These estimates were not weighted prevalence, which did not take into account of probability of survey respondents being included in the survey. A weighted prevalence will be available after CDC has completed the data weighting process.

Among survey respondents, 12 (18.2 percent) persons with IBD in 10 households were hospitalized in the past year. There was no difference in the percent of households with an IBD patient being hospitalized by race or by household income.

**GI Physician Survey**

The DOH received 113 completed survey questionnaires from GI physicians. The GI physicians who responded to the survey reported that 9,005 (7.3 percent) IBD patients were seen in the past 12 months among their 123,480 patients within that timeframe. Among IBD patients, approximately 14.2 percent were diagnosed in the past 12 months.

It was estimated that 40 percent of IBD patients were between the ages 20 and 45 years, and 30 percent were between the ages 45 and 65 years. IBD patients under age 20 years only accounted for approximately 10 percent.

Whites accounted for 93 percent of IBD patients; Blacks accounted for approximately 5 percent. Very few IBD patients were either Asian or other races.

Among IBD patients, females accounted for 51 percent and males for 49 percent. Approximately one quarter (22.4 percent) of patients had a family history of IBD, and one-eighth (12.2 percent) were hospitalized in the past 12 months.

The majority (94 percent) of IBD patients under the care of the responding physicians were enrolled in colon cancer surveillance.

**IBD Patient Survey**

The DOH received 27 completed survey questionnaires from IBD patients who voluntarily participated in the survey. The following are the results of the survey:

Age range of participants: 9 to 79 years

<table>
<thead>
<tr>
<th>Age</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;10</td>
<td>7.5</td>
</tr>
<tr>
<td>11-19</td>
<td>11</td>
</tr>
<tr>
<td>20-39</td>
<td>48</td>
</tr>
<tr>
<td>40-64</td>
<td>26</td>
</tr>
<tr>
<td>65 +</td>
<td>7.5</td>
</tr>
</tbody>
</table>

Average time living with IBD: 11.1 years
Gender: 78 percent Female  22 percent Male

Race/ethnicity: 96 percent Caucasian  4 percent Other

Jewish Decent: 33 percent yes, 63 percent no, and 4 percent unsure

Region of birth (within the US):
93 percent of respondents were born in the United States, of those:

<table>
<thead>
<tr>
<th>Region</th>
<th>Southeast</th>
<th>Midwest</th>
<th>Northeast</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>28</td>
<td>4</td>
<td>68</td>
</tr>
</tbody>
</table>

Type of IBD:

<table>
<thead>
<tr>
<th>Disease</th>
<th>Crohn’s</th>
<th>Colitis</th>
<th>Crohn’s &amp; Colitis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>56</td>
<td>40</td>
<td>4</td>
</tr>
</tbody>
</table>

Severity of symptoms:
78 percent of respondents reported their illness as active, of those:

<table>
<thead>
<tr>
<th>Severity</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>33</td>
<td>62</td>
<td>5</td>
</tr>
</tbody>
</table>

Family History:
- 18 percent had a family history; 78 percent reported no family history of IBD; and 4 percent unsure

Proximity to cattle:
- 19 percent lived near cattle prior to diagnosis.

Smoking status:
- 30 percent of respondents were current smokers, and 67 percent lived with a smoker prior to diagnosis. The percent of current smoking among IBD patients was higher than the 2004 state average prevalence (20.2 percent).

Colonoscopy:
- 56 percent had first colonoscopy due to IBD symptoms

Other medical conditions prior to diagnosis of IBD:
- 27 percent had serious medical illnesses
- 11 percent had psychological illnesses
- 37 percent were hospitalized
- 59 percent reported having surgeries

Of those reporting surgeries:
- 25.0 percent had appendectomies; 62.5 percent had tonsillectomies; 12.5 percent had other surgeries
- Other surgeries listed: liver transplant and c-section

Assessment of overall health:
- 18 percent said their health was poor
CONCLUSIONS

The Crohn’s disease and ulcerative colitis epidemiologic study was conducted by the DOH in conjunction with the University of Florida, AHCA, and BCBS, under the guidance of the Advisory Committee. This study is a large population-based study that combined multiple sources of data that covers a majority of Florida’s population. The data used in this study included 42,372,600 patient claim records in up to 10 years and survey data of approximately 2,000 households, providers, and patients.

This study was the first to provide state-specific data on IBD for Florida, in terms of estimating the prevalence of Crohn’s disease and ulcerative colitis, the demographic characteristics of IBD patients, and major risk factors of the IBD.

**Estimated prevalence of Crohn’s disease and ulcerative colitis**

**The Prevalence**

The population-based prevalence of Crohn’s disease is estimated at 222 per 100,000 people, and the prevalence of ulcerative colitis at 307 per 100,000 people. These estimates were calculated based on age distribution of Florida’s population and age-specific prevalence of Crohn’s disease and ulcerative colitis of BCBS members.

The BCBS data showed that the prevalence of IBD among BCBS members, including inpatients and outpatients was for:

- Crohn’s disease: 220 per 100,000 persons
- Ulcerative colitis: 300 per 100,000 persons
- Other colitis: 520 per 100,000 persons

BCBS data captured information on both hospitalizations (severe disease) and clinic visits (less severe disease). BCBS data were a good source in determining the prevalence of IBD because there is less disparity in access to health care among BCBS members. However, BCBS members are not a representative sample for overall Florida population, among which approximately 17 percent of people without a health insurance.

The estimates based on BCBS data were consistent with findings from previous epidemiologic studies in North America, which suggested population-based prevalence varied from 162 per 100,000 people to 199 per 100,000 people for Crohn’s disease and from 170 per 100,000 people to 246 per 100,000 people.

The combined hospital discharge data and ambulatory patient data showed that, among patients treated in hospitals, the prevalence of:

- Any IBD: 2,737.8 per 100,000 people (or 2.74 percent)
- Crohn’s disease and/or ulcerative colitis: 633.4 per 100,000 people
- Crohn’s disease: 293.3 per 100,000 people
- Ulcerative colitis: 364.2 per 100,000 people

The prevalence of Crohn’s disease and ulcerative colitis among inpatients and ambulatory patients was 32 percent and 19 percent, respectively, higher than the prevalence among BCBS members. The difference in prevalence might reflect a compositional difference of populations between hospital patients and BCBS members.
The prevalence of IBD among Medicaid recipients was lower than that among BCBS members; the prevalence of patients with:
- Crohn’s disease: 61 per 100,000 people.
- Ulcerative colitis: 26 per 100,000 people.
- Other colitis: 2,200 per 100,000 people.

The causes of low prevalence of IBD among Medicaid recipients were unknown based on the data of this study. More studies are needed to examine further the contribution factors of low prevalence of IBD, including access to health care and composition of the Medicaid population.

The BRFSS survey was unable to distinguish type of IBD due to the nature of a telephone survey of the general public. An overall prevalence of IBD was estimated as 2.1 percent for adults and 0.22 percent for children. The BRFSS data represented population-based estimates, although the estimate was un-weighted and might carry large sample errors due to small sample size. The estimate was in line with other data in this study.

**Number of Patients**

It is estimated that approximately 35,500 Floridians have Crohn’s disease and 49,000 have ulcerative colitis based on the estimated prevalence.

Hospitals in Florida served approximately 4,285 Crohn’s disease patients and 5,450 ulcerative colitis patients either as inpatients or as ambulatory patients every year, accounting for approximately 12 percent and 11 percent of Crohn’s disease and ulcerative colitis patients, respectively.

**Demographic Characteristics**

**Age**
The prevalence of Crohn’s disease was relatively low among children and the elderly (age 70 years and older). The majority of IBD patients were diagnosed between the ages 11 and 40. The prevalence increased with age until age 50, then decreased with age.

The age-distribution might vary by population depending on the source of data. For example, the age-specific prevalence of ulcerative colitis among Medicaid recipients began to decrease among people age 50 years and older, which might reflect the fact that most Medicaid recipients were under age 50. On the other hand, the age-specific prevalence did not decrease until age 80 and older among hospital inpatients, among whom there were more elderly.

**Sex:**
The overall prevalence was very close between males and females, with a slightly higher prevalence among females than among males.

Both BCBS and Medicaid are population-based data that show a slightly higher prevalence of IBD among females than among males. However, the prevalence was slightly higher among males than among females for patients seen in hospitals, which might be due to the sex-distribution of hospital patients (more male patients than female patients are seen in hospitals).

**Race/ethnicity:**
Non-Hispanic Whites had a higher prevalence than non-Hispanic Blacks, Hispanics, and people of other races. Crohn’s disease and ulcerative colitis occurred in all racial/ethnic groups.

**Household Income:**
No difference in prevalence by household income was found according to data from the BRFSS survey.

**Type of Health Insurance:**
Patients who were Medicare beneficiaries or who had private insurance had a higher prevalence rate of Crohn’s disease or ulcerative colitis. Medicaid recipients had the lowest prevalence for both Crohn’s disease and ulcerative colitis.

Type of medical insurance was the only variable available in the claim data and might be a surrogate indicator of socioeconomic status. The difference in prevalence might be attributable to the disparity in access to health care and the difference in race and age composition of the populations.

**Residential County:**
Based on hospital discharge data and ambulatory patient data, the following counties had high prevalence rates:
- Pinellas, Sarasota, and Seminole had a high prevalence of Crohn’s disease.
- Citrus, Collier, Gulf, Hernando, Lake, and Sarasota had a high prevalence of ulcerative colitis.

Among BCBS members, those who resided in Glades and Wakulla counties had a high prevalence of Crohn’s disease, and those who resided in Wakulla and Liberty counties had a high prevalence of ulcerative colitis.

Sarasota and Palm Beach counties were the only two counties that had a high prevalence of Crohn’s disease and ulcerative colitis in all hospital discharge data, ambulatory patient data, and BCBS data.

**Risk factors**
Previous epidemiologic studies on risk factors of Crohn’s disease and ulcerative colitis suggested that although genetic factors might be strongly associated with IBD, environmental factors would explain most variations in the prevalence of IBD. The data in this study supported the findings from previous studies.

**Genetic factors**
A family history was found among approximately 20 percent of patients from the patient survey, physician survey, and BRFSS survey. Both claim data and survey data indicated that the majority of patients were non-Hispanic White. The patient survey data showed that nearly two thirds of IBD patients were born in the Northeast region of the U.S. and many of IBD patients were of Jewish descent.

The consistency of the finding of family history across surveys and aggregation of IBD in a population indicated a strong association between genetic factors and occurrence of IBD.
Environmental factors

Previous studies suggested several environmental risk factors, including cigarette smoking, consumption of milk, contact with cattle, and receiving certain types of surgery, might be associated with IBD. However, none of these environmental risk factors has been confirmed.

In this study, the DOH surveyed a small group of IBD patients for these potential risk factors. The survey found that the prevalence of cigarette smoking was higher than the state’s average prevalence. Many patients were exposed to second-hand smoke, and had surgical procedures, such as tonsillectomy and appendectomy. However, because of the nature of the survey (a self-reported survey without a control group) and small sample size of the survey, no causal relationship could be established between these risk factors and IBD.

Recommendations for Future Studies

This study collected a great deal of data about IBD, and laid a foundation for future studies about IBD in Florida. To better assess IBD and to serve IBD patients in Florida, more studies are needed to:

- Increase sample size for the BRFSS survey to obtain a more accurate estimate of the population-based prevalence of IBD.
- Conduct a case-control study to identify risk factors of IBD.
- Develop an IBD patient voluntary registry through healthcare providers. This registry will provide data for a longitudinal follow-up study of IBD patients and many other studies on treatment, outcome, and patient’s quality of life.
ATTACHMENTS

Attachment 1: GI PHYSICIAN SURVEY

A Survey about Inflammatory Bowel Disease Patients

The purpose of this survey is to collect data on inflammatory bowel disease patients, particularly for those who may not have been hospitalized. All data collected from this survey will be kept strictly confidential. Please give your best approximation for the following questions.

1. How many patients have you seen in the past 12 months? (please check one)
   □ <100  □ 100-499  □ 500-999  □ 1000-1499  □ 1500 and more

How many of your patients are diagnosed with an Inflammatory Bowel Disease, such as Crohn’s disease or ulcerative colitis? ____

2. Please estimate the number of IBD patients from question 2 for the following:

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<th>20-44 yrs</th>
<th>45-64 yrs</th>
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<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td># Patients</td>
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</table>

3. Among those IBD patients, how many have been hospitalized for IBD in the past 12 months? ____

4. How many of your patients with IBD report a family history of the illness? ____

5. Among all IBD patients, about how many were diagnosed within the past 12 months? ____

6. Do you enter your IBD patients into the colon cancer surveillance program? 
   ____yes ____no

7. Please provide any additional information or comments about your IBD patients:
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________

Thank you very much for completing the survey. Your information will greatly assist our study. In case we need to contact you for further information, please provide the following information:

Your name: ______________________________
Your office phone number: (              ) __________ - __________

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**Attachment 2: IBD PATIENT SURVEY**

**Inflammatory Bowel Disease Patient Questionnaire**

Dear Respondent: As you may be aware, the Florida Department of Health is conducting a study to uncover the potential role of genetic and environmental risk factors associated with Inflammatory Bowel Disease (as mandated by House Bill 869, also known as the “Crohn’s & Colitis Disease Research Act”). This is a short survey designed to evaluate potential genetic and environmental exposures for patients with IBD. If you have been diagnosed with IBD, please answer the following questions to the best of your ability. You are not obliged to answer every question, though we kindly ask that you answer as many questions as you feel comfortable in giving a response. **All information provided will remain confidential.** We are not asking for any personal identifiers (such as name, date of birth, or social security number), to ensure that your information is also anonymous. You are an invaluable resource in the development of this area of research. Your time, effort, and comments are greatly appreciated. If you have any questions or comments about this study, please contact the Crohn’s & Colitis Research Coordinator at the Florida Department of Health, (850) 245-4444 extension 2424.

1. Current age:

2a. Age at Diagnosis of Inflammatory Bowel Disease:
   1) 10 or under  2) 11-19  3) 20-39  4) 40-64  5) 65 or older

2b. Time you have lived with the disease in years (or months if less than 1 year):

3. Gender:  1) Male    2) Female

4. Ethnicity:    1) Caucasian   2) African American   3) Asian   4) Hispanic   5) Other:

5. Are you of Jewish descent?  1) Yes    2) No    3) Partly  4) Don’t know/unsure

6a. Do you have:
   1) Ulcerative Colitis 2) Crohn’s Disease 3) Both CROHN’S DISEASE & ULCERATIVE COLITIS  4) Unsure

6b. Where is your disease located?
   1) small intestine  2) large intestine  3) both small and large intestines
   4) other  5) unsure

6c. Currently, is your disease active?  1) No    2) Yes
   If yes, would you say your symptoms are:  1) mild    2) moderate  3) severe
7a. Do you have a family member who is also diagnosed with an IBD? 
   1) No  2) Yes

7b. If yes, please select all who have been diagnosed: 
   1) Mother  2) Father  3) Brother  4) Sister  5) Your child/children  6) Other:

8a. Were you born in the United States?  1) Yes  2) No

8b. If yes, what area of the United States were you born? 
   1) NorthEast  2) SouthEast  3) Midwest  4) NorthWest  5) SouthWest

9. Before you were diagnosed with an IBD, did you live near cattle?  1) Yes  2) No

10. Before you were diagnosed with an IBD, did you smoke cigarettes regularly, meaning on most or all days? 
   1) Yes-# of years:  2) No

11a. Before you were diagnosed with an IBD, did the other people living in your residence smoke cigarettes?  1) No  2) Yes

11b. If yes, please list the number of years you lived in this residence prior to your diagnosis:

12a. Did you receive a colonoscopy before you were diagnosed with an IBD? 
   1) Yes  2) No  3) Unsure

12b. If yes, was your first colonoscopy a result of your IBD symptoms? 
   1) Yes  2) No  3) Unsure

13a. Before you were diagnosed with an IBD, did you have any of the following: 
   Medical illnesses  1) Yes  2) No  3) Don’t know/unsure
   Psychological illnesses  1) Yes  2) No  3) Don’t know/unsure
   Medical hospitalizations  1) Yes  2) No  3) Don’t know/unsure
   Surgeries  1) Yes  2) No  3) Don’t know/unsure

13b. Before you were diagnosed with an IBD, did you have any of these procedures: 
   Appendectomy  1) Yes  2) No  3) Don’t know/unsure
   Tonsillectomy  1) Yes  2) No  3) Don’t know/unsure
   Other (please list):

14. In general, would you say your health is:  1) Excellent  2) Good  3) Average  4) Poor