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Inflammatory Bowel Disease Prevalence: Surveillance data from the U.S. National Health and Nutrition Examination Survey

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ABSTRACT

Determining the overall US prevalence of Inflammatory Bowel Disease (IBD) is essential to national level prevention programs and population risk assessment; however currently US IBD prevalence remains uncertain. We used US National Health and Nutrition Examination Survey (NHANES) data to estimate the population-based prevalence of a self-reported history of medically diagnosed IBD, comparing to prior reports. Lifetime IBD prevalence for adults aged 20 + years was estimated in the independently conducted NHANES II (1976–80) and NHANES 2009–10 surveys. Participants were considered to have IBD if they reported being told by a physician they had Crohn's Disease (CD) or ulcerative colitis (UC). Clinically relevant NHANES data were analyzed to assess the self-reports. Survey design variables and sample weights were used to account for the complex survey design. The NHANES 2009–10 US IBD diagnosed prevalence was 1.2% (95% CI 0.8,1.6%), or an estimated 2.3 million persons. UC prevalence was 1.0% (95% CI 0.5,1.4%; 1.9 million persons) and CD prevalence was 0.3% (95% CI 0.1,0.4%; 578,000 persons). NHANES II UC prevalence was 1.0 (95% CI 0.8,1.2%), similar to 2009–10. UC prevalence was higher for ages ≥ 50 years in both surveys. NHANES 2009–10 data showed no UC sex differences, but women had higher UC prevalence in NHANES II. Remarkably, UC prevalence was similar between the two NHANES surveys fielded 30 years apart. The NHANES data are consistent with IBD prevalences reported in previous US nationally representative surveys, indicating that diagnosed IBD may affect approximately 1% of the US adult population.

1. Introduction

Ulcerative colitis (UC) and Crohn's Disease (CD), known collectively as inflammatory bowel disease (IBD), are chronic conditions with significant morbidity and personal as well as societal costs. Estimating IBD prevalence in the US general population is an important public health objective (Long et al., 2014). It defines the general population IBD burden and provides a national surveillance benchmark for primary and secondary IBD prevention programs, e.g. it is key to reducing IBD incidence and assuring that all those with IBD receive early treatment to prevent end organ damage and comorbidities Currently the US overall population prevalence remains uncertain. IBD epidemiology studies have thus far relied on medical insurance data or geographically limited surveys or registries, potentially under or overrepresenting certain risk factors like race/ethnicity or environmental exposures such as cigarette smoking, all of which are known to affect disease prevalence (Ho et al., 2019; Kappelman et al., 2007; Loftus, 2004; Sands et al., 2009; Shapiro et al. 2016; Shivashankar et al., 2017). Also, administrative database ICD codes may underestimate IBD prevalence by missing those who are in long term remission or lost to care; further, studies based on specific insurance plans, or special groups like veterans, are not nationally representative (Abramson et al., 2010; Hou et al., 2013; Long et al., 2014; Scott et al, 2019).

Active population-based US IBD prevalence data have been reported from the US National Center for Health Statistics' (NCHS) National Health Interview Study (NHIS). NHIS estimated the overall US adult prevalence of self-reported, medically diagnosed IBD at 0.9% in 1999 and 1.3% in 2015 (Dahlhamer et al., 2016; Longobardi et al., 2004;

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Nugyen et al., 2014). Currently, these are the only nationally representative US IBD prevalence studies. However, limitations are that the NHIS IBD questionnaire only addressed overall IBD and not UC and Crohn's disease separately and that the IBD self-reports are currently unvalidated. Addressing this limitation is a recognized priority in US national IBD surveillance (Long et al., 2014).

NCHS also fields the US National Health and Nutrition Examination Survey (NHANES), a nationally representative survey based on interviews, health examinations, and laboratory data. NHANES also asked participants about physician diagnosed IBD in two independently fielded survey cycles: NHANES II (1976–80) and NHANES 2009–10. Although not designed specifically as IBD studies and with insufficient data to validate IBD self-reports, these surveys did collect data on gastrointestinal symptoms, colonoscopy at the time of IBD diagnosis, past abdominal surgery, IBD related comorbidities, and other pertinent health information. Published studies on the 2009–10 IBD data have evaluated inflammatory biomarkers, environmental risk factors, comorbidities, and uveitis prevalence (Bhandari et al., 2017; de Silva et al., 2017; González et al., 2018; Ikonomi et al., 2016). One study cited an overall US IBD prevalence similar to the NHIS estimates but did not provide any details (Ikonomi et al., 2016). To our knowledge the NHANES II IBD prevalence data are not previously published. Our aim in this report is to provide detailed lifetime diagnosed IBD prevalence estimates for US adults with the NHANES data and to assess UC prevalence trends in the US over a 30-year period. Rates of medical interventions (colonoscopy at the time of diagnosis, abdominal surgery), gastrointestinal symptoms, and IBD complications are compared to those in the general population to provide perspective on the validity for using NHIS interview self-reports of diagnosed IBD as an IBD surveillance tool.

2. Methods

2.1. Sample

NHANES is a series of cross-sectional surveys conducted over the last 50 years monitoring the health of non-institutionalized US civilians. Each NHANES survey cycle is nationally representative. Household interviews are conducted followed by health examinations in mobile examination centers. The NHANES survey is demographically based using a complex, multistage design to minimize bias (Curtin et al., 2013). The NCHS Ethics Review Board approves survey protocols, survey conduct, and NHANES public data releases (National Center for Health Statistics, 2022a).

2.2. Measures

A lifetime history of diagnosed UC was collected in NHANES II; both UC and CD data were collected in NHANES 2009–10. Participants were considered to have IBD if they answered "yes" to a question asking about prior medical provider diagnoses of CD or UC. NHANES 2009–10 also asked whether colonoscopy was performed at the time of IBD diagnosis. Gastrointestinal symptom questionnaires were administered during health examinations in 2009–10 using confidential computer-assisted interviews; in NHANES II questionnaires were monitored by health technicians and reviewed by staff nurses (National Center for Health Statistics, 1980). The NHANES 2009–10 National Bowel Health Survey questionnaire (National Center for Health Statistics, 2022b) included the validated Bristol Stool Scale of usual stool consistency (Heaton et al, 1992; Heaton et al., 1994), the Fecal Incontinence Severity Index (Rockwood et al., 1999), and bowel movement frequency. Both surveys collected health care utilization and hospitalization data. NHANES 2009–10 had a limited 30-day recall of home use prescription medications but NHANES II did not. No data were collected for office administered medications (e.g., biologics, IV iron) or over the counter antidiarrheals. IBD extraintestinal disease manifestations data was collected in NHANES 2009–10 but not in NHANES II. We also analyzed the NHANES II question "Has a doctor ever told you that you had spastic colon or mucous colitis?" (SCMC) (Sandler, 1990).

2.3. Analysis

We estimated US IBD prevalence and detailed demographic distributions in 1976–80 and 2009–10 and tested for temporal trends in UC. The 2-year 2009–10 dataset is the minimum size for estimating NHANES prevalences. Survey design variables and sample weights were used to account for differential probabilities of participant selection to obtain nationally representative estimates. Sample weights also adjust for nonresponse and noncoverage. Data assembly and analysis used SAS^{TM} (Release 9.4, SAS Institute, Inc., Cary, NC SurveyMeans and SurveyReg), SUDAAN (Release 11.0.3) and NCHS statistical reliability testing program code (National Health & Nutrition Examination Survey. 2022). In NHANES 2009–10, 2 cases reported a doctor's diagnosis of both UC and CD (both with colonoscopy at diagnosis) with the final diagnosis unknown. As a practical matter, since only 2 cases were involved, the UC and CD prevalence estimates in our study did not materially change regardless of how they were classified (i.e. as combinations of UC or CD, or permutations of deleting cases). In our prevalence programming code for UC and CD, any UC report was classified as UC and any CD report as CD.

Ages surveyed were 12–74 years in 1976–80 (25–74 years for bowel symptom questions) and 20–69 years in 2009–10. UC survey comparisons here use the 20–69 year age range. Age adjustment used direct standardization. Standard errors were estimated by Taylor series linearization. NCHS criteria were used to assess the statistical reliability of estimated proportions, based on effective sample size, absolute and relative confidence interval widths and degrees of freedom (National Health & Nutrition Examination Survey, 2022; Parker et al. 2017). Prevalences comparisons and trend testing were used Student's t test with $\alpha = 0.05$ level.

3. Results

3.1. IBD prevalence estimates

NHANES II had 15,357 survey participants ages 20–74 years: 172 with self-reported UC. Lifetime UC prevalence in 20–69 year-olds was 1.0% (95% CI 0.8,1.2%) (Table 1). The 1976–80 UC prevalence was higher at ages 50–69 years than at 20–49 years (1.6% vs. 0.7%; $p < 0.01$), and higher among women than men (1.5% vs. 0.5%; $p < 0.01$). The latter was due to significantly higher UC prevalence in 50–69 year-old women (2.3%; 95% CI 1.6,3.0%) compared to younger adults. NHANES II did not oversample minorities and the NHANES II white category included Hispanic Americans. There were too few African-American participants with UC to estimate prevalence. Those reporting UC also were asked whether they "still had UC." The self-reported "currently active" and "prior" UC groups had the same prevalence, 0.4% (95% CI 0.3,0.5%).

Among 5105 NHANES 2009–10 participants, 62 reported an IBD diagnosis; 53 reported UC and 11CD (2 reported both UC and CD; both reported colonoscopy at the time of diagnosis).

Overall self-reported 2009–10 IBD prevalence was 1.2 % (95% CI 0.8,1.6%; or 2.3 million persons); UC prevalence was 1.0% (95% CI 0.5,1.4%; 1.9 million persons); and CD prevalence was 0.3% (95 %CI 0.1,0.4%; 578,000 persons). In NHANES 2009–10, 70% of those with IBD reported colonoscopy at diagnosis; two thirds of those with UC and 90% of those with Crohn's. Overall self-reported US IBD prevalence with diagnostic colonoscopy was 0.9% (95% CI 0.6,1.3%); UC prevalence with diagnostic colonoscopy was 0.7% (0.3,1.1%); not significantly different from overall self-reported IBD and UC prevalences. IBD and UC prevalences were higher at older ages and in females, but this was not statistically significant. Remarkably, estimated US national UC prevalence was not significantly different between the two independently

Table 1
NHANES Inflammatory Bowel Disease Sample Demographics.

NHANES 1976–80: Ulcerative Colitis	N	Cases	Prevalence (95 %CI)
All Ages (20 to 74) Years)	15,357	171	1.0 (0.8,1.2)
Ages 20 to 69 Years	13,730	144	1.0 (0.8,1.2)
Age 20 to 49 Years	7,439	46	0.7 (0.5,0.9)
Age 50 to 69 Years	6,291	98	1.6 (1.2,1.9)
Women	7,348	106	1.5 (1.2,1.9)
Men	6,382	38	0.5 (0.2,0.7)
White	11,874	140	1.1
Black	1,589	4	0.5*
NHANES 2009–2010:			
All IBD (20 to 69 Years)	5,105	62	1.2 (0.8,1.6)
Age 20 to 49 years	3,190	23	0.9 (0.5,1.3)
Age 50 to 69 years	1,915	39	1.8 (0.9,2.7)
Women	2,631	39	1.3 (0.7,2.0)
Men	2,474	23	1.1 (0.5,1.6)
Mexican American	1,025	17	1.6 (0.9,2.3)
Non-Hispanic-White	2,245	29	1.4 (0.9,1.9)
Non-Hispanic Black	963	7	0.8*
Ulcerative Colitis	5,096	53	1.0 (0.5,1.4)
Age 20- to 49 years	3,185	18	0.7 (0.3,1.1)
Age 50 to 69 years	1,911	35	1.4 (0.6,2.3)
Women	2,629	34	1.0 (0.4,1.6)
Men	2,469	19	0.9 (0.4,1.4)
Mexican American	1,023	15	1.4 (0.9,1.9)
Non-Hispanic White	2,243	23	1.1 (0.5,1.6)
Non-Hispanic Black	962	6	0.7*
Crohn's Disease	5,091	11	0.3 (0.1,0.4)

Abbreviations: IBD = Inflammatory Bowel Disease; N = Total Sample; CI = Confidence Interval. *Variance estimate not statistically reliable. Notes: For race/ethnicity, only the data for the 3 major US race/ethnic groups are shown; NHANES II had less detailed race/ethnicity data; 2 individuals reported both UC and Crohn's Disease.

fielded NHANES survey cycles fielded 30 years apart (t = 0.93, p. 0.35).

3.2. IBD clinical data

Table 2 presents NHANES II clinical results. 37% of persons with UC reported fair or poor health, significantly different from the general population (19%; p <.01). Two thirds reported current gastrointestinal symptoms compared to 23% of the US reference population (p <.01) and 30% reported recent diarrhea compared to 6% of the general population (p <.01). A history of gastrointestinal blood loss, melena or blood-streaked stools was seen in 27%, 17%, and 35% of those with UC respectively as compared to 4%, 5%, and 5% of other adults in the US. 44% with UC had an anemia history vs. 16% of the non-UC population (p <.01). Overall recent hospital- based care (including transfusion history) was increased in UC (37% vs. 15% of all others, p <.01) and abdominal surgery rates were significantly elevated in UC (53% in UC vs. 35% among others, p =.02). 39% of persons with UC reported regular use of "aspirin or an aspirin like medication" vs. 26% in the reference population (p =.02). 39% of those with UC reported a medical diagnosis of arthritis vs. 20% of the US reference population (p <.01). 32% of persons with UC reported a history of diagnosed spastic colon/mucous colitis. In the subsample of persons 25 to 74 years old with no history of SCMC, UC prevalence was 0.7% (95% CI 0.5,0.9%).

Table 3 presents NHANES 2009–10 clinical results. 33% of those with IBD reported fair or poor health, compared to 16% of the general population (p =.02). 60% of persons with IBD reported recent gastrointestinal symptoms or illness compared to 31% of other US adults (p =.01) and 65% of these reported recent periodic or constant diarrhea compared to 23% of those without IBD. 23% rated their current usual stool type as Bristol Scale grade 6 or 7 (unformed, watery) as opposed to 6% of non-UC persons (p =.01). 9.2% of those with IBD reported fecal urgency "always" or "most of the time" versus 2.9% among others. Twenty three percent of those with IBD had experienced a gastrointestinal illness in the previous 30 days compared to 7% of those without

Table 2
NHANES 1976–80 Ulcerative Colitis Clinical Data.

	Ulcerative Colitis		No Ulcerative Colitis		
	n	% (95% CI)	n	% (95% CI)	*p value*
Self-Reported Health Status					
Good, Excellent	96	63.6 (53.7,73.4)	11,528	81.5 (80.0,83.0)	<0.01
Fair, Poor	75	36.5 (26.6,46.4)	3637	18.5 (17.0,20.1)	<0.01
Illness Now Affects Digestion/Appetite	63	31.3 (22.0,40.6)	1772	10.5 (9.7,11.3)	<0.01
Illness is Colitis	26	13.5 (7.0,20.1)	184	1.0 (0.8,1.2)	<0.01
Current Gastrointestinal Symptoms:					
Overall GI Symptoms:	94	67.4 (56.8,78.0)	2852	23.2 (22.0,24.4)	<0.01
Diarrhea	37	29.5 (20.2,38.9)	638	5.9 (5.2,6.6)	<0.01
Constipation	35	15.0 (7.6,23.4)	1820	13.7 (12.4,14.9)	0.73
Detailed Distribution:					
Only Diarrhea	34	25.7 (17.1,34.4)	1791	4.2 (3.7,4.8)	<0.01
Only Constipation	32	17.0*	585	10.6 (9.7,11.6)	n.a.
Both Diarrhea and Constipation	3	1.9 *	146	1.0 (0.8,1.2)	n.a.
Neither Diarrhea nor Constipation	67	55.4 (44.0,66.8)	11,666	84.2 (83.0,85.3)	<0.01
Loss of Blood Stomach or Bowels	37	26.5 (15.9,37.2)	422	3.5 (3.0,3.9)	<0.01
Gray Stools	3	1.9*	83	0.6 (0.4,0.8)	n.a.
Melena	25	17.1*	605	4.8 (4.2,5.4)	n.a.
Blood-streaked Stools	36	35.2 (24.7,45.7)	618	5.4 (4.9,5.9)	<0.01
Overall Medical Therapy:	106	65.2 (54.6,75.8)	5585	36.4 (35.2,37.5)	<0.01
Any Current Prescription Medication	115	60.5 (51.1,69.9)	5682	32.3 (31.4,33.3)	<0.01
Regular ASA or ASA-Like Med Use	72	38.8 (28.6,49.0)	4118	25.9 (24.8,27.0)	0.02
Diagnosed Anemia	55	44.1 (32.7,55.5)	2190	15.9 (15.0,16.8)	<0.01
Had Iron Therapy for Anemia	47	37.2 (24.4,50.0)	1745	12.9 (12.1,13.7)	<0.01
Current Anemia Therapy	9	8.4*	276	1.8 (1.6,2.1)	n.a.
Overall Hospital Treatment History:	54	36.5 (25.4,44.7)	2443	15.0 (14.2,15.8)	<0.01
Hospitalized in Last 12 Months	42	26.3 (16.3,36.2)	2260	13.7 (12.9,14.5)	0.01
Reason is GI Disorder	6	5.0*	72	0.4 (0.2,0.5)	n.a.
History of Transfusion	13	11.0*	263	1.9 (1.5,2.2)	n.a.
Abdominal Surgery	85	52.7 (38.4,67.1)	4323	35.3 (33.9,36.6)	0.02
Disease Associations					
Diagnosis of Arthritis	89	38.7 (28.2,49.2)	3756	20.3 (19.2,21.4)	<0.01
Any Cancer Diagnosis	14	5.9*	603	3.4 (3.1,3.7)	n.a.
Diagnosis Spastic Colon/Mucous Colitis	54	31.8 (21.9,41.8)	500	3.3 (2.8,3.8)	<0.01

Abbreviations: n = sample size; 95 %CI = 95% confidence interval; ASA = aspirin; n.a. = not applicable.
Notes: Mobile exam center interview adult target age range was 25 to 74 years. Item samples sizes vary by data collection location: household interview (15,357); mobile exam center interview (current gastrointestinal symptoms 11,854; physician exam, abdominal surgical scar (11,854). *Variance estimate not statistically reliable.

Table 3
NHANES 2009–10 IBD Clinical Data.

	All IBD		UC		No IBD		
	n	% (95 %CI)	n	%	n	% (95 %CI)	*p-value*
Colonoscopy Confirmation*	43	69.4	35	66	n.a.		n.a.
Self-Reported Health							
Good, Excellent	33	66.6 (52.0,81.3)	24	45	3860	83.7 (81.9,85.6)	0.02
Fair, Poor	29	33.4 (18.7,48. 0)	29	55	1181	16.3 (14.4,18.1)	0.02
Current GI Symptoms	36	60.0 (40.0,80.2)‡	31	59	1631	31.0 (29.0,32.8)	0.01
Bristol Stool Type-Diarrhea	16	22.9 (11.0,34.8)	14	29	317	6.1 (5.4,6.7)	0.01
Diarrhea Last 12 Mos:							
Always, Most of the Time	6	8.6*	5	10*	158	1.2 (0.8,1.6)	n.a.
Sometimes	21	55.9 *	25	51	1143	22.0 (20.3,23.6)	n.a.
Rarely, Never	29	35.5 (20.5,50.4)	19	39	3015	76.8 (75.3,78.3)	0.01
Fecal Urgency	27	52.0 (34.0,69.8)	23	47	1301	24.6 (22.9,26.4)	0.01
Always, Most of the Time	6	9.2*	5	10*	158	2.9 (2.5,3.2)	n.a.
Sometimes	21	46.8*	18	37	1143	25.2 (23.4,27.0)	n.a.
Rarely, Never	29	44.0 (29.9,58.1)	26	53	3015	71.9 (70.0,73.8)	0.01
Recent GI Illness	11	23.4*	11	23	323	7.3 (6.0,8.6)	n.a.
Medical Therapy:	12	22.6 (11.8,33.4)	10	19	370	7.0 (5.9,8.1)	0.01
> 4 Dr. Visits Last 12 Mos.	22	36.8 (17.7,56.0)	21	41	637	14.3 (12.5,16.1)	0.03
Anemia Rx Last 3 Mos.	4	5.3*	4	8*	193	3.3 (2.6,4.0)	n.a.
Home IBD Medication (30d)	2	4.3*	2	4*	3	0.1*	n.a.
History Steroid Use > 1 Mo.	7	13.6*	5	9*	196	3.9 (3.2,4.7)	n.a.
Hospital Treatment:	28	27.7*	25	47	922	15.9 (14.7,17.1)	n.a.
Hospitalized Last 12 Mos.	17	21.0 (6.1,35.8)	15	28	585	9.6 (8.4,10.8)	0.11
History of Transfusion	15	13.0*	13	25	450	8.3 (7.5,9.1)	n.a.
EIM; Complications	16	24.1 (9.3,38.8)	14	26	204	3.8 (3.3,4.4)	0.01
Uveitis/Iritis Diagnosis	4	6.3*	3	6*	23	0.5 (0.2,0.7)	n.a.
Colon Cancer Diagnosis	3	4.2*	3	6*	10	0.2*	n.a.
Osteoporosis Diagnosis	10	15.3	9	17*	161	3.0 (2.5,2.5)	n.a.
Ankylosing Spondylitis	4	3.0*	4	8*	24	0.4 (0.2,0.6)	n.a.
Arthritis Diagnosis	26	30.6 (13.8,47.4)	23	43	1041	19.1 (17–8,20.3)	0.18

Abbreviations: IBD = inflammatory bowel disease; UC = ulcerative colitis; CD = Crohn's Disease; CI = confidence interval; GI = Gastrointestinal; mos = months; d = days; n = sample size; EIM = IBD extra-intestinal manifestation; n.a. not applicable.
Notes: Colonoscopy estimates are crude percents; number of doctor visits is not included in the overall Medical Therapy estimate; gastrointestinal symptoms data was collected in the NHANES mobile exam center n = 4,372. ‡ Absolute CI width = 30.6, relative CI width = 49.57, 36 events, 11 degrees of freedom. *Variance estimate not statistically reliable.

IBD. History of anemia treatment and of steroid use ≥ 1 month were more common in IBD compared to the general population, but sample sizes precluded analysis. Persons with IBD had low IBD home medication utilization rates in the 30-day recall. 21% of persons with IBD reported hospital admission within the last year compared to a 9.6% rate in the general US population. 24% reported a history of IBD extra-intestinal manifestations or associated disease (uveitis, colon cancer, osteoporosis, ankylosing spondylitis) compared to 4% in the general population (p =.01). 31% had a history of diagnosed arthritis, not significantly different from 19% in the general population.

4. Discussion

A priority in US IBD public health prevention planning is to obtain additional data to confirm or adjust current US national IBD prevalence estimates (Farraye et al., 2017; Long et al., 2014; Weaver and Long, 2019). These data from two independently conducted NHANES surveys fielded 30 years apart complement the prior NHIS estimates and provide an initial perspective on NHIS IBD self-report accuracy. The short data collection cycles and a 1% IBD prevalence meant that sample sizes were not sufficient for all analyses. However, US IBD, UC and CD prevalence estimates and most IBD clinical estimates were statistically reliable.

In 2009–10, 1.2% of the US population, or 2.3 million adults ages 20–69 years reported a prior IBD medical diagnosis: 1.0 % or 1.9 million persons had a history of UC; and 0.3% or 578,000 persons had diagnosed CD. These NHANES results are consistent with NHIS IBD estimates from 1999 (0.9%) and 2015 (1.2%) (Dahlhamer et al., 2016; Nguyen et al., 2014). Further, the 2018 Canadian national prevalence of clinically diagnosed IBD was recently estimated at 0.7% (Kaplan et al., 2019). The preponderance of IBD seen in NHANES 2009–10 is UC and the NHANES 1976–80 and 2009–10 UC prevalence estimates are not statistically different despite a thirty-year time difference when the studies were fielded. This finding is remarkable as in the literature global UC prevalences are considered to have increased over time (Molodecky et al. 2012). However, this has not been the case in all published studies (Loftus, 2004) and US general population UC prevalences over time have yet to be determined with certainty, so the NHANES data are potentially significant. However additional studies are clearly needed for corroboration. NHANES 1976–80 showed higher UC prevalence at older ages and in older women, also seen in the NHIS studies (Dahlhamer et al., 2016; Nugyen et al., 2014). Despite advancements in IBD treatments, one third of those with IBD in 2009–10 considered their health as 'fair or poor,' unchanged from 1976 to 80. This is concerning since poor self-reported health is a known predictor of adverse clinical outcomes and mortality (Bowling, 2005).

An important caveat is that our estimates are cumulative lifetime prevalences, so not directly comparable to US regional studies reporting period or point prevalences (Molodecky et al., 2012; Sands et al., 2009; Shapiro et al., 2016; Shivashankar et al., 2017). For example, the NHANES sampling frame potentially captures the estimated 50% of IBD patients who are clinical remission (Baumgart and Sandborn, 2007), the 25% of UC patients post colectomy (Aniwan and Loftus, 2021; Grieco and Remzi, 2020), and those not well-connected to medical care due to socioeconomic problems. Also, many CD patients have mild or inactive disease (e.g., Loftus et al., 2002, Figure 1) and UC patients may have limited, non-progressive local disease (Roda et al. 2017). These patient groups may not be completely captured in recent medical records-based IBD studies. A NHIS linked US Medical Expenditure Panel Survey (MEPS) study estimated the prevalence of currently treated US IBD at 0.2% (Wang et al., 2013), although this may be an underestimate (Machlin et al., 2022). A US administrative insurance database study estimated the prevalence of currently treated IBD at 0.4% (Kappelman

et al., 2007).

A chief limitation is NHANES surveys were not fielded as planned IBD studies and no clinical records were available, so we cannot validate the self-reported medically diagnosed IBD estimates. The extent of possible misdiagnosis cannot be determined (e.g incorrectly diagnosing IBD or mistakenly diagnosing IBD for another disease). Key clinical data for IBD classification by modern criteria (Paris, Montreal), extent of disease, biopsy results, a full medications and surgical procedures history and IBD biomarkers were lacking (Cioffi et al., 2015; Vermeire et al., 2012). On the other hand, certain factors suggest that the NHANES self-reports of diagnosed IBD could be factual. 70% of those with IBD in 2009–10 reported colonoscopy at the time of diagnosis. With respect to the older NHANES 1976–80 UC data, it is relevant that UC has been a named clinically entity for over 100 years and clinical case definitions generally compatible with contemporary ones were available in the 1950′s (Kirsner, 1988, Mulder et al. 2014). Modern fiberoptic colonoscopy was introduced in 1971 and was in general use during the NHANES II data collection time-frame (Marks, 1974, Williams and Teague, 1973; Wolff and Shinya, 1971). NHANES IBD home interviews were performed in person by trained, professional interviewers. Only a small minority of participants reported an IBD diagnosis, suggesting selectivity in responding to IBD questions. NHANES 2009–10 gastrointestinal symptoms were assessed with validated questionnaires, and in 1976–80 a trained nurse reviewed the detailed medical history questionnaire. Both NHANES surveys show significantly increased rates of gastrointestinal symptoms consistent with IBD, increased clinical care and hospitalization rates. Gastrointestinal bleeding, anemia, and abdominal surgery were all significantly higher in UC as were weighted transfusion rates. The 2009–10 data also showed increased IBD extraintestinal manifestations (EIM) with crude prevalence rates similar the literature, concerning since EIM may persist in IBD remissions or occur independently of IBD disease activity (Garber and Regueiro, 2019; Greuter and Vavricka, 2019).

In IBD population studies, irritable bowel syndrome (IBS) could be considered a confounder. However, there are high rates of IBS symptoms in IBD patients in confirmed remission (Halpin and Ford, 2012, Henriksen et al., 2018). Also, IBS is not an IBD exclusion criterion since IBD and IBS co-occur at a minimum by the product of their respective population prevalences (neither confers immunity from the other). We did not use the NHANES SCMC variable as an IBS variable since 1) mucus stools occur in a wide variety of gastrointestinal disorders and 2) IBS criteria were not available in the 1976–80 time-frame (Almy, 1973). Also, if all those in 1976–80 with UC reporting SCMC were classified as not having UC, the US UC population prevalence was 0.7% (95% CI 0.5, 0.9%), not materially different from the full sample UC prevalence (1.0%; 95% CI 0.8, 1.2%).

If the NHANES data reported here had been purposefully designed as NHANES IBD studies, most of our study limitations would not have occurred. In particular, a minimum of 6, not 2 or 4-year data sets are recommended NHANES prevalence studies. For example, in NHANES 2009–10, CD prevalence was lower than UC prevalence which did not appear consistent with the literature. The CD estimate here should be considered preliminary pending further studies since in a standard 6-year study CD prevalence could well have been higher. However, even these initial data indicate the feasibility of designing and fielding a US national IBD surveillance system. This would require developmental studies however we suggest that a coordinated NHIS and NHANES US IBD surveillance program could be useful, particularly since NHIS is linked to MEPS patient clinical records data (Agency for Healthcare Research & Quality, 2022). NHANES has demonstrated capability for collecting health examination data, biomarkers, imaging, and genetic studies (National Center for Health Statistics, 2022c; National Center for Health Statistics, 2022d; National Center for Health Statistics, 2022e). For example, NHANES recently defined the US national prevalence of nonalcoholic fatty liver disease and its genetic associations (Hernaez et al., 2013; Lazo et al.,2013). Also, both NHIS and NHANES are linked to Medicare and Medicaid data and the US National Death Index. (National Center for Health Statistics, 2022f).

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data are publicly available from the US National Center for Health Statistics.

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Ethics Approval and Consent to Participate

The NCHS Ethics Review Board approves survey protocols, conduct and NHANES public data releases. All NHANES survey participants provided written informed consent.

Consent for Publication

Participant informed consent included deidentified reporting of NHANES data results in journals and at scientific meetings.

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