

The impact of social and economic factors on outcomes within people living with Crohn's and Colitis in the UK: A scoping review

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Executive summary / scientific abstract

Crohn's and colitis can impact on any and all areas of a person's life. It is not clear how social and economic factors impact on different groups within those affected by Crohn's and Colitis or how these groups are differently affected by the conditions.

This scoping review set out to systematically map the evidence base exploring these issues, summarise main findings, propose areas for systematic review and suggest appropriate future research areas.

In June 2023, an initial search strategy was devised and several rounds of pilot searching completed to refine and revise it. A final search strategy was agreed and the search ran on 26th June 2023 in Medline/EMBASE. Separate screening by two researchers of 5,462 citations was completed for potential inclusion, with all disagreements solved by discussion to research consensus. A total of 100 studies were selected for full text review and this was also completed in duplicate. The final sample of 77 studies was extracted, again in duplicate, for key demographics, research findings and conclusions.

The studies reported a total of 1,212,558 participants. The studies primarily originated from the UK (15), USA (27) and Canada (10). The participants included were mostly mixed groups of Crohn's and Colitis patients. A variety of methods were included, but no experimental studies were included.

There was a broad range of topics included, but the majority of studies focused on racial factors, with a quarter of the studies focused on racial distribution of patients at either diagnosis or in cross-sectional studies. A further quarter of studies focused on racial disparity in disease outcomes or management.

The core findings of the studies were related to race, including racial patterns in incidence of IBD, as well as disease outcomes and management. International studies were unclear and conflicting in findings in this area. UK based studies found south Asians have both higher incidence of more severe morbidity with Crohn's and Colitis and yet lower rates of some key therapies, such as biologics. Further studies found younger people were particularly affected by cultural barriers to their care and a number of suggested cultural factors that may explain such barriers to south Asians with Crohn's and Colitis.

International studies described the economic impact of Crohn's and Colitis on those it affects as a direct result of the cost of therapies and the ability to continue employment and that lower socio-economic status patients were less likely to have participated in a peer mentoring or education program and less likely to reach out to patient support groups. No exploration of the causes of these

differences was included. A small number of studies investigated gender, findings were rates of sickness in women with Crohn's and higher mental health illness in pregnant people with IBD.

Gaps in research were related to further and more in-depth investigation of religious, economic and gender factors. Future systematic review could focus on UK based studies of race-based outcomes in Crohn's and Colitis. Future primary research could focus on content gaps in the areas above, but once demographic trends are found, qualitative methods that can investigate 'how' and 'why' such differences occur may be particularly indicated.

Introduction

A recent project tender from CCUK highlights previous research in IBD demonstrating impairment to daily activities and impact on an individual's ability to progress with key milestones. What is not clear is how social and economic factors impact on different demographic groups within the Crohn's and Colitis community. This could be considered through a range of potential group characteristics including:

- Age
- Educational stage
- Racial origin
- Social economic
- Gender
- Mental wellbeing or health
- Religion

It was not clear from the tender what the focus of the commissioning society was for consideration of study types, questions of relevance or outcomes of interest. This is not unusual when a complicated conceptual paradigm is considered within research, particularly when there is a new or emerging focus on this area.

This report details the findings of a scoping review to address this area of interest.

Scoping review is a type of evidence synthesis that uses a systematic and iterative approach to identify and synthesize an existing or emerging body of literature on a given topic (Thomas 2017). While there are several reasons for conducting a scoping review, the main reasons are to map the extent, range, and nature of the literature, identifying peaks of converging findings to inform future systematic reviews, as well as to determine possible gaps in the literature on a topic (Peters 2020).

Scoping reviews are particularly helpful when the literature is complex and heterogeneous, as in this area. Scoping reviews can provide useful insight for decision-makers into the nature of a concept and how that concept has been studied in the literature over time. They can be used to develop a research agenda, advance the field, and identify areas for future systematic reviews or other types of evidence synthesis, informing options for consideration in future research (Peters 2020).

Despite many examples of poor practice (4), as with guidance for the more traditional systematic reviews, the guidance for scoping reviews explicitly addressed the need for scoping reviews to be

rigorously conducted, transparent, and trustworthy (Peters 2014). Most importantly, this tradition should be employed for the correct reasons (3).

For this review, the specific aims were defined after review by the commissioners to understand how social and economic factors impact on different demographic groups and in particular how ethnicities and people from different economic demographics living with IBD may differ within the relative impact of these factors.

The research goals were to:

- To map the literature using a scholarly and systematic approach,
- Identifying current peaks of converging evidence
- Identifying evidence gaps
- Determine areas for future review of evidence

Methods

This scoping review was conducted in a rapid timeframe (8 weeks from protocol completion to this report). The speed with which it was conducted, however, did not compromise rigor or systematicity, as we have exemplified in previous published works (7). The work was guided by the model for scoping reviews described by Arksey and O'Malley (8) and the more recent update by Peters et al (2020). The report aligns with the reporting standards of the PRISMA-SR (9).

The five stages of a scoping review followed (Arksey and O'Malley 2005) were:

Stage 1: identifying the research aims/questions (as stated above)

Stage 2: identifying relevant studies

Stage 3: study selection

Stage 4: charting the data

Stage 5: collating, summarizing and reporting the results

Stage 2: identifying relevant studies

This is a vital stage within a scoping review. Because scoping reviews are amenable to the inclusion of diverse methodologies on broad and wider ranging questions, as well as considering wide ranging types of research, there is a strong risk that the search and the inclusion criteria informing this search are flawed. This can lead to falsely focussed searches with minimal evidence, not reflecting the literature. Alternatively, too wide a search can lead to unfocussed low utility findings.

The three core elements to consider are the participants, the context and the concept or focus.

The participants were described as people with Crohn's or Colitis who are adults (over 16, matching NHS service delivery in the UK).

The context was the list of factors stated within the introduction and stated below in the search strategy.

The concept was the most challenging element. It was unclear from the needs of the commissioner and initial discussion as to what the concept or phenomena of interest was or specific outcomes or interventions.

Considering the lack of clarity on the concept, the search strategy was designed to focus on Participants and context.

Studies of any research method focussing on how these context factors affected the course of Crohn's or Colitis or in turn how Crohn's or Colitis impacted these factors were all considered for inclusion. Whilst global research was within scope, a focus on UK based works underpinned the search.

Our initial inclusion criteria were defined as follows:

- Papers that described social and economic factors impacting on people with Crohn's and colitis
- Studies using any methodology, including observational, cross-sectional, action based, before and after, non-randomised and randomised trials
- Studies in any language and from any date

Our exclusion criteria will be as follows:

- Opinion pieces, commentaries, editorials, perspectives, calls for change, needs assessments and other studies where no actual new knowledge had been developed
- Studies in multiple conditions where data from Crohn's and Colitis cannot be separated
- Studies in Children exclusively

The strategy was designed with an expert information specialist and a first pilot search was ran on 3rd June 2023. This led to 100,000 results. Further refinement and limitation to title and abstract dropped this to 10,000 results. Review of these results found little of interest with less than 1 potential relevant result per 100 citations. Further refinement was completed and a search submitted to the commissioners on 12th June 2023. On joint review of potential results, some concepts were clarified, including the addition of terms to capture educational and mental wellbeing focussed studies. A final strategy was agreed on 20th June 2023. This had no language or date limitations and all citation types were considered. There had been a total of ten iterations of the strategy with sample searches, discussion with CCUK as the commissioning body and further refinement of terms to ensure the validity and reliability of the approach and in alignment with

scoping review, which allows for post hoc revision of criteria, as authors become more familiar with the evidence base (Levac et al. 2010).

The search terms are shown in **Table 1**.

Participants	Context
crohn disease	social factors
Ulcerative colitis	Economic
inflammatory bowel diseases	unemployed
crohn	financial factors
Crohn's	employment
inflammatory bowel disease	employed
IBD	absenteeism
Colitis	Education
	Travel
	transport
	Race
	minority background
	Religion
	Stigma
	Ethnic
	Ethnicity
	mental illness
	mental health

Table 1. Search terms used for online databases.

The two groups of search terms were combined using Boolean OR operations and then the final lists were combined using AND operations, with limits to title and abstract.

Inter-rater reliability will be calculated using Cohen's Kappa. Full texts will be retrieved and independently reviewed by two authors. Discrepancies at all stages will be resolved through discussion, including a third author as needed, until consensus is reached.

Stage 3: study selection

Deduplication was conducted using Endnote. Retrieved citations were uploaded in Covidence, an online data management system for performing systematic reviews. All titles and abstracts were independently screened by two authors against the criteria defined above.

Disagreements were highlighted in the covidence system and discussed to reach consensus for inclusion.

All potential citations were then accessed and downloaded in full. Further independent screening by two team members was completed to determine relevance for inclusion. Once again, any disagreements were discussed in full to reach consensus.

Stage 4: charting the data

We developed a data-charting form modified from the form used in our prior review (5) to align with the aims of this scoping review. The form was loaded into MS Teams to facilitate sharing of data. A team meeting was held to ensure shared understanding of terms and focus of extraction, prior to wider article distribution. Primary studies were once again extracted separately by two authors and any disagreements resolved on completion.

Quality assessments were planned to be undertaken if studies were of an interventional methodology that lend themselves to this (Risk of bias for randomised trials)

Data extracted included:

- Article identifiers (author(s), month of publication)
- Context items of focus
- Geographic origin
- Participants (both type and number), disease type, mix
- Data on patient's demographics including any data on social economic status, ethnicity, nationality and other diversity data. The lack of data in this area will be actively extracted.
- Study methods and quality assessment if appropriate
- Description of core findings
- Primary results with associated data
- Outcome of any intervention or experimental study

Stage 5: collating, summarizing and reporting the results

Utilizing data from the MS teams extraction sheets, the authors collated the data into a number of tables and figures for easy visualization, to provide a map of the current evidence base. After charting the large volume of data, we will also produce a narrative account of our findings that considers the extent and range of data included in the review, as well as the outcomes assessed. This will follow good practice for narrative review, but will not include specific meta-analysis. Instead, if data or studies exist with appropriate homogeneity to allow for such synthesis, this will be identified as a future research goal. We planned to use our charting process and visual aids to summarise broad areas of convergences and divergence to guide the commissioning organisation goals.

Thematic analysis of core factors found and the impact of these factors on patient outcomes was also planned if significant conceptual or theoretical data was available. This was planned to follow a three phase process of coding by two authors independently and then by consensus. These phases were open, axial and selective, with the themes from each phase informing the next. In the selective phase, a framework of whether and how core themes interact would be proposed. This was only planned to occur if the studies are aligned sufficiently with convergence of other characteristics as to be valid to do so. If the range of studies are divergent and heterogenous, no thematic analysis was to be performed and reasons described.

We planned to identify areas where a paucity of research exists and in particular where this is an area of clear agreement in multiple papers. We will suggest areas for future primary and secondary studies (i.e. systematic reviews).

Results

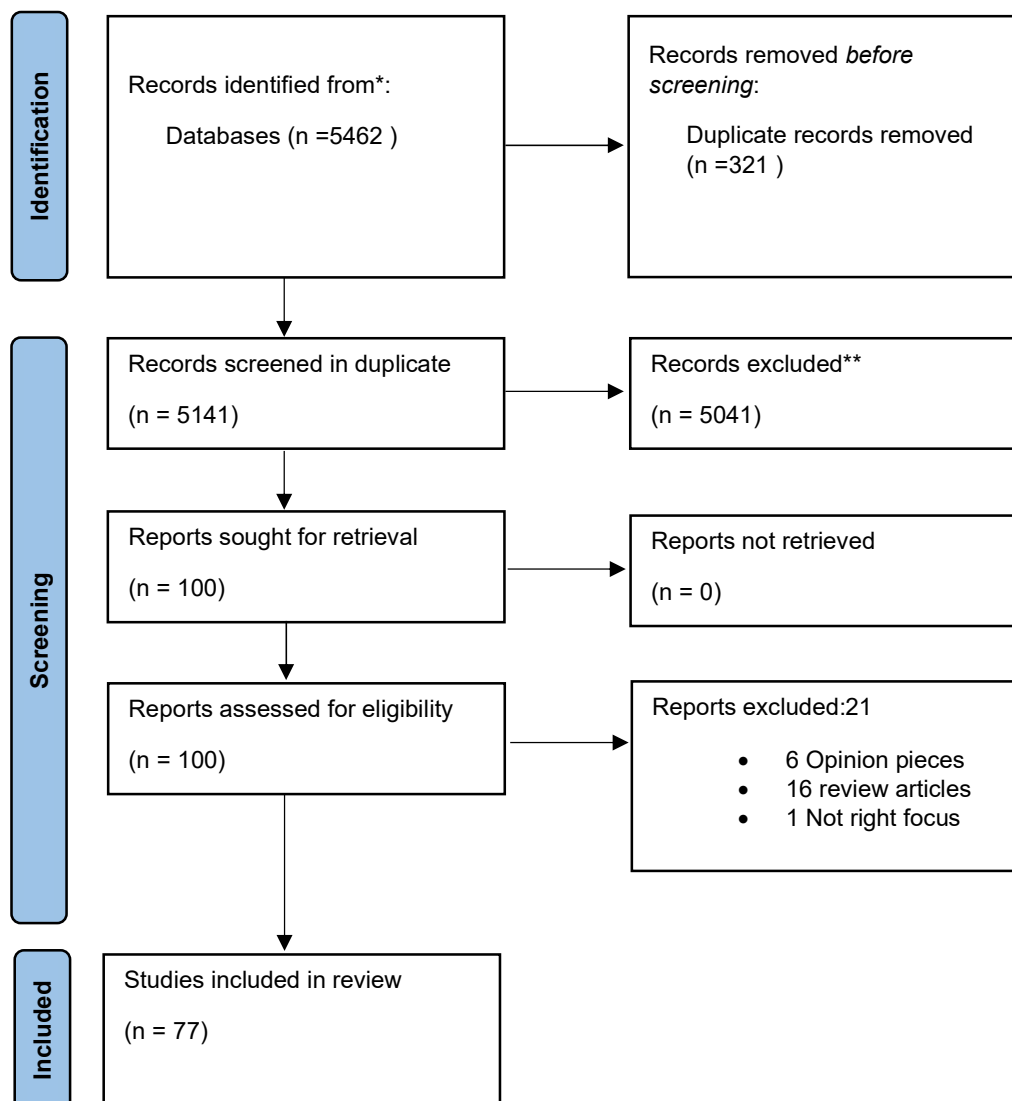
We electronically searched two databases (MEDLINE, EMBASE) on the 26th June 2023 with no date or language limitations. We included abstracts, such as from the recent DDW and UEGW meetings, to ensure studies not published in full were considered.

A total of 5462 citations were recovered, with 5141 after de-duplication. These were screened independently by two researchers. The agreement was calculated at 0.91, which is categorised as high reliability.

After meeting to discuss disagreements, this left 100 studies to review in full. All could be accessed and full text screening was completed again in duplicate. A total of 21 studies were excluded. This was due to 14 being review articles, 5 opinion pieces and 1 the wrong context focus.

This left a final cohort of 79 full studies included. The PRISMA flow diagram is shown in Figure 1.

Figure 1. PRISMA flow diagram



Demographics of included studies

There were a total of 1,212,558 participants reported as included in the studies, with 13 studies not specifying population sizes. The studies primarily originated from the UK (15), USA (27) and Canada (10), with other countries including Israel, Brazil, Norway, Holland, Sweden, Switzerland and Hungary.

The participants included were mostly mixed groups of Crohn's and Colitis patients in 60 of the studies, with 10 studies focusing on Crohn's and 7 focusing on Colitis.

A variety of methods were included, but no experimental studies were included. The most common method was Cohort studies (23), followed by Big data (22), Qualitative research (21), Cross-sectional (9) and Audits (2).

There was a broad range of topics included, but the majority of studies focused on racial factors, with a quarter of the studies focused on racial distribution of patients at either diagnosis or in cross-sectional studies. A further quarter of studies focused on racial disparity in disease outcomes or management.

The remaining studies had a broader focus, with some examples included Factors that affect outcomes in IBD (14), Broader impacts of IBD on life (5), Impacts on employment (4) and factors affecting the choices of treatments (3).

Table 2 is a detailed summary of the characteristics of included studies.

Supplementary appendix 1 is a full database of the included studies and their references, together with demographics. Supplementary appendix 2 is the full data set of studies included, together with the previous studies supplied by the commissioner.

Study ID	Topic	Condition	Methods	Location	Sample Size	Key findings	Conclusions
Kaplan 2015	Global epidemiology	IBD	Audit of published studies	Canada	UNCLEAR		Over 1 million residents in the USA and 2.5 million in Europe are estimated to have IBD, with substantial costs for health care. IBD increasing in newly industrialized countries and forecasts the global effects of IBD in 2025.
Sedano 2022	Representation in trials	IBD	Audit of published trials	canada	19476	22% of Induction and 26% of maintenance trials don't report race.	Potential under-representation of minorities in trials in IBD
Aniwan 2019	Racial distribution IBD	IBD	Big data	USA	UNCLEAR	Adjusted annual incidence rate of IBD for whites was 21.6 cases per 100,000 person-years and for nonwhites it was 13 per 100,000 and increased by 39% and 134%, respectively, from 1970 through 2010.	There were significant racial and ethnic differences in the incidence and temporal trends of IBD over the last four decades in this US population-based cohort.
Asotibe 2022	Racial disparities in outcomes	IBD	Big data	USA	177574	There was no significant difference in inpatient mortality for black vs white patients and no difference in the odds of developing septic shock	White patients hospitalized with a principal diagnosis of IBD had no difference in inpatient mortality or septic shock but had worse outcomes such as increased odds of bowel perforation compared to black patients.
Barnes 2018	Racial disparities in outcomes	IBD	Big data	USA	5537	Black patients were more likely to report a Crohn's disease (CD)-related complication at baseline (adjusted odds ratio [aOR], 1.44; 95% confidence interval [CI], 1.06-1.95). Black patients with ulcerative colitis were more likely to have proctitis (24% vs 13%, P = 0.033) at baseline.	Black patients with CD demonstrated increased complications at baseline and during follow-up in this cohort.
Barnes 2021b	Patterns of drugs use based on drugs	IBD	Big data	USA	14735	there was no significant difference in the odds of anti-tumor necrosis factor use by race for CD (adjusted odds ratio [aOR] = 1.13; 95% confidence interval [CI], 0.99-1.28) or ulcerative colitis (aOR = 1.12; 95% CI, 0.96-1.32).	Disparities in IBD treatment discussed in prior literature seem to be driven by socioeconomic or other issues affecting access to care, not race.
Barnes 2022	Racial distribution IBD	IBD	Big data	USA	212393	Black adult patients were significantly less likely than White patients to have a diagnosis of CD (odds ratio [OR], 0.53; 95% CI, 0.52-0.54) or UC (OR, 0.41; 95% CI, 0.40-0.43). Pediatric Black patients were also less likely to have a diagnosis of CD (OR, 0.41; 95% CI,	CD and UC are modestly less prevalent among patients of non-White races and Hispanic ethnicity.

						0.39-0.43) or UC (OR, 0.38; 95% CI, 0.35-0.41).	
Bernstein 2001	broad determinants	IBD	Big data	Canada	UNCLEAR	In study A we found that, compared with the general population, patients with IBD were more likely to be unemployed. Crohn's disease appeared to affect employment more than ulcerative colitis	Individuals with IBD at some time in the course of their illness are more likely not to be working than are those in the general population
DosSantosMarques 2022	Racial factors impacting distribution of drug use	IBD	Big data	USA	14735	barriers to a positive surgical experience included inadequate personal knowledge of IBD, ineffective written and verbal communication, lack of a support system and complications after surgery	Black and White patients with IBD have varied surgical experiences but all stressed the importance of accurate, trustworthy and understandable health information. These findings highlight the value of providing health literacy-sensitive care in surgery.
Eglinton 2012	Racial distribution Peri-anal disease	CD	Big data	new Zealand	715	Perianal disease was associated with younger age at diagnosis (P < 0.0001), complicated intestinal disease (P < 0.0001), and ileal disease location (P = 0.002). There was no association with gender, ethnicity, smoking, or breast feeding.	This study suggests that younger age at diagnosis, complicated disease behavior, and ileal disease location are risk factors for perianal CD.
Farrukh 2015b	Racial factors impacting distribution of drug use	CD	Big data	UK	UNCLEAR	In three Trusts, the number of South Asian patients who received such treatment was significantly less than British/White patients. These were: Pennine Acute Hospitals NHS Trust covering Oldham and North Manchester, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust.	It is unacceptable for there to be a difference based on racial grounds.
GunnellsDJr 2016	Racial disparities in outcomes (surgery)	IBD	Big data	USA	2523	On multivariable analysis, black race remained a significant predictor for 30-day readmissions in patients with IBD (odds ratio 1.6, 95% confidence interval 1.1-2.5).	Black patients with IBD have an increased risk for readmission after colorectal surgery.
Kochar 2018	Racial distribution IBD	IBD	Big data	USA	5412	Adjusting for confounders, Asians had half the odds of being treated with biologics compared with whites (OR: 0.45, 95% CI: 0.30-0.67). Adjusting for disease behavior and remission status, there were no differences in IBD-related surgery or hospitalization, new biologic or steroid prescription or relapse rates between Asians and whites at follow-up.	Asians are more likely to have perianal disease and ocular extra-intestinal manifestations. After controlling for confounders, Asians were less likely to be treated with biologic agents.

Lichtenstein 2020	Impact of age on economic burden of IBD	IBD	Big data	USA	164375	Lifetime total cost was \$405,496, consisting of outpatient (\$163,670), inpatient (\$123,190), pharmacy (\$105,142), and ER (\$13,493) costs.	we estimated lifetime costs for patients with CD or UC to exceed previously published estimates.
Longobardi 2003	Employment impact of IBD	IBD	Big data	Canada	UNCLEAR	Based on this, the indirect cost of nonparticipation attributable to IBD in 1998/1999 was more than \$3.6 billion U.S. dollars (USD) or \$5228 USD per person with IBD and symptoms. According to the second weighted logistic regression, for those who are in the labor force, having IBD had no association with the duration of work.	This method of estimation can be used to predict the overall paid-employment burden of IBD.
Malhotra 2015	Racial distribution IBD	IBD	Big data	USA	30812	UC was more commonly associated with Indian and Jewish ethnicity and less commonly associated with East Asian and Hispanic ethnicity. Similar patterns also applied to CD and to all types of IBD analyzed jointly.	Patients of Indian origin living in the United States have a greater risk for all types of IBD than other American populations.
Misra 2016	Racial differences in colectomy rates	UC	Big data	UK	212430	Indians had a significantly higher colectomy rate than WE (9.8% versus 6.9%, $p < 0.001$). Indian patients were 21% more likely to require colectomy for UC compared with WE group (OR: 1.21, 95% CI: 1.04-1.42, and $p = 0.001$).	The colectomy rate in this cohort was higher in Indians compared to WE
Misra 2019	Racial distribution IBD	IBD - Inception study	Big data	UK	339	The age adjusted incidence of IBD and UC were significantly higher in the Indian group (25.2/100000 and 20.5/100000) compared to White European (14.9/100000, $P = 0.009$ and 8.2/100000, $P < 0.001$) and Pakistani groups (14.9/100000, $P = 0.001$ and 11.2/100000, $P = 0.007$). The Indian group were significantly more likely to have extensive disease than White Europeans (52.7% vs 41.7%, $P = 0.031$). There was no significant difference in time to diagnosis, disease activity and treatment.	This is the only prospective study to report the incidence of IBD in an ethnically diverse United Kingdom population. The Indian ethnic group showed the highest age-adjusted incidence of UC (20.5/100000).
Probert 1992	Racial distribution IBD	CD	Big data	UK	UNCLEAR	The mean standardized incidence in Bangladeshis was 1.2/10(5)/year in the 1970s and 2.3/10(5)/year in the 1980s compared with 3.8/10(5)/year and 4.1/10(5)/year in Europeans, and 4.6/10(5)/year and 5.4/10(5)/year in West Indians, respectively.	The apparent similarity of the incidences of Crohn's disease in Bangladeshis and Europeans contrasts with findings in other South Asians.

						None of the changes with time was statistically significant.	
Sewell 2010	Racial disparities in outcomes	IBD	Big data	USA	UNCLEAR	The proportion of hospitalizations including a discharge diagnosis of IBD increased significantly from 1994 to 2006 among the total population and among Asian, black, and white patients separately.	The proportion of hospitalizations including a discharge diagnosis of IBD increased significantly among minority and nonminority patients from 1994 through 2006. The causes underlying these changes are not certain and should be further investigated.
Shapira 1994	Racial distribution IBD	CD	Big data	israel	UNCLEAR	he mean annual incidence rate in the Kinneret sub-district among Jews was 1.96/100,000 during 1960-1990 and 2.98/100,000 in the last decade. The prevalence rate in 1990 among Jews was 45.9/100,000 and was twofold among European-American-born compared to other ethnic groups.	(1) morbidity rate of Crohn's disease increased over time, and (2) in the last decade incidence rates among Jews of Asian-African origin are similar to, or even higher than those of European-American origin.
Vigod 2019	Pregnancy association with mental health in IBD	IBD	Big data	Canada	UNCLEAR	About 22.7% of women with IBD had new-onset mental illness versus 20.4% without, risk was elevated in the post partum (aHR 1.20, 95%â€‰CI 1.09 to 1.31).	Women with IBD were at an increased risk of new-onset psychiatric diagnosis in the postpartum period, but not during pregnancy.
Vij 2019	Racial disparities in outcomes (Colon cancer)	IBD	Big data	USA	57542	In patients with IBD, advanced age conferred an increased risk for developing CC while female gender conferred a protective effect. In this subset of patients, black race conferred a protective effect	Racial disparity exists in the overall incidence of CC and among patients with IBD who develop CC. Interestingly, black race conferred a protective effect for patients with IBD, contrary to what is seen in the general population.
Wang 2013	Racial distribution IBD	IBD	Big data	USA	202468	The prevalence of IBD was higher in Whites [Crohn's disease: 154; ulcerative colitis (UC): 89] than Blacks (Crohn's disease: 68; UC: 25), Hispanics (Crohn's disease: 15; UC: 35), and Asians (Crohn's: 45; UC: 40) (all p < 0.05, except for UC in Asians).	There were significant racial/ethnic differences in the prevalence of IBD in the USA.
Zhornitskiy 2021	Racial distribution IBD	IBD	cohort	USA	UNCLEAR	Prevalence of IBD per 100,000 people was 418 (95% CI 341-512) for Hispanics and 557 (95% CI 431-739) for NHWs. Notably, the proportion of Hispanic IBD patients with a history of smoking was 21.5% vs 50.8% in NHWs (p = 0.011).	In one of the largest US studies of Hispanics with IBD, and the only one to have both clinical and histopathologic confirmation as inclusion criteria, we found the incidence and prevalence of IBD among Hispanics to be higher than previously recognized and comparable to NHWs.

Gadhok 2020	Outcomes depending on race	IBD	Cohort study	UK	224	Bangladeshi patients started an anti-TNF 4.3 years earlier after diagnosis than Caucasian patients (3.9 years vs. 8.2 years: $p < 0.01$). Bangladeshi patients experienced shorter failure-free survival than Caucasian patients (1.8 vs. 4.8 years $p < 0.01$).	This is the first study to suggest that Bangladeshi patients resident in the UK with CD respond less well to treatment with TNF antagonists than Caucasian patients.
Bernstein 2020	Impact of lower socio-economic status	IBD	Cohort study	Canada	9298	Comparing persons with Lower Socioeconomic State (LSS) vs those without any markers of LSS, there were increased rates of annual outpatient physician visits (relative risk [RR] = 1.10, 95% confidence interval [CI] = 1.06-1.13), hospitalizations (RR = 1.38, 95% CI = 1.31-1.44), intensive care unit admission (RR = 1.94, 95% CI = 1.65-2.27), use of corticosteroids >2,000 mg/yr (RR = 1.12, 95% CI = 1.03-1.21), and death (hazard ratio 1.53, 95% CI = 1.36-1.73).	LSS was associated with worse outcomes in persons with IBD. Social determinants of health at time of diagnosis should be highly considered and addressed.
Wetwittayakhleng 2023	Factors associated with diagnosis	IBD	cohort study - three timer periods	hungary	2240	Rates of active smoking significantly decreased over time in Crohn's disease (CD): 60.2%, 49.9%, and 38.6% in cohorts A/B/C ($p < 0.001$). In UC, the rates were low and stable: 15.4%, 15.4%, and 14.5% in cohorts A/B/C ($p = 0.981$).	The association between trends of known environmental factors and IBD is complex. Smoking has become less prevalent in CD, but no other major changes occurred in socioeconomic factors over the last four decades that could explain the sharp increase in IBD incidence.
Acosta-Ramírez 2001	MEntal healht characteristics in ibd	IBD	cross-sectional	Puerto Rico	67	Patients older than 34 years old had three times higher probability of developing a depressive disorder ($p = 0.043$, OR = 3.22). Patients with a psychiatric history had seven times higher probability of developing depressive disorder ($p = 0.004$, OR = 7).	The risk factors identified with an increased probability of developing a depressive disorder were age older than 34 years and psychiatric history.
Can 2022	Factors affecting medication adherence	IBD	cross-sectional	Turkey	253	Intentional (29.3% in ulcerative colitis and 16.3% in Crohn's disease [$P = .031$] and unintentional non-adherence to treatment (28.1% in ulcerative colitis, 16.3% in Crohn's disease [$P = .037$]) were significantly higher in ulcerative colitis than in Crohn's disease. Female gender (odds ratio = 2.59, $P = .005$), low education level (odds ratio = 4.8, $P = .015$), distal involvement in ulcerative colitis	The negative perception of treatment in inflammatory bowel disease affects adherence to the treatment.

						(P = .014), and thoughts about the disease would last too soon in Crohn's disease (odds ratio = 4.17, P = .049) were risk factors for non-adherence to treatment.	
Click 2016	Predictors of high healthcare utilisation	IBD	cross-sectional	USA	400	In multivariate analysis, unemployment (Crohn's disease [CD]: odds ratio [OR], 3.04; 95% confidence interval [CI], 1.32-7.02; ulcerative colitis [UC]: OR, 2.68; 95% CI, 1.20-5.99), psychiatric illness (UC: OR, 2.08; 95% CI, 1.03-4.19), opiates (CD: OR, 5.61; 95% CI, 2.67-11.82; UC: OR, 5.14; 95% CI, 2.52-10.48), prior surgery (CD: OR, 3.29; 95% CI, 1.59-6.82; UC: OR, 2.72; 95% CI, 1.39-5.32), penetrating CD (OR, 3.29; 95% CI, 1.02-10.62), and corticosteroid requirement (CD: OR, 3.78; 95% CI, 1.86-7.65; UC: OR, 2.98; 95% CI, 1.51-5.90) remained independently associated with high charges.	High expenditure IBD patients were affected by more severe disease. The high prevalence of depression, anxiety, and chronic pain in these patients suggests the need for focused treatment of these comorbidities ultimately to reduce financial burden.
Damas 2022	Social barriers impact on outcomes	IBD	cross-sectional	USA	316	Social barriers associated with poor IBD outcomes included low educational attainment, poor health literacy, and financial insecurity. High social barrier scores was associated with greater depressive symptoms [odds ratio (OR) 1.94, 95% confidence interval (CI) 1.21-2.9, p = 0.001] and lower reported use of medications.	Our study identifies social barriers that may impact IBD care and are disproportionately higher in non-Hispanic Blacks and Hispanics in the United States.
DosSantosMarques 2020	Factors impacting health literacy in IBD	ibd	cross-sectional	USA	175	On multivariable analysis, low health literacy was associated with older age and African American race (P < 0.05). Of 83 IBD patients undergoing abdominal surgery, mean postoperative LOS was 5.5 days and readmission rate was 28.9%.	Low health literacy is present in IBD populations and more common among older African Americans.
Farrukh 2016	Racial disparities in outcomes	IBD	cross-sectional	UK	70	South Asian patients were significantly less likely to see a consultant and more likely to be discharged. South Asian patients were admitted to hospital more often but had significantly fewer tests than European patients.	Patients with ulcerative colitis who are of South Asian origin receive poorer quality clinical care than their European counterparts.
Greenberg 2015	Factors affecting utility weights	CD	cross-sectional	Israel	425	significant predictors of utility weights in a multivariable regression analysis were the HBI [$\beta^2 = -0.494$; p < 0.001], economic status [$\beta^2 =$	Utility weights for patients in the remission and mild disease states were generally lower as compared with values

	(health economics)					0.198; p < 0.001], time since diagnosis [$I^2 = 0.106$; p < 0.001], male [compared with female] gender [$I^2 = 0.099$; p = 0.009], hospital admission in the past year for any cause	used in published cost-effectiveness analyses.
Naftali 2022	Factors effecting patient preference	IBD	cross-sectional	israel	361	Multivariable regression analysis revealed that higher patient preferences were associated with Jewish ethnicity (OR 4.77; 95%CI 2.36-9.61, P < 0.001) and disease activity.	The highest priority for treatment outcomes was symptom relief., Patients preferences were impacted by ethnicity, gender, and socio-economic disparity.
Nazarinasab 2019	Mental health characteristics in CD	CD	cross-sectional	Iran	96	Multivariate analysis of mental health showed that steroid consumption (P value < 0.001) and nonsmoking (P value = 0.038) were associated with higher mental health in the individuals.	Crohn's patients suffered from decreased mental parameters
Nguyen 2010	Racial disparities in utilisation	IBD	cross-sectional	Canada	286	blacks were less likely than whites to be under the regular care (defined as at least annual visit) of a gastroenterologist (adjusted odds ratio (aOR) 0.43; 95% confidence interval (CI): 0.25-0.75) or IBD specialist (aOR 0.37; 95% CI: 0.22-0.61).	There are racial differences in utilization of IBD-related specialist services, ED visits, and infliximab that are independent of income and education.
Odufalu 2023	broad determinants	UC	cross-sectional	GLOBAL	1000	Low-income vs high-income patients were less likely to have participated in a peer mentoring (OR, 0.30) or UC education program (OR, 0.51). Patients not employed were less likely to report being in "good/excellent" health (OR, 0.58) than patients employed full time. Patients with low vs high educational levels were less likely to have reached out to patient associations/organizations (OR, 0.59). Patients aged younger than 50 years vs those aged 50 years and older were less likely to have visited an office within an inflammatory bowel disease center/clinic in the past 12 months (OR, 0.53).	Substantial differences in disease management and health care experience were identified
Walldorf 2021	Factors impacting childlessness	IBD	cross-sectional	Germany	533	Poor knowledge was not associated with increased childlessness (CCKnow of ≤ 8 was found in 29.8% of patients with children and 28.9% of childless patients, p=0.5). Instead, the patients'	Factual knowledge does not reduce disease-related concerns or childlessness.

						education, medical advice, FPP-related concerns, impaired body image, and sexual dysfunction had a significant impact on childlessness.	
Schenker 2021	Guideline for Transgender IBD	IBD	Guideline / position statement	USA	UNCLEAR	Despite an increase in provider awareness of TGNC health over the past decade, no original research or societal guidelines exist on TGNC patients with inflammatory bowel disease (IBD).	high-quality care to the Trans-gender IBD population can be divided into 3 categories: medications, anatomy, and mental health.
Montgomery 1999	Racial distribution IBD	IBD	Longitudinal birth cohort study	UK	UNCLEAR	Young Asians born in Britain were significantly more likely than indigenous Europeans to have a diagnosis of IBD by age 26 years, with relative odds of 6.10 (95% CI 2.14-17.33).	Young Asians who were born in Britain are at a significantly higher risk of developing IBD than the indigenous European population.
Ediger 2007	Factors determining medical adherence	IBD	Propsective cohort	Canada	326	or men, predictors of low adherence included diagnosis (UC: OR 4.42, 95% CI 1.66-11.75) and employment status (employed: OR 11.27, 95% CI 2.05-62.08). For women, predictors of low adherence included younger age (under 30 versus over 50 OR 3.64, 95% CI 1.41-9.43; under 30 vs. 40-49 yr: OR 2.62, 95% CI 1.07-6.42). High scores on the Obstacles to Medication Use Scale strongly related to low adherence for both men (OR 4.05, 95% CI 1.40-11.70) and women (OR 3.89, 95% CI 1.90-7.99).	Approximately one-third of IBD patients were low adherers. Predictors of adherence differed markedly between genders
Acciari 2019	Social aspects influence wellbeing vs clinical aspects	IBD	Qualitative research	Brazil	104	There were also significant differences in the use of Coping: usually, women used more developed escape and avoidance strategies; single, married or in stable-union patients used more self-control; not religious used positive revaluation strategy; the ones who were employed showed more self-control and positive reassessment; the ones who had lower family income indicated that they used less the self-control; the ones who had higher family income used more positive re-evaluation; patients who were diagnosed with Crohn's disease between the second decade of life showed to use mores more the	Social aspects influenced psychological well-being, resilience and Coping in patients with Crohn's disease more strongly than clinical aspects.

						positive reassessment strategy than those who were 20 years old or younger.	
Agrawal 2019	Factors influencing disability in IBD	IBD	Qualitative research	USA	323	On multivariable analysis, Hispanic ethnicity (aOR 2.7, 95% CI 1.3-5.6), non-Hispanic non-black minority race (aOR 3.5, 95% CI 1.3-8.9), public payer (aOR 2.1, 95% CI 1.1-4.0) and low annual household income (aOR 3.0, 95% CI 1.7-5.4) were associated with moderate-to-severe disability controlling for disease characteristics.	IBD patients who are minorities, have public insurance, or low household income, are 2-3 times more likely to report moderate-to-severe disability independent of disease characteristics in the United States.
Alexakis 2015	Factors associated with challenges in IBD in young people	IBD	Qualitative research	UK	20	A thematic analysis of their experiences identified many commonalities with other young people with IBD, such as the problematic route to formal diagnosis and the impact of IBD on education. The young people also experienced tensions between effective self-management strategies and cultural norms and practices relating to food. Moreover, the ability of parents to provide support was hampered for some young people by the absence of culturally competent services that were responsive to the families' communication needs.	The findings highlight the need for more culturally appropriate information concerning IBD, and improved responsiveness to young people with IBD within primary care and the education system
Bernklev 2006	Employment impact of IBD	IBD	Qualitative research	Norway	495	Sick leave for all causes was reported in 47% with ulcerative colitis and 53% with CD, whereas IBD-related sick leave was reported in 18% and 23%, respectively. A majority (75%) had been sick <4 weeks, and a relatively small number of patients (25%) contributed to a large number of the total sick leave days. Both unemployment and DP reduced HRQOL scores, but the most pronounced effect on HRQOL was found in patients reporting IBD-related sick leave, measured with SF-36 and N-IBDQ.	Unemployment or sick leave is more common in IBD patients than in the Norwegian background population.
Blumenstein 2013	Racial differences in knowledge	IBD	Qualitative research	Germany	303	German patients obtained knowledge from a wider range of sources than Irish patients ($p<0.001$), most notably from the internet ($p<0.001$), newspapers and magazines ($p=0.002$).	Our data suggest few differences between German and Irish IBD patients, despite cultural and linguistic differences, with regard to disease related knowledge of IBD.

Chrobak-BieÅ,, 2018	Factors affecting acceptance of UC	UC	Qualitative research	Poland	50	Analysis of the results showed a reduced degree of acceptance of the disease among patients in the phase of exacerbation of the disease. The mean point score of the AIS scale for the study group was 29.65, which indicates the average level of acceptance of the disease among respondents	People with higher education, professionally active and treated conservatively, accepted their illness to a better extent.
Engel 2021	Psychological parameters across key factors	IBD	Qualitative research	Germany	62	Levels of depression and anxiety were higher in CD/UC patients than in HC with large effect sizes. Comparing personality functioning in CD/UC with HC, psychodynamic structural characteristics differed between CD/UC and HC with medium effect sizes, with structural differences occurring primarily in the domain of self-perception and regulation.	Our data show that compared to HC, patients with CD/UC are characterized by a higher level of psychological burden and structural alterations in the domain of self.
Freitas 2015	Religious coping as predictor for other factors	IBD	Qualitative research	Brazil	147	Positive religious coping was negatively associated with anxiety ($b = 0.256$; $p = 0.007$) as well as with overall, physical, and mental health HRQoL. Religious struggle was significantly associated with depression ($b = 0.307$; $p < 0.001$) and self-reported adherence ($b = 0.258$; $p = 0.009$). Finally, anxiety symptoms fully mediated the effect of positive religious coping on overall HRQoL.	Religious coping is significantly associated with psychological distress, HRQoL, and adherence in IBD.
Harvey 2022	Perspectives of patients with lower educational attainment	IBD	Qualitative research	Canada	23	Thematic analysis found focus on communication with health care professionals, access to care, symptoms and treatment, and outside support. Access to an IBD specialist was the most important aspect of care. Good care, kind and receptive staff, and a lengthy delay to diagnosis were frequently reported experiences. IBD specialists, nurses, and family and friends were most helpful in managing disease. Physical and emotional symptoms, reduced social engagement, and medications were difficult aspects of living with IBD.	An ideal IBD clinic would provide access to traditional and non-traditional services and assist with obtaining support to help patients engage in social activities, increase affordability of care, and maintain employment.
Larussa 2020	Factors affecting willingness to	IBD	Qualitative research	Italian	145	Multivariate analysis showed a significant positive association between interest in clinical trials and previous experience ($p = 0.014$), high education ($p < 0.001$), poor QoL	In a native local resident series of IBD patients, the majority of the patients were willing to participate in a clinical therapeutic trial. A long-standing

	take part in trials					(p = 0.016), money retributions (p = 0.03) and informative materials (p = 0.02). On the other hand, a long-standing disease (p = 0.017), the possibility of receiving a placebo (p = 0.04) and the frequent colonoscopies required by the study protocol (p = 0.04) were significantly associated with the lack of interest in clinical trials	disease, placebo and invasive procedures represented a barrier to enrollment while previous experience, high education, monetary compensation and adequate information could be facilitative.
Long 2014	Factors associated with depression in edlerly	IBD	Qualitative research	USA	359	ower education levels (p=0.001), higher corticosteroid use (<0.01) and lower exercise levels (<0.001) were associated with depression. For both CD and ulcerative colitis (UC), those with depression had increased disease activity (short Crohn's disease activity index 52.5 versus 29, p=0.005, and simple clinical colitis activity index 5 versus 2, p=0.003).	Depression is common in this geriatric IBD cohort. Depression is independently associated with reduced medication adherence.
Mahlich 2017	Employment impact of IBD	IBD	Qualitative research	Japan	1068	We found that the labor force participation rate is lower and unemployment higher for patients with IBD compared to the general population. Factors associated with unemployment in the IBD sample are older age, female gender, and the prevalence of depression.	IBD constitutes a high burden for patients in Japan regarding employment outcome.
Moradkhani 2013	Racial disparities in outcomes	IBD	Qualitative research	USA	134	Multivariate analyses revealed that the variables most strongly associated with HRQOL were perceived stress (p<0.001), number of previous IBD relapses (p<0.001), gender (p<0.001), and perceived social support (p<0.05).	Individuals with IBD who report higher perceived stress, lower perceived social support, greater number of relapses, or are female may be at increased risk for decreased HRQOL.
Mukherjee 2021	South asian patients experiences	IBD	Qualitative research	UK	33	Although many experiences align with those of the general IBD population, participants believed that South Asian cultures and/or religions can lead to additional challenges. These are linked to: family and friends' understanding of IBD; self and family attributions regarding IBD; stigma surrounding ill health; the taboo of bowel symptoms; managing 'spicy food'; beliefs about food and ill health; roles within the family; living with extended family; the use of	Gastroenterology services have an important role to play in helping patients to overcome the challenges they encounter in their everyday life, both by providing individual patients with culturally appropriate care and advice.

						complementary and alternative therapies; and visits to family overseas. Religious faith helped many to cope with having IBD	
Multone 2015	Factors of non-responders to national surveys	IBD	Qualitative research	Switzerland	1943	Factors inversely associated with non-response to study questionnaires were: age >30 years, colonic only disease location, higher education and higher IBD-related quality of life for CD, and age >50 years or having a positive social support for UC	Characteristics of non-responders differed between UC and CD. The risk of non-response to repetitive solicitations (longitudinal versus transversal study) seemed to decrease with age.
Pittet 2017	Gender impact on coping	IBD	Qualitative research	Switzerland	1102	We identified six domains of concern: socialization and stigmatization, disease-related constraints and uncertainty, symptoms and their impact on body and mind, loss of body control (including sexuality), disease transmission, and long-term impact of the disease. Cancer concerns were among the highest scored by all patients (median 61.8).	Patients have numerous concerns related to their illness that need to be reassessed regularly. Concerns differ between men and women
Sarid 2017	Gender difference in coping with IBD	IBD	Qualitative research	Israel	402	A model split by gender and disease activity showed that in active CD economic status impacted SIBDQ in men ($\hat{I}^2 = 0.43$) more than women ($\hat{I}^2 = 0.26$); emotional coping impacted SWLS in women ($\hat{I}^2 = 0.36$) more than men ($\hat{I}^2 = 0.14$).	Gender differences in coping and the impacts of economic status and emotion-focused coping vary with activity of CD.
Sorensen 1987	broad determinants	CD	Qualitative research	Norway	106	54% of patients with Crohn's disease felt exacerbations of their disease strained their professional and personal life. During the previous year 23% reported decreased working capacity and 21% reported decreased leisure activities, compared with their own expectations.	During the previous year 23% reported decreased working capacity and 21% reported decreased leisure activities, compared with their own expectations.
Stjernman 2011	Broad determinants	IBD	Qualitative research	Sweden	497	Women with CD had higher rates of sickness and disability than men with CD and were more often living single, though procreation was not affected.	CD had higher impact on HRQL, compared with UC. Women with CD had worse outcome in subjective health status, but not in objective assessment of disease activity.
Farrukh 2015	Racial factors impacting distribution of drug use	CD	Retrospective cohort	UK	139	Based on a population composition, rather than prevalence data, in which 24% of the Leicester community should have been of South Asian origin, 33 patients would have received biologics compared with 92 patients	Suggested reasons for these differences have included concerns about the animal origins of infliximab as well as difficulties associated with accessing the service, such as the provision of

						of English origin (66%). This is significantly different to the 13 patients who did receive treatment ($z=-3.2$, $P\hat{A} < \hat{A} 0.001$).	information in an appropriate language through appropriate media.
Hoie 2007	Broad determinants	UC	Retrospective cohort	10 countries	771	The time to first relapse showed a greater hazard ratio (HR) (1.2, CI 1.0-1.5) for women and for patients with a high level of education (1.4, CI 1.1-1.8). The number of relapses decreased with age, and current smokers had a lower relapse rate (0.8, CI 0.6-0.9) than nonsmokers. The relapse rate in women was 1.2 (CI 1.1-1.3) times higher than in men.	In 67% of patients, there was at least one relapse. Smoking status, level of education, and possibly female gender were found to influence the risk of relapse.
Jayanthi 1992	Racial distribution IBD	CD	Retrospective cohort	UK	UNCLEAR	The standardized incidence in Europeans has risen significantly to 4.7/10(5)/year from 3.4/10(5)/year in the 1970s ($\chi^2 = 8.1$, p less than 0.005). In Leicester this increase can be accounted for entirely by new cases of colonic disease.	Overall, Hindus have a much lower incidence of Crohn's disease than Europeans.
Jordan 2022	Depression rates amongst AA	IBD	Retrospective cohort	USA	UNCLEAR	Overall prevalence of major depressive disorder was 25.3%; 45.8% had minimal, 8.3% mild, 33.3% moderate, and 12.5% severe depression. A total of 34.7% of patients were never screened for depression, and 13.8% had other psychiatric conditions. There was a difference in depression rates based on psychiatric conditions ($p\hat{A} = \hat{A} 0.00$), but no difference based on sex ($p\hat{A} = \hat{A} 0.37$), IBD subtype ($p\hat{A} = \hat{A} 0.34$), or medical conditions ($p\hat{A} = \hat{A} 0.84$).	Rates of depression among minority patients, predominantly African American, with inflammatory bowel disease were higher than previously reported for all patients with inflammatory bowel disease.
Li 2014	Racial disparities in outcomes	UC	Retrospective cohort	USA	7350	Compared with whites, the male-to-female ratio differed for African-Americans (0.68 vs. 0.91, $p\hat{A} < \hat{A} 0.01$) and Asians (1.3 vs. 0.91, $p\hat{A} < \hat{A} 0.01$). Asians had fewer co-morbid conditions ($p\hat{A} < \hat{A} 0.01$) than whites, whereas more African-Americans had hypertension and asthma ($p\hat{A} < \hat{A} 0.01$). Use of immunomodulators did not differ significantly among race and/or ethnic groups.	In this population of UC patients with good access to care, overall health-care utilization patterns and clinical outcomes were similar across races and ethnicity. Asians may have milder disease than other races whereas Hispanics had a trend toward more aggressive disease, although the differences we observed were modest.
Mangat 2011	Racial distribution IBD	IBD	Retrospective cohort	Canada	186	The South Asian population had a higher rate of UC, with an increased rate of complications and male predominance. Interestingly, the	These racial differences - which were statistically significant - suggest a role for ethnodiversity and environmental

						rate of CD and UC was lowest in the Pacific Asian population.	changes in the prevalence of IBD in Vancouver.
MontgomerySRJr 2018	Racial disparities in outcomes (surgery)	IBD	Retrospective cohort	USA	14679	After adjustment, black patients remained at increased risk of DSM compared white patients (OR: 1.37; 95% CI 1.14-1.64). CONCLUSIONS: Black patients are at increased risk of post-operative DSM following surgery for IBD	Black patients are at increased risk of post-operative DSM following surgery for IBD. The elevated rates of DSM are not explained by traditional risk factors like obesity, ASA class, emergent surgery, or stoma creation.
Moore 2012	Racial distribution IBD	UC	Retrospective cohort	USA	311	African American patients had a shorter median duration (8.0, interquartile range [IQR] = 4.0, 14.0) of UC than Caucasians (10.0, IQR = 6.0, 18.0) (P = 0.006). African American disease patients had more distal disease than controls. African Americans were significantly less likely to use corticosteroids (74.2% vs. 88.8%, P = 0.002), or use immunomodulators (25.8% vs. 69.7%, P < 0.001) than Caucasians.	There appear to be differences in the natural history of UC in our African American patients when compared with Caucasian controls, while ethnicity was not shown to be a risk factor for colectomy.
Norwood 2009	Racial disparities in outcomes (surgery)	IBD	Retrospective cohort	UK	107	Postoperative complications occurred in 40 (37%) patients, being major in 11 (10%) patients with relaparotomy required in 9 (8%) with no difference between South Asian and non-South Asian Caucasian patients. Long-term pouch function, with a median of five times over 24 h (range 2-15), was similar between the two groups. The incidence of pouchitis was 57 (53%) and this was significantly greater in the South Asian population [17/21 (77%); 39/86 (46%); P = 0.006].	Surgical results were similar in South Asian and non-South Asian Caucasian patients, but the incidence of pouchitis was greater in the former group.
Pressman 2008	Factors associated with medication use	CD	Retrospective cohort	USA	2964	Initiators were appreciably younger than controls (P < 0.001), but were similar to controls with respect to sex and race/ethnicity. The presence of at least 1 comorbidity was related to a modest increase in the risk of initiating (compared with none: 1 comorbidity, odds ratio [OR] = 1.52 with 95% confidence interval [CI] 1.16-2.00; 2 comorbidities, OR = 1.38 with CI 0.89-2.13). By 3 years after initiating, only 20% of patients remained on infliximab.	In a community-based setting infliximab use has steadily increased. Age and comorbidity are associated with initiation, but sex and race/ethnicity are not.

Smith 2023	Barriers to success of post surgical enhanced recovery	IBD Post surgical	Retrospective cohort	USA	466	In multivariable analysis stratified by enhanced recovery period, Black race was associated with increased odds of complications in the pre-ERP (OR 3.6, 95%CI 1.4-9.3) and ERP groups (OR 3.1 95%CI 1.3-7.6). Race was not a predictor of LOS or readmission in either group. High social vulnerability was associated with increased odds of readmission pre-ERP (OR 15.1, 95%CI 2.1-136.3), but this disparity was mitigated under ERPs (OR 1.4, 95%CI 0.4-5.6).	While enhanced recovery period mitigated some disparities by social vulnerability, racial disparities persist in IBD populations even under ERPs.
Walker 2011	Racial distribution IBD	IBD	Retrospective cohort	UK	367	63.0% of South Asian UC patients had extensive colitis compared with 42.5% of the Northern European cohort (P < 0.0001). Proctitis was uncommon in South Asian UC patients (9.9 vs. 26.1% in Northern European patients, P<0.0001). In the South Asian CD cohort, disease location was predominantly colonic (46.8%). CD behavior differed significantly between the groups, with less penetrating disease compared with Northern Europeans (P=0.01) and a reduced need for surgery (P=0.003).	The phenotype of IBD in South Asians living in North West London is significantly different from that of a white Northern European IBD cohort.
Farrukh 2022	Racial disparities in outcomes	UC surgery	Retrospective cross sectional	UK	476	There was no statistically significant difference in the distribution across the types of surgery undergone by the two communities overall ($\chi^2(2) = 1.3$, ns) and the proportions who underwent an ileo-anal anastomosis with pouch (z = -1.2, ns). However, within individual trusts, at the University Hospital Southampton NHS Foundation Trust, a significantly greater proportion of South Asian patients had an ileo-anal anastomosis with pouch compared to White British patients.	These findings reinforce the argument that inflammatory bowel disease surgery should be performed in a limited number of high-volume centres rather than across a wide range of hospitals so as to ensure procedures are carried out by surgeons with sufficient and on-going experience.
Stamatiou 2022	Factors affecting surgical outcomes	IBD	Retrospective observational	UK	1620	Ethnic minority background and higher IMD score were further associated with surgical complications for CD but not UC patients.	Ethnic minority status and socioeconomic deprivation were associated with worse surgical outcomes within our cohort of IBD patients.

Frieder 2022	Racial disparities in outcomes	IBD Post surgical	Retrospective cohort	USA	38143	After multivariable analysis, African American patients had significantly higher overall risk of complications (OR = 1.27; 95% CI, 1.15-1.40) and extended hospital stay (OR = 1.59; 95% CI, 1.45-1.75) than Caucasians. On bivariate analysis, there was no significant difference in mortality between AA and Caucasian patients.	African American patients requiring segmental colectomy for inflammatory colorectal conditions experience significantly higher rates of postoperative complications, longer hospital stays, and lower rates of private insurance.
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Table 2. Characteristics of included studies.

Key research findings

The core findings of the studies were most commonly focussed on race as a determinant of both disease and care. The general trend of increase in prevalence of IBD in industrialised countries, as well as the exponential growth in countries which are industrialising, was noted. Specific research highlighted differences by ethnic and religious groups is well documented. Findings from big data studies was unclear. Even though these involved large samples, the findings were often contradictory. For example, some studies showed clearly worse outcomes for black patients and paradoxically one of the largest big data studies (Asotibe 2022) with almost 200,000 participants found worse outcomes for white patients.

Of particular note are UK based studies suggesting that south Asians have both higher incidence of more severe morbidity with Crohn's and Colitis and yet lower rates of some key therapies, such as biologics. One small UK qualitative study (Mukherjee 2021) found participants believed that South Asian cultures and/or religions can lead to additional challenges linked to a number of social cultural factors affecting communities. This was also seen in another small study focusing on young patients (Alexakis 2015) suggesting that key to supporting care is overcoming cultural communication barriers.

A number of international studies describe findings related to economic status of patients and their families. Notably, the economic impact of Crohn's and Colitis on those it affects as a direct result of the cost of therapies and the ability to continue employment. More recently, a global study (Odufalu 2023) found that lower socio-economic status patients were less likely to have participated in a peer mentoring or education program and less likely to reach out to patient support groups. However, unemployed people were more likely to report being in excellent health. No exploration of the causes of these differences was included.

A small number of studies investigated gender. A Swedish study (Stiernmann 2011) found Women with CD had higher rates of sickness and disability than men. A Canadian study (Vigod 2019) found higher rates of new-onset mental illness in mothers with IBD, although the risk reduced in the post-partum phase. One study reported guidelines for trans-gender patients with IBD

Gaps in research

Despite the patterns in racial morbidity and inequality in treatment distributions, there is limited evidence to explore how and why these differences occur. Specifically, work investigating whether delays in diagnosis or cultural risk factors may be leading to worse disease presentations and perhaps more importantly why there are distinct differences in delivery of therapies to these groups are key. There is also limited work investigating other communities noted globally with similar patterns in the IBD community, for example African Americans in the USA and Ashkenazi Jews globally.

Such research must recognise the complex and confounding nature of the evidence in these studies and deploy methods to account for or explore them. This will begin to explain some of the conflicting studies, but also move past 'what' differences exist due to these factors, but 'how' and 'why' they occur.

There are also key content areas that appear to be under-represented in the UK, including studies investigating gender, religion, education and mental health. The studies that existed in these areas suggested relevant important findings but once again these focussed on demographic descriptions of difference.

Future systematic review areas

Whilst it is likely that many studies were not included in this review, given the nature of those included, their own references to the literature and the methodological rigour of the process followed, it appears that in most areas future systematic reviews are not currently warranted and instead primary research is proposed.

The exception to this may be the area of race. There is clearly much work on this topic and a systematic review limited to the UK would allow direct consideration of both UK based differences in incidence and morbidity, but also in outcome measures.

Limitations

A key limitation of this scoping review is that by focussing on the initial question commissioned and thereby searching for studies with the primary goal of exploring the social and economic factors of interest, this has limited studies with subgroup or incidental findings of interest regarding this factors. This is often a finding of such broad studies, but paradoxically, such reviews are vital to inform the very process of refinement of the core questions for future study.

Several stages of iteration within the search strategy were completed with the commissioning organisation. This attempted to balance the impact of a large and complicated search (this study considered over 5,000 citations) with the commissioned requirement to complete this report within a very rapid timeframe. If significantly more time and funds were available, a far more wide search could have been completed and this is a clear limitation. However, it must be noted that there is no evidence base within methodological studies that such wider searches will increase the final yield of studies (Peters 2020). Rather, the scoping reviews is a key step within the scholarly journey within this context and will inform the next steps in spite of any pragmatically enforced limitations.

Future research proposals

Future studies need to consider not just the missing content areas but deploying research methods that can investigate how and why these may occur. There are multiple dimensions and research traditions that could be suited for this.

Much improved data collection study publications are needed within the UK. These need to be deployed on a prospective and longitudinal basis and consider multiple factors. This will allow the interplay of clinical course, treatment deployment and multiple social economic factors to all be considered in multivariate analysis. Whilst such data clearly exists in practice, published and thereby research ready sources are limited.

Once completed, such studies and their data will allow patterns to be identified and potential hypotheses to be made. Then, different forms of research using qualitative methods are best deployed to explore questions from a constructivist paradigm. One that may be particularly suited is ethnography. Ethnography is a type of social science research that involves examining the behavior of the people within the context of their everyday lives and seeks to understand the group members' own interpretation of such behavior. Ethnographic research relies heavily on participant observation—on the researcher participating in the setting or with the people being studied, at least in some marginal role, and seeking to document, in detail, patterns of social interaction and the perspectives of participants, and to understand these in their local contexts.

Conclusions

Research on the impact of social and economic factors on outcomes in IBD is capricious and of a limited nature, focussing primarily on descriptive findings of patterns of clinical differences in IBD incidence that are related to broad outcome categories and often conflicting. Investigation of areas such as gender, religion, employment, and education are very limited. Future work must not only seek to clarify more broadly the factors impacting IBD outcomes for UK people, but also the likely complex causal reasons for these findings.

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Appendix 1 – Further data extraction table

Study ID	Topic	Condition	Methods	Location	Sample Size	Key findings	Conclusions
Kaplan 2015	Global epidemiology	IBD	Audit of published studies	Canada	UNCLEAR		Over 1 million residents in the USA and 2.5 million in Europe are estimated to have IBD, with substantial costs for health care. IBD increasing in newly industrialized countries and forecasts the global effects of IBD in 2025.
Sedano 2022	Representation in trials	IBD	Audit of published trials	Canada	19476	22% of Induction and 26% of maintenance trials don't report race.	Potential under-representation of minorities in trials in IBD
Aniwan 2019	Racial distribution IBD	IBD	Big data	USA	UNCLEAR	Adjusted annual incidence rate of IBD for whites was 21.6 cases per 100,000 person-years and for nonwhites it was 13 per 100,000 and increased by 39% and 134%, respectively, from 1970 through 2010.	There were significant racial and ethnic differences in the incidence and temporal trends of IBD over the last four decades in this US population-based cohort.
Asotibe 2022	Racial disparities in outcomes	IBD	Big data	USA	177574	There was no significant difference in inpatient mortality for black vs white patients and no difference in the	White patients hospitalized with a principal diagnosis of IBD had no difference in inpatient mortality or septic shock but had

						odds of developing septic shock	worse outcomes such as increased odds of bowel perforation compared to black patients.
Barnes 2018	Racial disparities in outcomes	IBD	Big data	USA	5537	Black patients were more likely to report a Crohn's disease (CD)-related complication at baseline (adjusted odds ratio [aOR], 1.44; 95% confidence interval [CI], 1.06-1.95). Black patients with ulcerative colitis were more likely to have proctitis (24% vs 13%, P = 0.033) at baseline.	Black patients with CD demonstrated increased complications at baseline and during follow-up in this cohort.
Barnes 2021b	Patterns of drugs use based on drugs	IBD	Big data	USA	14735	there was no significant difference in the odds of anti-tumor necrosis factor use by race for CD (adjusted odds ratio [aOR] = 1.13; 95% confidence interval [CI], 0.99-1.28] or ulcerative colitis (aOR = 1.12; 95% CI, 0.96-1.32).	Disparities in IBD treatment discussed in prior literature seem to be driven by socioeconomic or other issues affecting access to care, not race.
Barnes 2022	Racial distribution IBD	IBD	Big data	USA	212393	Black adult patients were significantly less likely than White patients to have a diagnosis of CD (odds ratio [OR], 0.53; 95% CI, 0.52-0.54) or UC (OR, 0.41; 95% CI, 0.40-0.43). Pediatric Black patients were also less	CD and UC are modestly less prevalent among patients of non-White races and Hispanic ethnicity.

						likely to have a diagnosis of CD (OR, 0.41; 95% CI, 0.39-0.43) or UC (OR, 0.38; 95% CI, 0.35-0.41).	
Bernstein 2001	broad determinants	IBD	Big data	Canada	UNCLEAR	In study A we found that, compared with the general population, patients with IBD were more likely to be unemployed. Crohn's disease appeared to affect employment more than ulcerative colitis	Individuals with IBD at some time in the course of their illness are more likely not to be working than are those in the general population
DosSantos Marques 2022	Racial factors impacting distribution of drug use	IBD	Big data	USA	14735	barriers to a positive surgical experience included inadequate personal knowledge of IBD, ineffective written and verbal communication, lack of a support system and complications after surgery	Black and White patients with IBD have varied surgical experiences but all stressed the importance of accurate, trustworthy and understandable health information. These findings highlight the value of providing health literacy-sensitive care in surgery.
Eglinton 2012	Racial distribution Perianal disease	CD	Big data	new Zealand	715	Perianal disease was associated with younger age at diagnosis ($P < 0.0001$), complicated intestinal disease ($P < 0.0001$), and ileal disease location ($P = 0.002$). There was	This study suggests that younger age at diagnosis, complicated disease behavior, and ileal disease location are risk

						no association with gender, ethnicity, smoking, or breast feeding.	factors for perianal CD.
Farrukh 2015b	Racial factors impacting distribution of drug use	CD	Big data	UK	UNC LEAR	In three Trusts, the number of South Asian patients who received such treatment was significantly less than British/White patients. These were: Pennine Acute Hospitals NHS Trust covering Oldham and North Manchester, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust.	It is unacceptable for there to be a difference based on racial grounds.
GunnellsD Jr 2016	Racial disparities in outcomes (surgery)	IBD	Big data	USA	2523	On multivariable analysis, black race remained a significant predictor for 30-day readmissions in patients with IBD (odds ratio 1.6, 95% confidence interval 1.1-2.5).	Black patients with IBD have an increased risk for readmission after colorectal surgery.
Kochar 2018	Racial distribution IBD	IBD	Big data	USA	5412	Adjusting for confounders, Asians had half the odds of being treated with biologics compared with whites (OR: 0.45, 95% CI: 0.30-0.67). Adjusting for disease behavior and remission	Asians are more likely to have perianal disease and ocular extra-intestinal manifestations. After controlling for confounders, Asians were less likely to be

						status, there were no differences in IBD-related surgery or hospitalization, new biologic or steroid prescription or relapse rates between Asians and whites at follow-up.	treated with biologic agents.
Lichtenste in 2020	Impact of age on economic burden of IBD	IBD	Big data	USA	164375	Lifetime total cost was \$405,496, consisting of outpatient (\$163,670), inpatient (\$123,190), pharmacy (\$105,142), and ER (\$13,493) costs.	we estimated lifetime costs for patients with CD or UC to exceed previously published estimates.
Longobar di 2003	Employment impact of IBD	IBD	Big data	Canada	UNC LEAR	Based on this, the indirect cost of nonparticipation attributable to IBD in 1998/1999 was more than \$3.6 billion U.S. dollars (USD) or \$5228 USD per person with IBD and symptoms. According to the second weighted logistic regression, for those who are in the labor force, having IBD had no association with the duration of work.	This method of estimation can be used to predict the overall paid-employment burden of IBD.
Malhotra 2015	Racial distribution IBD	IBD	Big data	USA	30812	UC was more commonly associated with Indian and Jewish ethnicity and less commonly associated with	Patients of Indian origin living in the United States have a greater risk for all types of IBD than other

						East Asian and Hispanic ethnicity. Similar patterns also applied to CD and to all types of IBD analyzed jointly.	American populations.
Misra 2016	Racial differences in colectomy rates	UC	Big data	UK	212430	Indians had a significantly higher colectomy rate than WE (9.8% versus 6.9%, $p < 0.001$). Indian patients were 21% more likely to require colectomy for UC compared with WE group (OR: 1.21, 95% CI: 1.04-1.42, and $p = 0.001$).	The colectomy rate in this cohort was higher in Indians compared to WE
Misra 2019	Racial distribution IBD	IBD - Inception study	Big data	UK	339	The age adjusted incidence of IBD and UC were significantly higher in the Indian group (25.2/100000 and 20.5/100000) compared to White European (14.9/100000, $P = 0.009$ and 8.2/100000, $P < 0.001$) and Pakistani groups (14.9/100000, $P = 0.001$ and 11.2/100000, $P = 0.007$). The Indian group were significantly more likely to have extensive disease than White Europeans (52.7% vs 41.7%, $P = 0.031$). There was no significant difference in time to diagnosis,	This is the only prospective study to report the incidence of IBD in an ethnically diverse United Kingdom population. The Indian ethnic group showed the highest age-adjusted incidence of UC (20.5/100000).

						disease activity and treatment.	
Probert 1992	Racial distribution IBD	CD	Big data	UK	UNC LEAR	The mean standardized incidence in Bangladeshis was 1.2/10(5)/year in the 1970s and 2.3/10(5)/year in the 1980s compared with 3.8/10(5)/year and 4.1/10(5)/year in Europeans, and 4.6/10(5)/year and 5.4/10(5)/year in West Indians, respectively. None of the changes with time was statistically significant.	The apparent similarity of the incidences of Crohn's disease in Bangladeshis and Europeans contrasts with findings in other South Asians.
Sewell 2010	Racial disparities in outcomes	IBD	Big data	USA	UNC LEAR	The proportion of hospitalizations including a discharge diagnosis of IBD increased significantly from 1994 to 2006 among the total population and among Asian, black, and white patients separately.	The proportion of hospitalizations including a discharge diagnosis of IBD increased significantly among minority and nonminority patients from 1994 through 2006. The causes underlying these changes are not certain and should be further investigated.
Shapira 1994	Racial distribution IBD	CD	Big data	israel	UNC LEAR	he mean annual incidence rate in the Kinneret sub-district among Jews was 1.96/100,000 during 1960-1990 and 2.98/100,000	(1) morbidity rate of Crohn's disease increased over time, and (2) in the last decade incidence rates among Jews of Asian-African

						in the last decade. The prevalence rate in 1990 among Jews was 45.9/100,000 and was twofold among European-American-born compared to other ethnic groups.	origin are similar to, or even higher than those of European-American origin.
Vigod 2019	Pregnancy association with mental health in IBD	IBD	Big data	Canada	UNCLEAR	About 22.7% of women with IBD had new-onset mental illness versus 20.4% without, risk was elevated in the post partum (aHR 1.20, 95%â€‰CI 1.09 to 1.31).	Women with IBD were at an increased risk of new-onset psychiatric diagnosis in the postpartum period, but not during pregnancy.
Vij 2019	Racial disparities in outcomes (Colon cancer)	IBD	Big data	USA	57542	In patients with IBD, advanced age conferred an increased risk for developing CC while female gender conferred a protective effect. In this subset of patients, black race conferred a protective effect	Racial disparity exists in the overall incidence of CC and among patients with IBD who develop CC. Interestingly, black race conferred a protective effect for patients with IBD, contrary to what is seen in the general population.
Wang 2013	Racial distribution IBD	IBD	Big data	USA	202468	The prevalence of IBD was higher in Whites [Crohn's disease: 154; ulcerative colitis (UC): 89] than Blacks (Crohn's disease: 68; UC: 25), Hispanics (Crohn's disease: 15; UC: 35), and Asians (Crohn's:	There were significant racial/ethnic differences in the prevalence of IBD in the USA.

						45; UC: 40) (all $p < 0.05$, except for UC in Asians).	
Zhornitskiy 2021	Racial distribution IBD	IBD	cohort	USA	UNCLEAR	Prevalence of IBD per 100,000 people was 418 (95% CI 341-512) for Hispanics and 557 (95% CI 431-739) for NHWs. Notably, the proportion of Hispanic IBD patients with a history of smoking was 21.5% vs 50.8% in NHWs ($p = 0.011$).	In one of the largest US studies of Hispanics with IBD, and the only one to have both clinical and histopathologic confirmation as inclusion criteria, we found the incidence and prevalence of IBD among Hispanics to be higher than previously recognized and comparable to NHWs.
Gadhok 2020	Outcomes depending on race	IBD	Cohort study	UK	224	Bangladeshi patients started an anti-TNF 4.3 years earlier after diagnosis than Caucasian patients (3.9 years vs. 8.2 years: $p < 0.01$). Bangladeshi patients experienced shorter failure-free survival than Caucasian patients (1.8 vs. 4.8 years $p < 0.01$).	This is the first study to suggest that Bangladeshi patients resident in the UK with CD respond less well to treatment with TNF antagonists than Caucasian patients.
Bernstein 2020	Impact of lower socioeconomic status	IBD	Cohort study	Canada	9298	Comparing persons with Lower Socioeconomic State (LSS) vs those without any markers of LSS, there were increased rates of annual outpatient	LSS was associated with worse outcomes in persons with IBD. Social determinants of health at time of diagnosis should be highly

						physician visits (relative risk [RR] = 1.10, 95% confidence interval [CI] = 1.06-1.13), hospitalizations (RR = 1.38, 95% CI = 1.31-1.44), intensive care unit admission (RR = 1.94, 95% CI = 1.65-2.27), use of corticosteroids >2,000 mg/yr (RR = 1.12, 95% CI = 1.03-1.21), and death (hazard ratio 1.53, 95% CI = 1.36-1.73).	considered and addressed.
Wetwittay akhlang 2023	Factors associated with diagnosis	IBD	cohort study - three timer periods	hungary	2240	Rates of active smoking significantly decreased over time in Crohn's disease (CD): 60.2%, 49.9%, and 38.6% in cohorts A/B/C ($p < 0.001$). In UC, the rates were low and stable: 15.4%, 15.4%, and 14.5% in cohorts A/B/C ($p = 0.981$).	The association between trends of known environmental factors and IBD is complex. Smoking has become less prevalent in CD, but no other major changes occurred in socioeconomic factors over the last four decades that could explain the sharp increase in IBD incidence.
Acosta-Ramírez 2001	Mental health characteristics in ibd	IBD	cross-sectional	Puerto Rico	67	Patients older than 34 years old had three times higher probability of developing a depressive disorder ($p = 0.043$, OR = 3.22). Patients with a psychiatric history had seven times higher probability	The risk factors identified with an increased probability of developing a depressive disorder were age older than 34 years and psychiatric history.

						of developing depressive disorder (p = 0.004, OR = 7).	
Can 2022	Factors affecting medication adherence	IBD	cross-sectional	Turkey	253	Intentional (29.3% in ulcerative colitis and 16.3% in Crohn's disease [P = .031] and unintentional non-adherence to treatment (28.1% in ulcerative colitis, 16.3% in Crohn's disease [P = .037] were significantly higher in ulcerative colitis than in Crohn's disease. Female gender (odds ratio = 2.59, P = .005), low education level (odds ratio = 4.8, P = .015), distal involvement in ulcerative colitis (P = .014), and thoughts about the disease would last too soon in Crohn's disease (odds ratio = 4.17, P = .049) were risk factors for non-adherence to treatment.	The negative perception of treatment in inflammatory bowel disease affects adherence to the treatment.
Click 2016	Predictors of high healthcare utilisation	IBD	cross-sectional	USA	400	In multivariate analysis, unemployment (Crohn's disease [CD]: odds ratio [OR], 3.04; 95% confidence interval [CI], 1.32-7.02; ulcerative colitis [UC]: OR, 2.68; 95% CI, 1.20-5.99), psychiatric illness (UC: OR, 2.08; 95% CI, 1.03-	High expenditure IBD patients were affected by more severe disease. The high prevalence of depression, anxiety, and chronic pain in these patients suggests the need for focused treatment of

						4.19), opiates (CD: OR, 5.61; 95% CI, 2.67-11.82; UC: OR, 5.14; 95% CI, 2.52-10.48), prior surgery (CD: OR, 3.29; 95% CI, 1.59-6.82; UC: OR, 2.72; 95% CI, 1.39-5.32), penetrating CD (OR, 3.29; 95% CI, 1.02-10.62), and corticosteroid requirement (CD: OR, 3.78; 95% CI, 1.86-7.65; UC: OR, 2.98; 95% CI, 1.51-5.90) remained independently associated with high charges.	these comorbidities ultimately to reduce financial burden.
Damas 2022	Social barriers impact on outcomes	IBD	cross-sectional	USA	316	Social barriers associated with poor IBD outcomes included low educational attainment, poor health literacy, and financial insecurity. High social barrier scores was associated with greater depressive symptoms [odds ratio (OR) 1.94, 95% confidence interval (CI) 1.21-2.9, $p < 0.001$] and lower reported use of medications.	Our study identifies social barriers that may impact IBD care and are disproportionately higher in non-Hispanic Blacks and Hispanics in the United States.
DosSantos Marques 2020	Factors impacting health literacy in IBD	ibd	cross-sectional	USA	175	On multivariable analysis, low health literacy was associated with older age and African American race ($P < 0.05$). Of 83 IBD patients	Low health literacy is present in IBD populations and more common among older African Americans.

						undergoing abdominal surgery, mean postoperative LOS was 5.5 days and readmission rate was 28.9%.	
Farrukh 2016	Racial disparities in outcomes	IBD	cross-sectional	UK	70	South Asian patients were significantly less likely to see a consultant and more likely to be discharged. South Asian patients were admitted to hospital more often but had significantly fewer tests than European patients.	Patients with ulcerative colitis who are of South Asian origin receive poorer quality clinical care than their European counterparts.
Greenberg 2015	Factors affecting utility weights (health economics)	CD	cross-sectional	Israel	425	significant predictors of utility weights in a multivariable regression analysis were the HBI [$\hat{\rho}^2 = 0.494$; $p < 0.001$], economic status [$\hat{\rho}^2 = 0.198$; $p < 0.001$], time since diagnosis [$\hat{\rho}^2 = 0.106$; $p < 0.001$], male [compared with female] gender [$\hat{\rho}^2 = 0.099$; $p = 0.009$], hospital admission in the past year for any cause	Utility weights for patients in the remission and mild disease states were generally lower as compared with values used in published cost-effectiveness analyses.
Naftali 2022	Factors affecting patient preference	IBD	cross-sectional	israel	361	Multivariable regression analysis revealed that higher patient preferences were associated with Jewish ethnicity (OR 4.77; 95%CI 2.36-9.61, $P < 0.001$) and disease activity.	The highest priority for treatment outcomes was symptom relief., Patients preferences were impacted by ethnicity, gender, and socio-

							economic disparity.
Nazarinas ab 2019	Mental health characteristics in CD	CD	cross-sectional	Iran	96	Multivariate analysis of mental health showed that steroid consumption (P value < 0.001) and nonsmoking (P value = 0.038) were associated with higher mental health in the individuals.	Crohn's patients suffered from decreased mental parameters
Nguyen 2010	Racial disparities in utilization	IBD	cross-sectional	Canada	286	blacks were less likely than whites to be under the regular care (defined as at least annual visit) of a gastroenterologist (adjusted odds ratio (aOR) 0.43; 95% confidence interval (CI): 0.25-0.75) or IBD specialist (aOR 0.37; 95% CI: 0.22-0.61).	There are racial differences in utilization of IBD-related specialist services, ED visits, and infliximab that are independent of income and education.
Odufalu 2023	broad determinants	UC	cross-sectional	GLOBAL	1000	Low-income vs high-income patients were less likely to have participated in a peer mentoring (OR, 0.30) or UC education program (OR, 0.51). Patients not employed were less likely to report being in "good/excellent" health (OR, 0.58) than patients employed full time. Patients with low vs high educational levels were less likely to have reached out	Substantial differences in disease management and health care experience were identified

						to patient associations/organizations (OR, 0.59). Patients aged younger than 50 years vs...those aged 50 years and older were less likely to have visited an office within an inflammatory bowel disease center/clinic in the past 12 months (OR, 0.53).	
Walldorf 2021	Factors impacting childlessness	IBD	cross-sectional	Germany	533	Poor knowledge was not associated with increased childlessness (CCPKnow of ≤ 8 was found in 29.8% of patients with children and 28.9% of childless patients, $p=0.5$). Instead, the patients' education, medical advice, FPP-related concerns, impaired body image, and sexual dysfunction had a significant impact on childlessness.	Factual knowledge does not reduce disease-related concerns or childlessness.
Schenker 2021	Guideline for Transgender IBD	IBD	Guideline / position statement	USA	UNC LEAR	Despite an increase in provider awareness of TGNC health over the past decade, no original research or societal guidelines exist on TGNC patients with inflammatory	high-quality care to the Transgender IBD population can be divided into 3 categories: medications, anatomy, and mental health.

						bowel disease (IBD).	
Montgomery 1999	Racial distribution IBD	IBD	Longitudinal birth cohort study	UK	UNCLEAR	Young Asians born in Britain were significantly more likely than indigenous Europeans to have a diagnosis of IBD by age 26 years, with relative odds of 6.10 (95% CI 2.14-17.33).	Young Asians who were born in Britain are at a significantly higher risk of developing IBD than the indigenous European population.
Ediger 2007	Factors determining medical adherence	IBD	Prospective cohort	Canada	326	For men, predictors of low adherence included diagnosis (UC: OR 4.42, 95% CI 1.66-11.75) and employment status (employed: OR 11.27, 95% CI 2.05-62.08). For women, predictors of low adherence included younger age (under 30 versus over 50 OR 3.64, 95% CI 1.41-9.43; under 30 vs. 40-49 yr: OR 2.62, 95% CI 1.07-6.42). High scores on the Obstacles to Medication Use Scale strongly related to low adherence for both men (OR 4.05, 95% CI 1.40-11.70) and women (OR 3.89, 95% CI 1.90-7.99).	Approximately one-third of IBD patients were low adherers. Predictors of adherence differed markedly between genders
Acciari 2019	Social aspects influence well-being vs	IBD	Qualitative research	Brazil	104	There were also significant differences in the use of Coping: usually, women used more developed escape	Social aspects influenced psychological well-being, resilience and Coping in patients with Crohn's

	clinical aspects					and avoidance strategies; single, married or in stable-union patients used more self-control; not religious used positive reevaluation strategy; the ones who were employed showed more self-control and positive reassessment; the ones who had lower family income indicated that they used less the self-control; the ones who had higher family income used more positive re-evaluation; patients who were diagnosed with Crohn's disease between the second decade of life showed to use more more the positive reassessment strategy than those who were 20 years old or younger.	disease more strongly than clinical aspects.
Agrawal 2019	Factors influencing disability in IBD	IBD	Qualitative research	USA	323	On multivariable analysis, Hispanic ethnicity (aOR 2.7, 95% CI 1.3-5.6), non-Hispanic non-black minority race (aOR 3.5, 95% CI 1.3-8.9), public payer (aOR 2.1, 95% CI 1.1-4.0) and low annual household income (aOR 3.0, 95% CI	IBD patients who are minorities, have public insurance, or low household income, are 2-3 times more likely to report moderate-to-severe disability independent of disease

						1.7-5.4) were associated with moderate-to-severe disability controlling for disease characteristics.	characteristics in the United States.
Alexakis 2015	Factors associated with challenges in IBD in young people	IBD	Qualitative research	UK	20	A thematic analysis of their experiences identified many commonalities with other young people with IBD, such as the problematic route to formal diagnosis and the impact of IBD on education. The young people also experienced tensions between effective self-management strategies and cultural norms and practices relating to food. Moreover, the ability of parents to provide support was hampered for some young people by the absence of culturally competent services that were responsive to the families' communication needs.	The findings highlight the need for more culturally appropriate information concerning IBD, and improved responsiveness to young people with IBD within primary care and the education system
Bernklev 2006	Employment impact of IBD	IBD	Qualitative research	Norway	495	Sick leave for all causes was reported in 47% with ulcerative colitis and 53% with CD, whereas IBD-related sick leave was reported in 18%	Unemployment or sick leave is more common in IBD patients than in the Norwegian background population.

						and 23%, respectively. A majority (75%) had been sick <4 weeks, and a relatively small number of patients (25%) contributed to a large number of the total sick leave days. Both unemployment and DP reduced HRQOL scores, but the most pronounced effect on HRQOL was found in patients reporting IBD-related sick leave, measured with SF-36 and N-IBDQ.	
Blumenstein 2013	Racial differences in knowledge	IBD	Qualitative research	Germany	303	German patients obtained knowledge from a wider range of sources than Irish patients ($p < 0.001$), most notably from the internet ($p < 0.001$), newspapers and magazines ($p = 0.002$).	Our data suggest few differences between German and Irish IBD patients, despite cultural and linguistic differences, with regard to disease related knowledge of IBD.
Chrobak-Bielecka, 2018	Factors affecting acceptance of UC	UC	Qualitative research	Poland	50	Analysis of the results showed a reduced degree of acceptance of the disease among patients in the phase of exacerbation of the disease. The mean point score of the AIS scale for the study group was 29.65, which indicates the average level of acceptance of the	People with higher education, professionally active and treated conservatively, accepted their illness to a better extent.

						disease among respondents	
Engel 2021	Psychological parameters across key factors	IBD	Qualitative research	Germany	62	Levels of depression and anxiety were higher in CD/UC patients than in HC with large effect sizes. Comparing personality functioning in CD/UC with HC, psychodynamic structural characteristics differed between CD/UC and HC with medium effect sizes, with structural differences occurring primarily in the domain of self-perception and regulation.	Our data show that compared to HC, patients with CD/UC are characterized by a higher level of psychological burden and structural alterations in the domain of self.
Freitas 2015	Religious coping as predictor for other factors	IBD	Qualitative research	Brazil	147	Positive religious coping was negatively associated with anxiety ($b = 0.256$; $p = 0.007$) as well as with overall, physical, and mental health HRQoL. Religious struggle was significantly associated with depression ($b = 0.307$; $p < 0.001$) and self-reported adherence ($b = 0.258$; $p = 0.009$). Finally, anxiety symptoms fully mediated the effect of positive religious coping on overall HRQoL.	Religious coping is significantly associated with psychological distress, HRQoL, and adherence in IBD.
Harvey 2022	Perspectives of	IBD	Qualitative	Canada	23	Thematic analysis found focus on	An ideal IBD clinic would provide

	patients with lower educational attainment		research			communication with health care professionals, access to care, symptoms and treatment, and outside support. Access to an IBD specialist was the most important aspect of care. Good care, kind and receptive staff, and a lengthy delay to diagnosis were frequently reported experiences. IBD specialists, nurses, and family and friends were most helpful in managing disease. Physical and emotional symptoms, reduced social engagement, and medications were difficult aspects of living with IBD.	access to traditional and non-traditional services and assist with obtaining support to help patients engage in social activities, increase affordability of care, and maintain employment.
Larussa 2020	Factors affecting willingness to take part in trials	IBD	Qualitative research	Italian	145	Multivariate analysis showed a significant positive association between interest in clinical trials and previous experience ($p = 0.014$), high education ($p < 0.001$), poor QoL ($p = 0.016$), money retributions ($p = 0.03$) and informative materials ($p = 0.02$). On the other hand, a long-standing disease ($p = 0.017$), the	In a native local resident series of IBD patients, the majority of the patients were willing to participate in a clinical therapeutic trial. A long-standing disease, placebo and invasive procedures represented a barrier to enrollment while previous experience, high education,

						possibility of receiving a placebo (p = 0.04) and the frequent colonoscopies required by the study protocol (p = 0.04) were significantly associated with the lack of interest in clinical trials	monetary compensation and adequate information could be facilitative.
Long 2014	Factors associated with depression in elderly	IBD	Qualitative research	USA	359	lower education levels (p=0.001), higher corticosteroid use (<0.01) and lower exercise levels (<0.001) were associated with depression. For both CD and ulcerative colitis (UC), those with depression had increased disease activity (short Crohn's disease activity index 52.5 versus 29, p=0.005, and simple clinical colitis activity index 5 versus 2, p=0.003).	Depression is common in this geriatric IBD cohort. Depression is independently associated with reduced medication adherence.
Mahlich 2017	Employment impact of IBD	IBD	Qualitative research	Japan	1068	We found that the labor force participation rate is lower and unemployment higher for patients with IBD compared to the general population. Factors associated with unemployment in the IBD sample are older age, female gender, and the	IBD constitutes a high burden for patients in Japan regarding employment outcome.

						prevalence of depression.	
Moradkhani 2013	Racial disparities in outcomes	IBD	Qualitative research	USA	134	Multivariate analyses revealed that the variables most strongly associated with HRQOL were perceived stress ($p<0.001$), number of previous IBD relapses ($p<0.001$), gender ($p<0.001$), and perceived social support ($p<0.05$).	Individuals with IBD who report higher perceived stress, lower perceived social support, greater number of relapses, or are female may be at increased risk for decreased HRQOL.
Mukherjee 2021	South Asian patients experiences	IBD	Qualitative research	UK	33	Although many experiences align with those of the general IBD population, participants believed that South Asian cultures and/or religions can lead to additional challenges. These are linked to: family and friends' understanding of IBD; self and family attributions regarding IBD; stigma surrounding ill health; the taboo of bowel symptoms; managing 'spicy food'; beliefs about food and ill health; roles within the family; living with extended family; the use of complementary and alternative therapies; and visits to family	Gastroenterology services have an important role to play in helping patients to overcome the challenges they encounter in their everyday life, both by providing individual patients with culturally appropriate care and advice.

						overseas. Religious faith helped many to cope with having IBD	
Multone 2015	Factors of non-responders to national surveys	IBD	Qualitative research	Switzerland	1943	Factors inversely associated with non-response to study questionnaires were: age >30 years, colonic only disease location, higher education and higher IBD-related quality of life for CD, and age >50 years or having a positive social support for UC	Characteristics of non-responders differed between UC and CD. The risk of non-response to repetitive solicitations (longitudinal versus transversal study) seemed to decrease with age.
Pittet 2017	Gender impact on coping	IBD	Qualitative research	Switzerland	1102	We identified six domains of concern: socialization and stigmatization, disease-related constraints and uncertainty, symptoms and their impact on body and mind, loss of body control (including sexuality), disease transmission, and long-term impact of the disease. Cancer concerns were among the highest scored by all patients (median 61.8).	Patients have numerous concerns related to their illness that need to be reassessed regularly. Concerns differ between men and women
Sarid 2017	Gender difference in coping with IBD	IBD	Qualitative research	Israel	402	A model split by gender and disease activity showed that in active CD economic status impacted SIBDQ in men ($\hat{I}^2 = 0.43$) more than women	Gender differences in coping and the impacts of economic status and emotion-focused coping

						($\hat{I}^2 = 0.26$); emotional coping impacted SWLS in women ($\hat{I}^2 = 0.36$) more than men ($\hat{I}^2 = 0.14$).	vary with activity of CD.
Sorensen 1987	broad determinants	CD	Qualitative research	Norway	106	54% of patients with Crohn's disease felt exacerbations of their disease strained their professional and personal life. During the previous year 23% reported decreased working capacity and 21% reported decreased leisure activities, compared with their own expectations.	During the previous year 23% reported decreased working capacity and 21% reported decreased leisure activities, compared with their own expectations.
Stjernman 2011	Broad determinants	IBD	Qualitative research	Sweden	497	Women with CD had higher rates of sickness and disability than men with CD and were more often living single, though procreation was not affected.	CD had higher impact on HRQL, compared with UC. Women with CD had worse outcome in subjective health status, but not in objective assessment of disease activity.
Farrukh 2015	Racial factors impacting distribution of drug use	CD	Retrospective cohort	UK	139	Based on a population composition, rather than prevalence data, in which 24% of the Leicester community should have been of South Asian origin, 33 patients would have received biologics compared with 92	Suggested reasons for these differences have included concerns about the animal origins of infliximab as well as difficulties associated with accessing the service, such as the provision of information in an

						patients of English origin (66%). This is significantly different to the 13 patients who did receive treatment (z=-3.2, P < 0.001).	appropriate language through appropriate media.
Hoie 2007	Broad determinants	UC	Retrospective cohort	10 countries	771	The time to first relapse showed a greater hazard ratio (HR) (1.2, CI 1.0-1.5) for women and for patients with a high level of education (1.4, CI 1.1-1.8). The number of relapses decreased with age, and current smokers had a lower relapse rate (0.8, CI 0.6-0.9) than nonsmokers. The relapse rate in women was 1.2 (CI 1.1-1.3) times higher than in men.	In 67% of patients, there was at least one relapse. Smoking status, level of education, and possibly female gender were found to influence the risk of relapse.
Jayanthi 1992	Racial distribution IBD	CD	Retrospective cohort	UK	UNCLEAR	The standardized incidence in Europeans has risen significantly to 4.7/10(5)/year from 3.4/10(5)/year in the 1970s (chi 2 = 8.1, p less than 0.005). In Leicester this increase can be accounted for entirely by new cases of colonic disease.	Overall, Hindus have a much lower incidence of Crohn's disease than Europeans.
Jordan 2022	Depression rates	IBD	Retrospective cohort	USA	UNCLEAR	Overall prevalence of major depressive	Rates of depression among minority patients,

	amongst AA					<p>disorder was 25.3%; 45.8% had minimal, 8.3% mild, 33.3% moderate, and 12.5% severe depression. A total of 34.7% of patients were never screened for depression, and 13.8% had other psychiatric conditions. There was a difference in depression rates based on psychiatric conditions ($p = 0.00$), but no difference based on sex ($p = 0.37$), IBD subtype ($p = 0.34$), or medical conditions ($p = 0.84$).</p>	<p>predominantly African American, with inflammatory bowel disease were higher than previously reported for all patients with inflammatory bowel disease.</p>
Li 2014	Racial disparities in outcomes	UC	Retrospective cohort	USA	7350	<p>Compared with whites, the male-to-female ratio differed for African-Americans (0.68 vs. 0.91, $p < 0.01$) and Asians (1.3 vs. 0.91, $p < 0.01$). Asians had fewer co-morbid conditions ($p < 0.01$) than whites, whereas more African-Americans had hypertension and asthma ($p < 0.01$). Use of immunomodulators did not differ</p>	<p>In this population of UC patients with good access to care, overall health-care utilization patterns and clinical outcomes were similar across races and ethnicity. Asians may have milder disease than other races whereas Hispanics had a trend toward more aggressive disease, although the differences</p>

						significantly among race and/or ethnic groups.	we observed were modest.
Mangat 2011	Racial distribution IBD	IBD	Retrospective cohort	Canada	186	The South Asian population had a higher rate of UC, with an increased rate of complications and male predominance. Interestingly, the rate of CD and UC was lowest in the Pacific Asian population.	These racial differences - which were statistically significant - suggest a role for ethnodiversity and environmental changes in the prevalence of IBD in Vancouver.
MontgomerySRJr 2018	Racial disparities in outcomes (surgery)	IBD	Retrospective cohort	USA	14679	After adjustment, black patients remained at increased risk of DSM compared white patients (OR: 1.37; 95% CI 1.14-1.64). CONCLUSIONS: Black patients are at increased risk of post-operative DSM following surgery for IBD	Black patients are at increased risk of post-operative DSM following surgery for IBD. The elevated rates of DSM are not explained by traditional risk factors like obesity, ASA class, emergent surgery, or stoma creation.
Moore 2012	Racial distribution IBD	UC	Retrospective cohort	USA	311	African American patients had a shorter median duration (8.0, interquartile range [IQR] = 4.0, 14.0) of UC than Caucasians (10.0, IQR = 6.0, 18.0) (P = 0.006). African American disease patients had more distal disease than controls. African Americans were significantly less likely to use corticosteroids (74.2% vs. 88.8%,	There appear to be differences in the natural history of UC in our African American patients when compared with Caucasian controls, while ethnicity was not shown to be a risk factor for colectomy.

						P = 0.002), or use immunomodulators (25.8% vs. 69.7%, P < 0.001) than Caucasians.	
Norwood 2009	Racial disparities in outcomes (surgery)	IBD	Retrospective cohort	UK	107	Postoperative complications occurred in 40 (37%) patients, being major in 11 (10%) patients with relaparotomy required in 9 (8%) with no difference between South Asian and non-South Asian Caucasian patients. Long-term pouch function, with a median of five times over 24 h (range 2-15), was similar between the two groups. The incidence of pouchitis was 57 (53%) and this was significantly greater in the South Asian population [17/21 (77%); 39/86 (46%); P = 0.006].	Surgical results were similar in South Asian and non-South Asian Caucasian patients, but the incidence of pouchitis was greater in the former group.
Pressman 2008	Factors associated with medication use	CD	Retrospective cohort	USA	2964	Initiators were appreciably younger than controls (P < 0.001), but were similar to controls with respect to sex and race/ethnicity. The presence of at least 1 comorbidity was related to a modest increase in the risk of initiating (compared with	In a community-based setting infliximab use has steadily increased. Age and comorbidity are associated with initiation, but sex and race/ethnicity are not.

						<p>none: 1 comorbidity, odds ratio [OR] = 1.52 with 95% confidence interval [CI] 1.16-2.00; 2 comorbidities, OR = 1.38 with CI 0.89-2.13). By 3 years after initiating, only 20% of patients remained on infliximab.</p>	
Smith 2023	Barriers to success of post surgical enhanced recovery	IBD Post surgical	Retrospective cohort	USA	466	<p>In multivariable analysis stratified by enhanced recovery period, Black race was associated with increased odds of complications in the pre-ERP (OR 3.6, 95%CI 1.4-9.3) and ERP groups (OR 3.1 95%CI 1.3-7.6). Race was not a predictor of LOS or readmission in either group. High social vulnerability was associated with increased odds of readmission pre-ERP (OR 15.1, 95%CI 2.1-136.3), but this disparity was mitigated under ERPs (OR 1.4, 95%CI 0.4-5.6).</p>	<p>While enhanced recovery period mitigated some disparities by social vulnerability, racial disparities persist in IBD populations even under ERPs.</p>
Walker 2011	Racial distribution IBD	IBD	Retrospective cohort	UK	367	<p>63.0% of South Asian UC patients had extensive colitis compared with 42.5% of the Northern European cohort (P < 0.0001).</p>	<p>The phenotype of IBD in South Asians living in North West London is significantly different from that of a white</p>

						Proctitis was uncommon in South Asian UC patients (9.9 vs. 26.1% in Northern European patients, $P < 0.0001$). In the South Asian CD cohort, disease location was predominantly colonic (46.8%). CD behavior differed significantly between the groups, with less penetrating disease compared with Northern Europeans ($P = 0.01$) and a reduced need for surgery ($P = 0.003$).	Northern European IBD cohort.
Farrukh 2022	Racial disparities in outcomes	UC surgery	Retrospective cross sectional	UK	476	There was no statistically significant difference in the distribution across the types of surgery undergone by the two communities overall ($\chi^2(2) = 1.3$, ns) and the proportions who underwent an ileo-anal anastomosis with pouch ($z = -1.2$, ns). However, within individual trusts, at the University Hospital Southampton NHS Foundation Trust, a significantly greater proportion of South Asian patients had an ileo-anal anastomosis with	These findings reinforce the argument that inflammatory bowel disease surgery should be performed in a limited number of high-volume centres rather than across a wide range of hospitals so as to ensure procedures are carried out by surgeons with sufficient and on-going experience.

						pouch compared to White British patients.	
Stamatiou 2022	Factors affecting surgical outcomes	IBD	Retrospective observational	UK	1620	Ethnic minority background and higher IMD score were further associated with surgical complications for CD but not UC patients.	Ethnic minority status and socioeconomic deprivation were associated with worse surgical outcomes within our cohort of IBD patients.
Frieder 2022	Racial disparities in outcomes	IBD Post surgical	Retrospective cohort	USA	38143	After multivariable analysis, African American patients had significantly higher overall risk of complications (OR = 1.27; 95% CI, 1.15-1.40) and extended hospital stay (OR = 1.59; 95% CI, 1.45-1.75) than Caucasians. On bivariate analysis, there was no significant difference in mortality between AA and Caucasian patients.	African American patients requiring segmental colectomy for inflammatory colorectal conditions experience significantly higher rates of postoperative complications, longer hospital stays, and lower rates of private insurance.

Appendix 2 – Full search results

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