Challenging assumptions about the demographics of eosinophilic gastrointestinal diseases: A systematic review

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Background: The demographic characteristics of patients with eosinophilic gastrointestinal diseases (EGIDs) are poorly understood. Population-based assessments of EGID demographics may indicate health disparities in diagnosis.
Objectives: We aimed to characterize the demographic distribution of EGIDs and evaluate the potential for bias in reporting patient characteristics.
Methods: We conducted a systematic review, extracting data on age, sex, gender, race, ethnicity, body mass index, insurance, and urban/rural residence on EGID patients and the source population. Differences in proportions were assessed by chi-square tests. Demographic reporting was compared to recent guidelines.
Results: Among 50 studies that met inclusion/exclusion criteria, 12 reported ≥1 demographic feature in both EGID and source populations. Except for age and sex or gender, demographics were rarely described (race = 4, ethnicity = 1, insurance = 1) or were not described (body mass index, urban/rural residence).

A higher proportion of male subjects was observed for EoE or esophageal eosinophilia relative to the source population, but no difference in gender or sex distribution was observed for other EGIDs. "Sex" and "gender" were used interchangeably, and frequently only the male proportion was reported. Reporting of race and ethnicity was inconsistent with guidelines.
Conclusion: Current data support a male predominance for EoE only. Evidence was insufficient to support enrichment of EGIDs in any particular racial, ethnic, or other demographic group. Population-based studies presenting demographics on both cases and source populations are needed. Implementation of guidelines for more inclusive reporting of demographic characteristics is crucial to prevent disparities in timely diagnosis and management of patients with EGIDs. (J Allergy Clin Immunol Global 2024;3:100260.)

Key words: Eosinophilic esophagitis, eosinophilic gastroenteritis, eosinophilic colitis, race, sex

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Recognition of long-standing institutionalized social inequities in health care delivery has provided an impetus for researchers to examine implicit and explicit bias in the way research is designed, conducted, and reported. Assumptions regarding the demographic composition of a particular disease category may lead to health disparities in diagnosis and treatment.[1,2] Indeed, health-related stereotypes may foster inequalities that lead to delayed treatment and poor care.[3-5] For example, if a disease is reported as predominantly occurring in White individuals, patients of other racial groups may be underdiagnosed.

Methodologic approaches to defining demographics can also contribute to health disparities. The language used to describe or characterize different demographic groups in study-related documents and research reports may perpetuate bias. Common examples include: statistical comparisons of White versus non-White populations, which ignore the heterogeneity within racial groups; tabular display of racial groups in a particular order; and use of racial descriptors as nouns rather than adjectives. The AMA Manual of Style Committee recently provided updated guidance on reporting demographics, including race and ethnicity.[6] Similar calls have been made to examine optimal ways of reporting of sex and gender in research.[7] These guidelines advise use of inclusive language and reporting to promote diversity and encourage use of language in a manner that encourages inclusion and does not diminish any single group. While many journals reference the *AMA Manual of Style*[8] in their instructions for authors, demographic reporting in the literature is variable.

Eosinophilic gastrointestinal diseases (EGIDs) are a group of disorders characterized by esophageal or gastrointestinal (GI) dysfunction and tissue eosinophilia, the most common of which is eosinophilic esophagitis (EoE).[9-12] The prevalence of EoE in the United States has been reported at 0.5 per 1000 individuals.[13] EoE has traditionally been characterized as a disease that primarily affects White male subjects.[14-16] This presupposes that differences in biologic, social, and/or environmental factors may contribute to disease pathogenesis and presentation.[17,18] Much less is known about the demographics of the non-EoE EGIDs.

Population-based studies provide a unique opportunity to estimate the distribution of demographic variables with external validity. While existing studies of EGIDs frequently describe sample characteristics, most studies are not population based and therefore represent a subset of the true population affected by these conditions. It has been well described that certain populations (eg, White race, affluent individuals) are more likely to participate in clinical studies.[19-24] As a result, these included individuals may not adequately represent the entirety of the population affected by the disease. Limited generalizability of literature focusing on EGID demographics may serve as a blind spot impairing the design of future studies. For example, reported sex-related differences may influence hypothesis testing in animal experiments, while perceived race-related differences may bias subject recruitment in clinical research. We sought to characterize what is known about the demographics of EGIDs through a systematic review of population-based studies. We highlight the limitations of the current evidence with respect to the availability of evidence and compare past practices with more recent guidance on appropriate reporting of race, ethnicity, sex, and gender differences. As a result of our findings, we also provide suggestions for improving demographic data collection and reporting, with the ultimate goal of timely diagnosis and favorable outcomes for all patients with EGIDs.

METHODS

A systematic review of population-based databases examining EGIDs including EoE for all age groups was conducted based on the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines.[25] Studies were identified using subject heading and keyword searches in Ovid Embase, Ovid Medline, and Web of Science Core Collection, from database inception to March 1, 2021, with the assistance of an experienced medical librarian (S.W.). The search terms and strategy for inclusion are detailed in Table I.

Study selection

Citations were imported into Covidence, an online screening and data extraction tool for conducting systematic reviews, and were screened by 3 authors (M.C., B.L.W., E.T.J.) to determine whether they should be considered for full-text review. Each title and abstract was independently reviewed by 2 of these 3 authors, and conflicts were resolved through consensus discussions between all 3 authors.

Exclusion criteria included single/multicenter studies, animal studies, reviews, systematic reviews, conference proceedings, studies not reporting demographic information, studies not reported in English, and studies consisting of a voluntary registry rather than population-based data collection. In addition, studies describing other GI diseases with eosinophilia, including drug-induced GI eosinophilia, GI eosinophilia resulting from inflammatory bowel disease or parasitic infection, and GI eosinophilia compatible with eosinophilic granulomatosis with polyangiitis or hypereosinophilic syndrome, were excluded. Abstracts for which a full-text article was not published were also excluded.

Full-text screening was conducted by 2 authors (M.C., B.L.W.) using the same methodology. For studies that described overlapping populations, only the original study was included. No additional records were identified through other sources. Hand searches of the reference sections of identified articles were not performed; nor did we contact authors for additional unpublished data.

Data collection

Final studies to be extracted were imported into Systematic Review Data Repository Plus (SRDR+),[26] an online platform for extracting, archiving, and sharing data during systematic reviews. Data extraction was performed by 4 authors (M.C., B.L.W., E.T.J., K.A.P.). The following data were extracted: EGID types examined and case definitions used, study design, sample size of the total population under study, number of cases for each EGID type examined, whether the cases represented incident or prevalent EGID cases, data source description, years under study, and geographic region. In addition, any data supporting an assessment of diagnostic delay were noted. Demographics of the EGID and the source population, when available, were also extracted and included age distribution, sex or gender distribution, race distribution, ethnicity, body mass index (BMI), insurance status, and urban versus rural residence. Key questions were focused on characterization of the demographic distribution of each of the EGIDs; thus, no data were collected evaluating associations for effect, and a formal assessment for risk of bias was not warranted.

Once the full-text articles were abstracted, a subanalysis was performed by 4 authors (B.L.W., A.B.M., D.D.B., S.G.) to evaluate how sex, gender, race, and ethnicity were reported. Articles were analyzed to determine: (1) whether sex, gender, or both were reported for participants; (2) which sexes or genders were reported; and (3) whether appropriate terminology was used to describe sex (male and female vs men and women). We then evaluated the articles that included information on race and ethnicity using 18 selected criteria from the *AMA Manual of Style* guidelines.[8] These criteria offer specific guidance for formatting, terminology, study methods, and reporting to reduce bias in the medical literature. Articles were evaluated for each criterion whenever applicable. Descriptive statistics were used to summarize the results.

Data analysis

Where data were sufficient, differences between EGIDs and the source population were assessed by chi-square tests.

TABLE I. Search strategy

Database searched	Search strategy
Ovid Embase	1. exp eosinophilic gastrointestinal disorder/
	2. (Eosinophil* adj3 (gastrointestinal or gastroenteritis or colitis or esophagitis or gastrit* or enteritis or duoden*)).mp.
	3. 1 or 2
	4. ((Administrative or Population or Claims or Insurance or medicare or Medicaid or pathology or national or veterans or "Miraca Life Sciences") adj3 (database or data or analysis or record* or register*)).mp.
	5. (registry or database).mp.
	6. population based.mp.
	7. (electronic adj3 record*).mp.
	8. 4 or 5 or 6 or 7
	9. 3 and 8
	10. limit 9 to (books or chapter or conference abstract or conference paper or "conference review")
	11. 9 not 10
Ovid Medline	1. exp Gastrointestinal Diseases/ and exp Eosinophilia/
	2. (Eosinophil* adj3 (gastrointestinal or gastroenteritis or colitis or esophagitis or gastrit* or enteritis or duoden*)).mp.
	3. 1 or 2
	4. ((Administrative or Population or Claims or Insurance or medicare or Medicaid or pathology or national or veterans or "Miraca Life Sciences") adj3 (database or data or analysis or record* or register*)).mp.
	5. (registry or database).mp.
	6. population based.mp.
	7. (electronic adj3 record*).mp.
	8. 4 or 5 or 6 or 7
	9. 3 and 8
Web of Science Core Collection	(Eosinophil* NEAR/3 (gastrointestinal or gastroenteritis or colitis or esophagitis or gastrit* or enteritis or duoden*))
	((Administrative or Population or Claims or Insurance or medicare or Medicaid or pathology or national or veterans or "Miraca Life Sciences") NEAR/3 (data or analysis or record*))
	(registry OR register or database)
	"population based"
	(electronic NEAR/3 record*)
	Refined by: DOCUMENT TYPES: (ARTICLE OR EARLY ACCESS)

RESULTS

A search of the electronic databases yielded a total of 320 articles, of which 316 were screened after removing duplicates and 243 were excluded, resulting in 73 studies for full-text review (Fig 1). At full-text review, an additional 23 were excluded, leaving 50 studies for abstraction.

Assessment of distribution of demographic factors

Of the 50 studies with documentation of demographic distribution of age, race, ethnicity, sex, gender, BMI, rural versus urban residence, or insurance status, 12 provided data to support comparison of the demographic distribution of individuals with an EGID to that of the underlying source population (Table II).[27-38] Six of these studies were conducted using pathology databases, 2 were conducted using claims data, 3 were conducted using electronic health record (EHR) data sources, and 1 was conducted from a population-based online survey. All but 2 studies were conducted in populations in the United States, with one study using pathology data from New Zealand[35] and another study using EHRs from Spain.[36]

Data to support comparison of BMI, rural versus urban residence, and insurance status were not available. Age distribution could not be reliably compared because most studies reported prevalent cases only or because incidence versus prevalence could not be determined from the information provided. Ethnicity and insurance status were only reported in one study. This study was a population-based online survey of patient-reported physician diagnoses that included information on Hispanic ethnicity and insurance status.[37] The authors reported that 23.8% of patients with EoE self-identified as Hispanic, compared to 8.7% of the source population. Of those with EoE, 98% reported having insurance, compared to 92% in the overall study sample (Table II).

Three studies presented data from which racial distribution could be compared between EoE and non-EoE populations. However, 2 of these studies reported significant missing data, thus limiting any inferences about racial differences. For example, in the study by Adkins et al,[37] 23.9% of individuals with EoE (n = 399) had unknown or no race reported, and 8.7% of the study population (n = 31,129) had unknown or no reported race. In the Syed et al[34] study, which used EHR data, 84.0% of individuals with EoE (n = 5,370) were reported to be White race, compared to 61.1% of the source population (n = 27,183,310) reported to be White race, but 11.5% and 27.7%, respectively, of the EoE sample had missing race. In a study by Weerasekera et al[35] that used a pathology database maintained in New Zealand, a higher proportion of individuals with EoE (n = 152) were of European descent compared to the source population (n = 471,315) (85.5% vs 77%), although the specific counts for racial subgroups in the source population were not provided, thus limiting the utility of the data provided (Table II).

Data on possible sex or gender differences were included in 10 of 12 studies. Of the 10 studies, 9 reported on EoE (n = 4) or esophageal eosinophilia (n = 5), with 8 providing data sufficient for comparison (including counts and not just proportions). Of these, all indicated a significant enrichment of male subjects
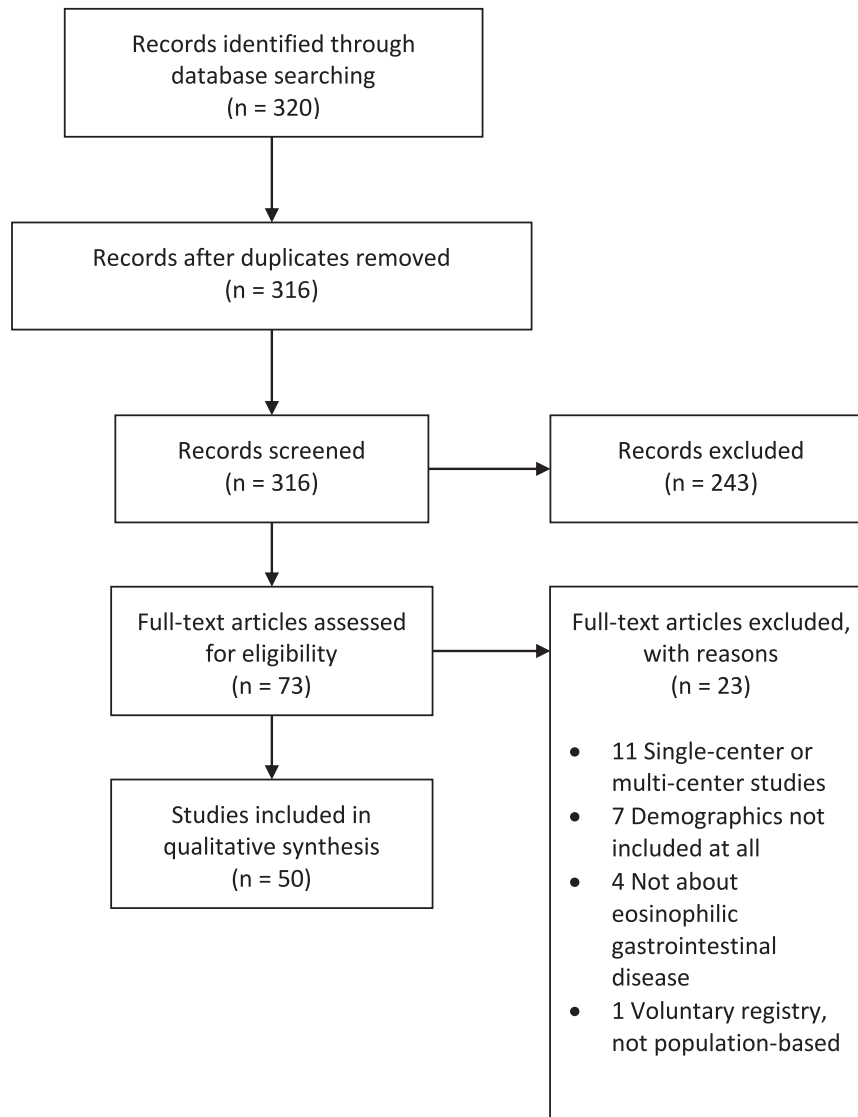
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┌─────────────────────────┐
│ Records identified through │
│    database searching     │
│        (n = 320)          │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│ Records after duplicates removed │
│         (n = 316)         │
└─────────────────────────┘
            │
            ▼
┌─────────────────────┐        ┌─────────────────────┐
│  Records screened    │──────▶ │  Records excluded     │
│     (n = 316)        │        │     (n = 243)         │
└─────────────────────┘        └─────────────────────┘
            │
            ▼
┌─────────────────────┐        ┌─────────────────────────────┐
│ Full-text articles   │──────▶ │ Full-text articles excluded, │
│ assessed for         │        │      with reasons            │
│ eligibility          │        │      (n = 23)                │
│     (n = 73)         │        │                              │
└─────────────────────┘        │  • 11 Single-center or       │
            │                   │    multi-center studies      │
            ▼                   │  • 7 Demographics not        │
┌─────────────────────┐        │    included at all           │
│  Studies included in │        │  • 4 Not about               │
│ qualitative synthesis│        │    eosinophilic              │
│     (n = 50)         │        │    gastrointestinal          │
└─────────────────────┘        │    disease                   │
                                │  • 1 Voluntary registry,     │
                                │    not population-based      │
                                └─────────────────────────────┘
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FIG 1. PRISMA flow diagram detailing search strategy and study selection process.

(range of 2:1 to 3:1 male:female ratio) among those with EoE or esophageal eosinophilia ($P < .001$ for all) (Table II). For the non-esophageal EGIDs, 2 studies provided sex or gender distribution data for both the EGID type examined and the source population.[33,38] Eosinophilic gastritis or gastric eosinophilia, eosinophilic gastroenteritis or duodenal eosinophilia, or eosinophilic colitis or colonic eosinophilia were examined, and with the exception of the Jensen et al[33] study (n = 11,569,217 in the source population), which reported a somewhat lower proportion of male patients for eosinophilic gastritis relative to the source population (38.6% vs 47.9%; $P = .004$), no significant differences were observed for sex or gender distribution (Table II).

Adherence to recent recommendations for reporting of sex, gender, race, and ethnicity

To assess for potential areas of improvement in reporting demographic characteristics, we compared the body of population-based studies for EGIDs with recent recommendations

for reporting of sex, gender, race, and ethnicity. Of note, all studies were published before the recommendations for reporting demographics were updated in the 11th edition of the *AMA Manual of Style*, which was published in 2020. We observed that few studies aligned with recently published recommendations. Table III notes how sex and gender were reported for the 50 studies abstracted in the systematic review. We found that investigators often used "sex" and "gender" interchangeably—indeed, at least 9 studies wrongly referred to "gender" as a biological variable. None of the studies reported both sex (biological variable) and gender (component of self-identity and health). Male subjects were commonly reported when a single sex or gender was reported; and in these studies, we could not infer the gender or sex of those not reported. The terms "men" and "women" were used in a few studies (3/50, 6%) instead of the preferred terms for sex as a biological variable: "male" and "female."

Fourteen studies provided demographic information on race or ethnicity. A comparison of past reporting practices with current guidelines for reporting is summarized in Table IV. Categories for

TABLE II. Summary of studies with both EGID and source population demographic data

Study (year)	EGID type	EGID definition	Source population description	No. cases/ no. source population	Age (years), mean ± SD or no. (%) (range) EGID	Age Source	Sex, no. (%) EGID	Sex Source	P	Race, no. (%) EGID	Race Source	Ethnicity, no. (%) EGID	Ethnicity Source	Insured, no. (%) EGID	Insured Source
Kapel (2008)[27]	Esophageal eosinophilia	Mean ≥20 eos/HPF across 5 sites or mean ≥30 eos/HPF in 2-4 HPFs, exclude if predominant eosinophilia in stomach or duodenum	Pathology database	363/ 74,162	37.6 ± NR (1.2-98)	56 ± NR (NR)	F 93 (25.6), M 270 (74.4)	F NR, M NR (50)	Not estimable	NR	NR	NR	NR	NR	NR
Dellon (2011)[28]	Esophageal eosinophilia	Prominent esophageal epithelial eosinophils	Pathology database	5,767/ 165,017	43.9 ± 16.9 (NR)	55.1 ± 16.5 (NR)	F NR, M 3592 (62)	F NR, M 71,488 (43.4)	↑ M, P < .001	NR	NR	NR	NR	NR	NR
Hurrell (2012)[29]	Esophageal eosinophilia	≥15 eos/HPF (peak) at esophageal biopsy	Pathology database	9,995/ 233,649	44.4 ± 16.1 (NR)	55.8 ± 16.2 (NR)	F NR, M 6,436 (64.4)	F NR, M 107,945 (46.2)	↑ M, P < .001	NR	NR	NR	NR	NR	NR
Dellon (2014)[30]	EoE	≥1 instance ICD-9 code	Health plan claims database	6,513/ 11,569,217	<20 y, 1813 (27.8); 20-64 y, 4700 (72.2) range: 0-64	<20 y, 3,587,571 (31.0); 20-64 y, 7,981,646 (69.0) (NR)	F 2256 (34.6), M 4257 (65.4)	F 6,024,643 (52.1), M 5,544, 574 (47.9)	↑ M, P < .001	NR	NR	NR	NR	NR	NR
Jensen (2015)[31]	Esophageal eosinophilia	≥15 eos/HPF at esophageal biopsy	Pathology database	4,101/ 88,517	39.6 ± 17.6 (NR)	51.1 ± 18.2 (NR)	F NR, M 2,347 (57.2)	F NR, M 33,786 (38.2)	↑ M, P < .001	NR	NR	NR	NR	NR	NR
Maradey-Romero (2015)[32]	EoE	Search for term 'eosinophilic oesophagitis'	EHR database	4,840/ 9,559,570	<18 y, 1120 (23.1), 18-65 y, 3,360 (69.4), <65 y, 360 (7.4 NR)	<18 y, 1,573,270 (16.5), 18-65 y, 6,045,200 (63.2), >65 y, 1,941,100 (20.3 NR)	F NR, M 3150 (65)	NR	Not estimable	Asian 40 (0.83), Black 430 (8.88), Hispanic 10 (0.2), White 4,390 (90.7)	NR	NR	NR	NR	NR
Jensen (2016)[33]	eosinophilic gastritis	≥1 instance of ICD-9 code 535.70	Health plan claims database	774/ 11,569,217	<20 y, 159 (20.5) (NR)	<20 y, 3,587,571 (31.0) (NR)	F 475 (61.4), M 299 (38.6)	F NR, M 5,544,574 (47.9)	↓ M, P = .004	NR	NR	NR	NR	NR	NR
NR	eosinophilic gastroenteritis	≥1 instance of ICD-9 code 558.41		954/ 11,569,217	<20 y, 385 (40.4 NR)	<20 y, 3,587,571 (31.0) (NR)	F 531 (55.7), M 423 (44.3)	F NR, M 5,544,574 (47.9)	No difference in M, P = .14	NR	NR	NR	NR	NR	NR
	eosinophilic colitis	≥1 instance of ICD-9 code 558.42		404/ 11,569,217	<20 y, 153 (37.9 NR)	<20 y, 3,587,571 (31.0) (NR)	F 231 (57.2), M 173 (42.8)	F NR, M 5,544, 574 (47.9)	No difference in M, P = .18	NR	NR	NR	NR	NR	NR
Syed (2017)[34]	EoE	≥1 instance of ICD-9 530.13; exclusion of prior diagnosis of BE, GERD, esophageal cancer	EHR database	5,370/ 27,183,310	<18 y, 760 (14.2), 18-65 y, 4,240 (79.0), >65, 350 (5.5 NR)	<18 y, 4,824,650 (17.7), 18-65 y, 17,660,660 (65.0), >65 y, 4,649 (17.1) (NR)	F NR, M 3580 (66.7)	F NR, M 12,245,970 (45.1)	↑ M, P < .001	Black 240 (4.5), White 4,510 (84.0), unknown 620 (11.5)	Black 3,048,450 (11.2), White 16,613,280 (61.1), unknown 7,521,580 (27.7)	NR	NR	NR	NR
Weerasekera (2019)[35]	EoE	≥15 eos/HPF, with symptoms of esophageal dysfunction and/or endoscopic appearance suggestive of EoE	Pathology database (New Zealand)	152/ 471,315	<16 y, 9 (5.9), ≥ 16 y, 143 (94.1) (NR)	<15 y, NR (19.5) (NR)	F 46 (30.3), M 106 (69.7)	NR	Not estimable	Asian 4 (2.6), European 130 (85.5), Maori 7 (4.6), Pacific Islander 3 (2.0), other 2 (1.3), unspecified, 8 (5.3)	Asian NR (10.5), European NR (77), Maori NR (13), Pacific Islander NR (8), other NR (3.3)	NR	NR	NR	30% with private hospital coverage

(Continued)

TABLE II. *(Continued)*

Study (year)	EGID type	EGID definition	Source population description	No. cases/ no. source population	Age (years), mean ± SD or no. (%) (range)		Sex, no. (%)		P	Race, no. (%)		Ethnicity, no. (%)		Insured, no. (%)	
					EGID	Source	EGID	Source		EGID	Source	EGID	Source	EGID	Source
Arias (2019)[36]	EoE	Symptoms consistent with EoE, ≥15 eos/HPF at biopsy, exclusion of other causes of eosinophilia	Health records from 2 hospital systems with universal coverage (Castilla–La Mancha, Spain)	117/ 104,747	29.8 ± 14 (5-82)	NR	F NR, M 102 (87.2)	F 8,787 (48.6), M 9,296 (51.4)	↑ M, P <.001	NR	NR	NR	NR	NR	NR
Adkins (2020)[37]	EoE	Self-report of physician diagnosis	Online population-based survey	399/ 31,129	36.1 ± 11.4 (NR)	46.5 ± 15.7 (NR)	F 148 (37.1), M 251 (62.9)	F NR, M 2,353 (47.1)	↑ M, P <.001	Asian 14 (3.5), Non-Hispanic Black 46 (11.5), Non-Hispanic White 226 (56.6), other 18 (4.5), unknown NR (23.9)	Asian 137 (2.7), Non-Hispanic Black 283 (5.7), Non-Hispanic White 3924 (78.5), other 221 (4.4), unknown NR (8.7)	Hispanic, 95 (23.8)	Hispanic, 433 (8.7)	391 (98%)	461 (92%)
Sonnenberg (2020)[38]	Esophageal eosinophilia	≥15 eos/HPF (peak) at esophageal biopsy	Pathology database	3,008/ 302,061	47.1 ± 15.9 (NR)	56.8 ± 15.2 (NR)	F 1,061 (35), M 1,925 (64), not specified, 13 (0.4)	F 174,600 (58), M 126,466 (42), not specified 995 (0.3)	↑ M, P <.001	NR	NR	NR	NR	NR	NR
	Gastric eosinophilia	≥30 eos/HPF across 5 HPFs at stomach biopsy		366/ 302,061	57.4 ± 15.5 (NR)	56.8 ± 15.2 (NR)	F 188 (51), M 177 (48), not specified 1 (0.3)	F 174,600 (58), M 126,466 (42), unknown, 995 (0.3)	No difference in M, P = .11	NR	NR	NR	NR	NR	NR
	Duodenal eosinophilia	≥30 eos/HPF across 3 HPFs at duodenal biopsy		10/ 302,061	41.1 ± 24.3 (NR)	56.8 ± 15.2 (NR)	F 4 (40), M 6 (60); not specified 0	F 174,600 (58), M 126,466 (42), unknown, 995 (0.3)	No difference in M, P = .37	NR	NR	NR	NR	NR	NR
	Colonic eosinophilia	≥50 eos/HPF across 5 HPFs at colon biopsy		124/ 302,061	50.6 ± 19.9 (NR)	56.8 ± 15.2 (NR)	F 70 (56), M 54 (44), not specified 0	F 174,600 (58), M (%) 126,466 (42), not specified 995 (0.3)	No difference in M, P = .77	NR	NR	NR	NR	NR	NR

BE, Barrett esophagus; *eos,* eosinophils; *F,* female; *GERD,* gastroesophageal reflux disease; *HPF,* high-power field; *M,* male; *NR,* not reported.

TABLE III. Reporting of sex and gender in 50 population-based studies of EGIDs

Demographic reported	No. (%)
Sex	20 (40)
Gender*	11 (22)
Sex and gender	0
Did not specify sex vs gender	19 (38)
Did not report sex or gender	3 (6)
Male only	21 (42)
Female only	1 (2)
Male and female	22 (44)
Men only	0
Women only	1 (2)
Men and women	2 (4)

*Only 2 of these were surveys/questionnaires where participants would have been asked to identify their gender at the time of the study.

race and ethnicity were reported in 42.9% of studies. Multiracial and multiethnic groups were not delineated by any authors. Half of the studies used the category "other" as a convenience grouping, and 28.6% made statistical comparisons between White and "non-White" groups. In 5 studies, racial or ethnic terms were used as nouns, and 6 studies used the term "Caucasian" instead of White. Regarding the text's formatting, none of the articles listed categories for race and ethnicity in alphabetical order in text and tables. Rather, the most common approach was to list these categories in descending order by percentage. Most studies capitalized the names of races and ethnicities and avoided abbreviations for these categories.

DISCUSSION

Given the potential for bias in reporting the demographics of EGIDs, we sought to characterize the published data through a systematic review of population-based studies. We examined EGID populations relative to their source population in each study across several demographic factors, and we found a paucity of data, except for sex and gender, as it relates to EoE only. Specifically, we found consistent evidence of enrichment of male subjects for EoE. No additional inferences could be made for other EGIDs as related to race, ethnicity, BMI, insurance status, age, and rural versus urban residence. In addition, demographic reporting was highly variable among studies, and multiple areas for improvement were identified after comparison with the most recently criteria published in 2020 in the 11th edition of the *AMA Manual of Style.*[8]

Reanalyses of the published data could further elucidate true differences in the demographic distribution of EGIDs. For example, additional investigation of the missing demographic information could help inform whether missing data are differential (ie, with some demographic groups more or less likely to be missing). Our assessment indicates a lower proportion of missing data for EGID patients relative to the source population, possibly due to increased health care encounters or more complete ascertainment of demographic factors for patients of certain demographic attributes. Another limitation is that the data available from these studies often include a mix of prevalent and incident cases, or that prevalence versus incidence could not be inferred from the reporting of the methods in these studies. This limited our ability to make inferences for differences in age

distribution. For claims-based, pathology, and EHR data sources, differences in age distribution may reflect differences in health care utilization patterns as opposed to differences in age distribution. Additionally, a lack of uniformity in EGID definitions among data sources may influence data interpretation. Finally, the majority of the studies analyzed were conducted in the United States or other Western European countries, so they do not fully represent the global distribution of EGID demographics.

Changing societal norms may influence demographic reporting over time. We did not specifically examine the relationship between year of publication and adherence to reporting guidelines because many of the guidelines did not apply to publications where limited demographic information was reported. It should also be noted that while studies did not consistently report on demographics as per published criteria, most of the studies predated the current criteria in the *AMA Manual of Style.*

More studies are needed where data on both the EGID population and the general population from which EGID patients arose are captured. These studies may more accurately define the demographics of patients with EGIDs and help eliminate provider bias, thereby reducing the diagnostic delays currently faced by many patients with EGIDs. Diagnostic delays have been associated with several demographic factors in EGIDs. For example, adult age has been identified as a predictor of diagnostic delay in eosinophilic gastritis/eosinophilic duodenitis.[39] In EoE, diagnostic delay is age and race dependent, being more prominent in adults and White patients, in children with Medicaid insurance, and in those residing in rural areas.[40,41] Delay in diagnosis can result in significant morbidity, increased burden of disease, and potential long-term complications.[42,43] Ascertaining the true demographics of EGIDs also helps us understand the heterogeneity of these diseases through identification of various disease phenotypes. As phenotypes are recognized, we can explore genotypic and possible mechanistic differences[17,44] and tailor therapies for better outcomes. On a larger scale, understanding disease demographics is crucial for resource allocation for clinical care, research, community engagement, and population health.

Careful data collection and reporting is crucial for the scientific community to avoid perpetuation of structural racism and discrimination. More specifically, accurate reporting of race, ethnicity, and other demographic characteristics may serve as a proxy for cultural differences that influence access to care, cultural behaviors and dietary practices, and environmental exposure, all of which have been shown to influence EoE diagnosis, pathogenesis, and/or response to therapy.[41,45-47] Furthermore, standardization of data reporting for demographic characteristics facilitates comparison across studies.

Going forward, to improve demographic data collection and reporting for EGIDs, we propose considering several factors. Missing data during collection need to be clearly reported, providing counts and not just proportions. This will allow more accurate conclusions and comparisons across studies. In addition, accurate terminology needs to be used, which we summarize in Table IV based on the most relevant recommendations put forth in the *AMA Manual of Style.* As a scientific community, it is important that we start implementing these recommendations not only as scientific writers but also as peer reviewers and journal editors. Adherence to these recommendations is essential to our efforts as clinicians and researchers to ensure that research and reporting of EGIDs do not perpetuate inequities in care.

TABLE IV. Comparison of demographic reporting in population-based studies of EGIDs with newly developed AMA guidelines for race and ethnicity

Category	Recommendation	Followed no./total no.* (%)
Reporting	Report race and ethnicity categories.	6/14 (42.9)
	Delineate the specific type of multiracial and multiethnic groups to the extent possible.	0/12 (0)
Methods	Do not use the nonspecific group label "other" for a convenience grouping or label unless it was a prespecified formal category in a database or research instrument. In such cases, define and report "other" groups.	7/14 (50.0)
	Avoid study design and statistical comparisons of White vs "non-White" groups.	10/14 (71.4)
	List categories in alphabetical order in text and tables.	0/13 (0.0)
	Avoid merging race and ethnicity with a virgule as "race/ethnicity," as a virgule often signifies "and/or."	1/3 (33.3)
Formatting	Names of races, ethnicities, and tribes should be capitalized.	12/14 (85.7)
	Do not hyphenate combinations of proper adjectives derived from geographic entities when used as racial or ethnic descriptors (eg, Asian American, African American).	6/9 (66.7)
	Avoid abbreviations of categories for race and ethnicity unless necessary because of space constraints.	14/14 (100)
	Do not use the general term "minorities" when describing groups or populations because it is vague and implies a hierarchy among groups.	12/14 (85.7)
	Use a modifier when using the word "minority" (eg, racial and ethnic minority groups or individuals), and do not use the term as a stand-alone noun.	1/2 (50.0)
	Avoid the term "mixed race" unless specifically used in data collection.	12/14 (85.7)
	Avoid collective reference to racial and ethnic minority groups as "non-White."	11/13 (84.6)
Terminology	Do not use racial and ethnic terms in the noun form (eg, avoid Asians, Blacks); the adjectival form is preferred (eg, Asian women, Black patients).	5/14 (35.7)
	Do not use the term "Caucasian" unless referring specifically to people from the Caucasus region in Eurasia.	6/14 (42.9)
	Do not use the terms "African American" or "Black" interchangeably unless both terms were formally used in the study.	9/10 (90)
	"American Indian" or "Alaska Native" are preferred to "Native American." The term "Indigenous" is also acceptable.	2/4 (50.0)
	"Latinx" and "Latine" are gender-inclusive or nonbinary terms for people of Latin American culture or ethnic identify in the United States.	0/3 (0)

From the *AMA Manual of Style*[8].

*Number of articles that followed specified recommendation. Total represents total number of articles where criterion was applicable.

To conclude, little is known about EGID demographics. Future studies on population-based demographic data conducted according to a minimum set of guidelines can provide a path forward for better understanding of EGID pathophysiology, phenotypes, and patient needs, with the goal of timely diagnosis and more favorable outcomes.

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