Incidence and prevalence of inflammatory bowel disease across the United Kingdom

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Summary of report

This is the final project report on inflammatory bowel disease (IBD) for the project 'Contemporary epidemiology of coeliac disease, dermatitis herpetiformis, Crohn's disease and ulcerative colitis in the United Kingdom' which is jointly funded by Coeliac UK and Crohn's and Colitis UK to explore incidence and prevalence over the past 20 years.

This report summarises the incidence of IBD across the United Kingdom between 2000 and 2020, and the prevalence in the year 2020. We used health care records from 38.3 million people registered with general practices contributing anonymised information to the Clinical Practice Research Datalink (CPRD). The CPRD population sample showed good representativeness of the total population from Office of National Statistics (ONS) information. Incidence analyses were adjusted for all population characteristics within each model. Prevalence estimates were provided along with age-standardised prevalence to compare across devolved nations.

Most of the English population (85%) had their general practice records linked to Hospital Episode Statistics (HES) records; this sub-group population had more detailed information for analysis.

Inflammatory bowel disease incidence between 2000 and 2020

Between 2000 and 2020, 103,609 people received a new diagnosis of IBD during 286,673,368 person-years of active general practice registration in the population. This represented a population incidence rate of 36.14 new cases per 100,000 person-years (i.e., 1 new case of IBD identified among every 2,767 people if they were each followed for 1 year). Incidence rates for England, Scotland, Wales and Northern Ireland were 36.4, 37.3, 30.9, and 35.6 new cases per 100,000 person-years respectively. Adjusted incidence was higher in Scotland and Northern Ireland compared with England and Wales. Within England, there was variation between regions with London having the lowest and the North East having the highest incidence.

For the UK as a whole and England, incidence in females was marginally higher than in males, however adjusted incidence was not different between females and males in Scotland, Wales and Northern Ireland. Incidence was lowest in those under age 15 years, after which it increased until age 20-24 and then remained reasonably stable until a slight decrease at age 80 and older. Incidence did not vary by socioeconomic deprivation. Incidence in the UK overall was highest in 2000-2004, after which it decreased but remained stable between 2005-2020; this change in incidence over time was not consistent within devolved nations.

For the English sub-group population with HES-linked records, the incidence rate was 36.01 new cases per 100,000 person-years (i.e., 1 new case of IBD identified among every 2,777 people if they were each followed for 1 year). Compared with the UK population and the overall English population, patterns of incidence were similar across age, gender, time and socioeconomic groups. Adjusted incidence was higher in people with recorded White ethnicity compared with all other ethnicity groups; people with Black or unknown ethnicity recorded had the lowest incidence.

Incidence rates of ulcerative colitis (UC), Crohn's disease and IBD unclassified were 19.00, 13.33, and 3.81 respectively in the UK population; within the English-subgroup population with HES-linked records the equivalent incidence rates were 19.87, 13.35, and 2.80. There were small variations in overall incidence between devolved nations, however, sociodemographic incidence patterns were similar.

Inflammatory bowel disease prevalence in 2020

From the CPRD population in 2020, we identified 131,074 people with IBD which represented a prevalence of 0.81%, equating to one in every 123 people with a diagnosis of IBD in the UK. Age-standardised prevalence was similar between England and Wales, and slightly higher in Scotland and Northern Ireland. Within England, age-standardised prevalence showed some variation across regions with the lowest prevalence in London.

Prevalence was marginally higher for females (0.83%) compared with males (0.80%) and increased with age for both groups. In the UK overall, prevalence decreased with increasing socioeconomic deprivation; this pattern was similar in England, Scotland and Northern Ireland, but not in Wales.

Within the English sub-group population with HES-linked records prevalence was 0.92%, equating to one in every 109 people with a diagnosis of IBD; this was higher than in the overall English population and for the UK overall. Prevalence was higher in people with recorded White ethnicity compared with all other ethnicity groups; people with Black, Mixed or Unknown ethnicity recorded had the lowest prevalence. Prevalence was higher in rural compared with urban areas.

Prevalence of ulcerative colitis (UC), Crohn's disease and IBD unclassified was 0.44%, 0.31%, and 0.07% respectively in the UK population; within the English-subgroup population with HES-linked records the equivalent prevalence was 0.51%, 0.35%, and 0.06%. There were small variations in prevalence between devolved nations, however, sociodemographic prevalence patterns were similar.

Faecal calprotectin testing prior to inflammatory bowel disease diagnosis

Among people with incident IBD diagnosed between 2009 and 2019, 2.7% had recorded faecal calprotectin testing (FCT) in their general practice record within the year before diagnosis. The prevalence of FCT prior to diagnosis was low prior to 2014 and then increased in England and Scotland (4.0% and 9.6% respectively in 2019), with less consistent use in Wales and Northern Ireland.

Diagnosis of irritable bowel syndrome prior to inflammatory bowel disease

Among people with incident IBD, 13.2% had diagnostic codes for irritable bowel syndrome, 23.9% had been prescribed antispasmodic drugs and 28.6% had either or both of these, prior to their IBD diagnosis. The median time between having an initial irritable bowel syndrome code or an antispasmodic drug prescription and their diagnosis of IBD was 5.5 years and 2.6 years respectively.

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List of Data Supplements with this report

The data supplements contain all tables in the report and additional tables (including separate tables for England, England sub-group with HES-linked data, Scotland, Wales and Northern Ireland)

datasheet_UoNreport2021_IBD_incidence.xlsm

datasheet_UoNreport2021_IBD_prevalence.xlsm

datasheet_UoNreport2021_UC_incidence.xlsm

datasheet_UoNreport2021_UC_prevalence.xlsm

datasheet_UoNreport2021_Crohns_incidence.xlsm

datasheet_UoNreport2021_Crohns_prevalence.xlsm

datasheet_UoNreport2021_IBDunclassified_incidence.xlsm

datasheet_UoNreport2021_IBDunclassified_prevalence.xlsm

Acronyms & Abbreviations

CI	confidence interval
CPRD	Clinical Practice Research Datalink
FCT	faecal calprotectin testing
GP	general practice
HES	Hospital Episode Statistics
IBD	inflammatory bowel disease
IBS	irritable bowel syndrome
ICD	International Classification of Diseases
IMD	Index of Multiple Deprivation (a measure of socioeconomic categorisation)
IRR	incidence rate ratio
ONS	Office of National Statistics
UC	ulcerative colitis
UK	United Kingdom

1 Introduction

This report summarises the incidence and prevalence of inflammatory bowel disease (IBD) across the UK. Figures are reported for the United Kingdom as a whole and separately for England, Scotland, Wales, and Northern Ireland. For England, figures are also reported separately for 10 geographical regions.

This work is part of a grant entitled 'Contemporary epidemiology of coeliac disease, dermatitis herpetiformis, Crohn's disease and ulcerative colitis in the United Kingdom' which is jointly funded by Coeliac UK and Crohn's and Colitis UK to explore incidence and prevalence over the past 20 years.

The research uses information from the Clinical Practice Research Datalink (CPRD), an internationally recognised source of real-world data, to provide estimates of UK-wide and country specific population incidence and prevalence. Information that is recorded prospectively as part of routine clinical practice for individuals across the United Kingdom (UK) is available in CPRD for research. All electronic health records are anonymised so individual patients cannot be identified by the researchers. Approval to carry out the research for this grant was obtained from the CPRD Independent Scientific Advisory Committee (Protocol approval No: 19_266A) in December 2019.

2 Study population and analysis

2.1 Developing the baseline population

The study population included all individuals who were actively registered with general practices (GP) at any time between January 2000 and July 2020, and who contributed anonymised data to CPRD. Prevalence was calculated on July 1st, 2020.

Individual patient records had to meet a minimum standard of data quality to be included in the study, defined by CPRD as 'acceptable' and 'up-to-standard' for research. There are two current GP databases provided by CPRD: CPRD GOLD, containing data contributed by practices using Vision® software, and CPRD Aurum, containing data from practices using EMIS Web® electronic patient record system software (https://www.cprd.com/). Data from CPRD GOLD include practices from across the UK whilst CPRD Aurum includes practices from England and Northern Ireland only.

This study used the whole CPRD population, by combining both CPRD GOLD and CPRD Aurum practices and retaining the most recent records of those patients who had transferred between GOLD and Aurum. For 85% of the English population, patients' general practice records were individually linked with their Hospital Episode Statistics (HES) records, which include all inpatient and outpatient hospital admissions in England. The English population with HES-linked data provided a sub-group baseline population with more details for analysis including high data completeness on recorded ethnicity.

Information on age and gender was obtained from each person's general practice record. Exact date of birth is not available in CPRD as a method of maintaining patient anonymity; age was thus available to the nearest month for those under age 16 and to the nearest year for those age 16 and older. We used CPRD's 3-option gender field to categorise people as male or female and excluded a small number of people (<0.01% and thus insufficient for analyses) recorded as having indeterminate gender. We did not use further information to attempt to comprehensively capture non-binary sexuality as the validity of this information in CPRD is not known.

The location of a person's household and their general practice is not available in CPRD to maintain patient anonymity. In a secure linkage process before data are supplied to researchers, CPRD uses a trusted third party (NHS Digital) to link the Index of Multiple Deprivation (IMD) with the location of contributing general practices across the UK. The IMD is an area-level measure of socioeconomic deprivation based on information collected from the national census. For England only, IMD and a binary rural-urban classification are also available for patient households. Available for analysis were quintiles of IMD for GPs across the UK (i.e., the GP-level socioeconomic deprivation quintile using the postcode for the practice where the patient was registered) and for households in England (household-level socioeconomic deprivation quintile, according to the patient's home postcode), and rural-urban classification for households in England (also using postcode).

Information on ethnicity was only obtained for the sub-group baseline population of people in England with individually linked HES data, by combining ethnicity coding from both GP and hospital records. For Scotland, Wales and Northern Ireland, ethnicity information was available from GP records, however, it was missing in 99%, 99% and 92% of the populations respectively and was thus considered unusable for analysis.

2.2 Defining inflammatory bowel disease

For all individual patients in the baseline population, cases with IBD were defined as those who had a relevant clinical diagnosis, coded as a CPRD medcode (Appendix A) in their electronic general practice record. CPRD medcodes align with the International Classification of Disease (ICD) diagnostic coding system but some medcodes provide more clinical detail. Individuals with IBD will have been diagnosed in secondary care following blood tests and endoscopy with macroscopic changes and inflammation found in the gut tissue.

Defining ulcerative colitis, Crohn's disease and unclassified IBD

Endoscopy results will indicate either a diagnosis of ulcerative colitis (UC), Crohn's disease, or may not be able to confirm either of these, resulting in a diagnosis of indeterminate colitis or unclassified IBD. For this study, we used CPRD medcodes to categorise the type of macroscopic IBD. Cases were defined as having ulcerative colitis if they had medcodes for ulcerative colitis, with or without generic IBD/indeterminate colitis codes but no codes for Crohn's disease. Cases were defined as having Crohn's disease if they had medcodes for Crohn's disease, with or without generic IBD/indeterminate colitis codes but no codes for ulcerative colitis. For individuals with medcodes showing diagnoses of both ulcerative colitis and Crohn's disease, we used the last diagnosis available in their medical record to assign them to one of the case groups. Remaining individuals were defined as cases with IBD unclassified; this case group comprised individuals with medcodes showing either an indeterminate colitis diagnosis, only generic IBD diagnosis or both ulcerative colitis and Crohn's diagnoses when these occurred on the same day in the patient's record and were the last diagnoses available. We did not include a separate group with indeterminate colitis as people with these codes could under-represent the true cases of indeterminate colitis, which may have instead been coded with generic IBD or dual diagnoses.

Individuals with generic IBD/indeterminate colitis who also had diagnostic codes for microscopic colitis were not included in as cases. Individuals with microscopic colitis will have been diagnosed in secondary care following blood tests and endoscopy that do not show macroscopic IBD, but biopsy samples show microscopic changes in gut tissue. The incidence and prevalence of microscopic colitis between 2000-2020 is described in a separate accompanying report (*Incidence and prevalence of microscopic colitis across the United Kingdom*).

Specificity of coding and justification for excluding medication from case definitions

In our CPRD medcodes we included only a list of codes specific to IBD, aligning with those previously externally validated using clinical records (Appendix A). We did not include less specific medcodes that could result in false positives (e.g., 'Colitis').

We did not use GP-prescribed medication to define IBD cases and HES data do not record medications prescribed in hospital. Whilst aminosalicylates (primarily Mesalazine, also called 5-aminosalicylic acid (5-ASA)) are mainly used for IBD, there are two main reasons that their use to define cases, in the absence of a diagnostic medcode in a patient's record, could lead to false positive cases: 1) They can also be prescribed for diverticular colitis which is not IBD; 2) They may be prescribed with unproven suspicion of IBD before diagnosis is confirmed, to start a patient on treatment with the aim of alleviating symptoms as early as possible.

Aminosalicylates also cannot be used to validate diagnosis as they are not universally used for all patients with IBD, so absence of a prescription does not invalidate diagnosis. Finally, aminosalicylates

are used for all types of IBD as well as microscopic colitis so cannot be used to distinguish case subtypes. We did, however, use aminosalicylate prescriptions to define the incidence timing of IBD among cases with diagnostic codes (details provided in 2.3.1).

Inclusion of hospital coding for cases in England with HES-linkage

For the sub-group of people in England with HES-linked information, IBD diagnoses were also extracted from hospital inpatient or outpatient admission records where available for the patient. Cases with IBD were defined as those who had a relevant clinical diagnosis in either their GP record or in their HES record. Recording in HES records used ICD-10 coding (Appendix A). Inpatient records indicate an individual was admitted to hospital; IBD may be the reason for hospital admission, however, it may also be recorded if a person with IBD is admitted for a different medical problem. Outpatient records indicate an individual had a day visit at a hospital for a minor procedure or consultation, however, limited information on the details of outpatient admissions are available in HES (e.g., consultant appointment may be recorded but a diagnosis not usually included in the electronic record).

It is possible that some hospital recordings of IBD could be related to initial hospital referral for the diagnostic process, including endoscopy. However, it would be expected that confirmed IBD is recorded in the patient's GP record because it is managed in primary care. Inclusion of people with a hospital record for possible but not confirmed IBD could therefore increase case numbers in error. For this reason, our case definition excluded people who had IBD coded in their hospital record on the same date as a day-case admission for an endoscopic procedure, unless they also had codes for IBD elsewhere in their hospital or general practice record at other points in time.

There is also the possibility that people living with IBD may have it recorded during a hospital admission but not have it recorded in their general practice record; whilst this should not occur in principle as people's general practice records should be complete, one situation in which this could occur is for a person who has been self-managing their IBD for a long time and may not have consulted their general practitioner. We therefore included people who had instances of IBD in their hospital record but not in their GP record (unless IBD was only recorded with a day-case endoscopy, as described above).

2.3 Data management and statistical analysis

Data were received from CPRD via secure download as flat text files and were transferred into Stata format. Stata16MP statistical software was used for all data management and analyses.

2.3.1 Incidence and prevalence

The measure of incidence provides information on the number of people who are being newly diagnosed with IBD. Incident cases of IBD were defined by the earliest date on which they had a clinical diagnosis or a prescription for aminosalicylates after the first 12 months of their actively registered time with the general practice. Recorded diagnoses or prescriptions within the first 12 months of registration are more likely to reflect prevalent cases so their inclusion may overestimate true incidence.

Incidence was defined as the number of incident cases per 100,000 person-years contributed by people in the baseline population. Person-years is a measure that captures how long each person has been actively registered at their GP which is the time during which we can measure a new diagnosis of IBD. It is calculated by adding together the total time each person in the population has been actively registered (e.g., if 3 people were registered for 1 year, 2.5 years and 7 years respectively, the total

person-years would be 10.5). Incidence (also called incidence rate) with 95% confidence intervals (CI) was calculated using the strate command.

The measure of prevalence provides information on the number of people who are living with IBD at a certain point in time. Prevalent cases were defined by having a clinical diagnosis on or before July 1st, 2020. For prevalent cases, we used the entirety of a person's health record, which included any recorded diagnoses before they joined their current general practice or diagnoses recorded in their medical history.

Prevalence was defined as the number of prevalent cases per 100 people in the baseline population on July 1st, 2020. Prevalence with 95% CI was calculated using the proportion command.

Incidence and prevalence were calculated for the United Kingdom as a whole and separately for England, Scotland, Wales, and Northern Ireland. For England, incidence and prevalence was separately calculated for 10 regions, based on the boundaries of Strategic Health Authorities which were part of the National Health Service structure between 2002 and 2013.

For the UK as a whole and for each country, incidence and prevalence were calculated for the total population and separately by age group, gender, GP-level socioeconomic deprivation quintile and calendar period. A sub-analysis of people in England who had HES-linked information was conducted which included age group, gender, ethnicity group, GP-level socioeconomic deprivation quintile, household-level socioeconomic deprivation quintile, rural-urban classification, and calendar period.

For incidence analyses, Poisson regression was used to calculate incidence rate ratios (IRR) with 95% CI to provide comparisons between groups (e.g., the ratio of the incidence of IBD in females compared with males). Unadjusted IRRs and fully adjusted IRRs were calculated. Fully adjusted IRRs were adjusted for all factors in the model, e.g., an IRR for females compared with males in England was adjusted for age, ethnicity, socioeconomic quintile, urban-rural classification, and calendar period.

Case and baseline population numbers on which incidence and prevalence was calculated are presented in the appendix (Appendix B). To prevent identification of individuals whose health records are used for CPRD research, numbers are suppressed as "<5" wherever fewer than 5 people populate a table cell.

Population pyramids (Appendix C) were created to compare the age and gender distribution of the CPRD baseline populations for the United Kingdom, England, Scotland, Wales, and Northern Ireland with Office of National Statistics (ONS) *Population estimates for the UK, England and Wales, Scotland and Northern Ireland: mid-2019, using April 2020 local authority district codes* (https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2019estimates). The dstdize command was then used to calculate overall age-standardised prevalence for each country (gender proportions were highly similar), using direct standardisation to the UK ONS population. This was also used to calculate overall age-standardised prevalence for each of the 10 regions of England.

It is important to note that coronavirus disease 2019 (COVID-19), a respiratory illness from a newly discovered coronavirus infection (SARS-CoV-2), was declared as a pandemic in early 2020. A 'lockdown' in the UK to contain the spread of SARS-CoV-2 meant that the population could not attend general practices or hospitals for non-urgent medical care. In comparison with other years in this study (2000-2019), only January to July follow up data were contributed in 2020. This follow-up time coincided with the declaration of the pandemic and national lockdown; it therefore may have affected diagnosis and follow-up of IBD and thus measured incidence and prevalence.

2.3.2 Faecal calprotectin testing prior to inflammatory bowel disease diagnosis

To assess the use of faecal calprotectin testing (FCT) in the diagnostic process of IBD we assessed prevalence of FCT recording within 1 year prior to the initial diagnosis of IBD/first use of aminosalicylates for incident cases diagnosed at age 15 years or older between 2000 and 2020. Due to lack of FCT use prior to 2009, proportions were calculated for 2009 onwards. This analysis included only FCT recording within a person's general practice record. Data on use of FCT within the secondary care diagnostic pathway was not available within the hospital data accessible from HES; there is no routine electronic recording of FCT that would be accessible for a nationally representative analysis.

2.3.3 Diagnosis of irritable bowel syndrome prior to inflammatory bowel disease

To assess whether people with IBD had a prior diagnosis of irritable bowel syndrome (IBS), we extracted diagnoses for IBS or antispasmodic drug prescriptions from their general practice records. We additionally used a code for functional abdominal pain before diagnosis, as young people under age 18 years are less likely to be diagnosed with IBS. We calculated the proportion of people with incident IBD who had prior IBS/functional abdominal pain diagnoses or treatment with antispasmodic drugs. We assessed whether this varied by age at IBD diagnosis and the time between the earliest IBS/functional abdominal pain diagnosis or treatment with antispasmodic drugs, and their later diagnosis of IBD.

2.4 Notes on sample size and guidance on interpretation of findings

This report used the largest available population-based sample in the United Kingdom and its devolved nations on which the population incidence and prevalence of diagnosed IBD could be reliably estimated between the year 2000 and 2020. No sample size calculations were conducted.

Because we are calculating incidence and prevalence based on a representative sample of the population (not the whole population), these should be interpreted as estimates. When interpreting these, the point estimate (labelled `Incidence' or `Prevalence' in tables) should be read with its accompanying CI (labelled `95% confidence interval' in tables). The 95%CI provides a range of values (from the lowest estimate to the highest estimate) that is compatible with a p-value of 0.05. A p-value of 0.05 indicates the calculated estimate range would have occurred by chance fewer than 5 times in 100. We are therefore confident that it provides a good estimate of incidence or prevalence.

When comparing incidence or prevalence estimates between groups (e.g., age, gender, countries) the 95% CI should be compared alongside the point estimates. We describe estimates as similar where they have overlapping CIs, even if the point estimates are slightly different. For example, when we describe prevalence in one group as being higher or lower compared with another group, we have observed that confidence intervals for the estimates do not overlap.

Some CIs will be wider than others (i.e., the incidence or prevalence estimate will be less precise) and this is because of the size of the sample population and cases available for a particular calculation (wider CIs will usually be from smaller sample populations).

For an incident rate ratio (IRR), its 95% confidence interval is interpreted as statistically significant when it excludes '1.00'. Because the IRR is a ratio measure comparing two rates, when it includes '1.00', this means that incidence rate estimates have overlapping CIs.

Examples of interpretation:

A point prevalence of 5% with a 95%CI of (2%-6%) indicates that we estimate the prevalence to be between 2% and 6% and we would consider this to be similar to a point prevalence of 6% with a 95%CI of (1%-8%) because the CIs are overlapping. However, the latter is a less precise estimate likely because it is calculated using a smaller sample population.

An incidence rate ratio of 2.2 is calculated by dividing 2 rates, as follows: incidence 22 (in females) / incidence 10 (in males) = IRR 2.2. The incidence in females may have a confidence interval that overlaps with that in males, however, so the 95% CI of the IRR may cross '1.00' indicating no statistically significant difference in incidence between females and males (e.g., IRR 2.2, 95% CI 0.85-2.60).

In this report, the sample population of England is considerably larger than those of Scotland, Wales and Northern Ireland (mirroring the true relative populations sizes of these countries), so CIs for most estimates are narrowest for England. Estimates for Northern Ireland show the least precision as this is the smallest sample population, yet it is still calculated using a baseline population of >549,580 people; >342,839 in 2020.

3 Description of report data supplement

This report contains the incidence and prevalence tables and graphs for the UK population with an appendix (Appendix B) that includes the baseline sample population numbers and case numbers on which incidence and prevalence were calculated. **The accompanying data supplements contain all tables in the report and additional tables (including separate tables for England, England sub-group with HES-linked data, Scotland, Wales, and Northern Ireland**):

datasheet_UoNreport2021_IBD_incidence.xlsm
datasheet_UoNreport2021_IBD_prevalence.xlsm
datasheet_UoNreport2021_UC_incidence.xlsm
datasheet_UoNreport2021_UC_prevalence.xlsm
datasheet_UoNreport2021_Crohns_incidence.xlsm
datasheet_UoNreport2021_Crohns_prevalence.xlsm
datasheet_UoNreport2021_IBDunclassified_incidence.xlsm
datasheet_UoNreport2021_IBDunclassified_prevalence.xlsm

4 Findings on study population representativeness

A total of 38.3 million people (38,323,590) comprised the baseline study population followed up over time for calculating incidence between 2000 and 2020. A total of 16.1 million people (16,087,994) comprised the baseline mid-year population for calculating prevalence in 2020.

The age, gender, and geographic breakdown for the total UK population is shown in Appendix B and is available in the data supplements by country. Population pyramids (Appendix C) of the age distributions for CPRD males and females are very similar to the total ONS UK, England, Scotland, Wales and Northern Ireland populations, showing excellent representativeness of the CPRD population for use in estimating disease prevalence.

5 Incidence of inflammatory bowel disease in the United Kingdom 2000-2020

Between 2000 and 2020, 103,609 people received a new diagnosis of IBD during 286,673,368 person-years of active general practice registration in the population, representing a population incidence rate of 36.14 new cases per 100,000 person-years (i.e., 1 new case of IBD identified among every 2,767 people if they were each followed for 1 year) (Table 5-1).

Table 5-1 shows incidence rates stratified by different population characteristics with unadjusted and adjusted incidence rate ratios. Incidence in females was marginally higher than in males. Incidence was 7.8 for young people under age 15 years, after which it increased until age 20-24 and remained stable until age 75-79, decreasing slightly at age 80 and older. Incidence was highest in 2000-2004 after which it decreased but then remained stable between 2005-2020. Incidence did not vary by socioeconomic deprivation.

The overall incidence rates for England, Scotland, Wales and Northern Ireland were 36.4, 37.3, 30.9, and 35.6 new cases per 100,000 person-years respectively. Adjusted incidence was higher in Scotland and Northern Ireland compared with England and Wales. Incidence patterns within devolved nations were generally similar to those in the UK overall, however, adjusted incidence was not different between females and males in Scotland, Wales and Northern Ireland (Tables in data supplement). In Scotland and Wales, incidence did not decrease sharply after 2004; instead, incidence in Scotland was highest in 2010-2014 and incidence in Wales was stable over time. Whilst incidence rates in Wales were similar across socioeconomic deprivation quintiles, adjusted incidence was higher in the 3rd and 5th deprivation quintiles compared with the least deprived quintile.

Within England, there was variation between regions; London had the lowest incidence and The North East had the highest incidence (Table in data supplement).

Table 5-1 Incidence of inflammatory bowel disease (United Kingdom 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	3481	44518514	7.82	7.56 - 8.08	1.00		1.00	
15-19	5100	15060052	33.86	32.95 - 34.81	4.33	4.15 - 4.52	4.33	4.15 - 4.53
20-24	7765	17074960	45.48	44.48 - 46.50	5.82	5.59 - 6.05	5.80	5.57 - 6.04
25-29	8455	18586007	45.49	44.53 - 46.47	5.82	5.59 - 6.05	5.80	5.57 - 6.03
30-34	8832	20534880	43.01	42.12 - 43.92	5.50	5.29 - 5.72	5.46	5.25 - 5.67
35-39	9048	21824402	41.46	40.61 - 42.32	5.30	5.10 - 5.51	5.26	5.06 - 5.47
40-44	8711	22055948	39.50	38.67 - 40.33	5.05	4.86 - 5.25	5.03	4.84 - 5.24
45-49	8252	21472570	38.43	37.61 - 39.27	4.91	4.72 - 5.11	4.92	4.73 - 5.12
50-54	8097	20136077	40.21	39.35 - 41.10	5.14	4.94 - 5.35	5.14	4.94 - 5.35
55-59	7759	18442422	42.07	41.15 - 43.02	5.38	5.17 - 5.60	5.37	5.16 - 5.59
60-64	7361	16236448	45.34	44.31 - 46.38	5.80	5.57 - 6.04	5.81	5.58 - 6.05
65-69	6509	14250600	45.68	44.58 - 46.80	5.84	5.61 - 6.09	5.85	5.61 - 6.09
70-74	5465	12180228	44.87	43.69 - 46.07	5.74	5.50 - 5.99	5.73	5.49 - 5.97
75-79	4196	9754619	43.02	41.73 - 44.34	5.50	5.26 - 5.75	5.48	5.24 - 5.73
80&over	4578	14545642	31.47	30.57 - 32.40	4.03	3.85 - 4.21	4.01	3.83 - 4.19
Gender								
Male	50966	143935069	35.41	35.10 - 35.72	1.00	-	1.00	-
Female	52643	142738299	36.88	36.57 - 37.20	1.04	1.03 - 1.05	1.04	1.02 - 1.05
Calender period								
2000 - 2004	25063	60862947	41.18	40.67 - 41.69	1.00	-	1.00	-
2005 - 2009	24743	70878250	34.91	34.48 - 35.35	0.85	0.83 - 0.86	0.85	0.84 - 0.87
2010 - 2014	24882	73314589	33.94	33.52 - 34.36	0.82	0.81 - 0.84	0.83	0.81 - 0.84
2015 - 2020	28921	81617583	35.43	35.03 - 35.85	0.86	0.85 - 0.88	0.86	0.85 - 0.88
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	17540	48806977	35.94	35.41 - 36.47	1.00	-	1.00	-
2	18372	50055578	36.70	36.18 - 37.24	1.02	1.00 - 1.04	1.01	0.99 - 1.03
3	19748	54283859	36.38	35.88 - 36.89	1.01	0.99 - 1.03	1.01	0.99 - 1.03
4	23833	65485221	36.39	35.94 - 36.86	1.01	0.99 - 1.03	1.01	0.99 - 1.03
5-most deprived	24116	68041733	35.44	35.00 - 35.89	0.99	0.97 - 1.01	1.00	0.98 - 1.02
Country								
England	89680	246652536	36.36	36.12 - 36.60	1.00	-	1.00	-
Scotland	7557	20266082	37.29	36.46 - 38.14	1.03	1.00 - 1.05	1.18	1.14 - 1.21
Wales	4297	13919497	30.87	29.96 - 31.81	0.85	0.82 - 0.88	0.97	0.94 - 1.01
Northern Ireland	2075	5835254	35.56	34.06 - 37.12	0.98	0.94 - 1.02	1.12	1.07 - 1.17
Total population	103609	286673368	36.14	35.92 - 36.36				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

For the English sub-group population with HES-linked records (Table 5-2), the incidence rate was 36.01 new cases per 100,000 person-years (i.e., 1 new case of IBD identified among every 2,777 people if they were each followed for 1 year). This was the same as the incidence estimated in the overall English population and in the UK overall.

Compared with the UK population and the overall English population, patterns of incidence were similar across calendar time and age, however, the point estimate of adjusted incidence peaked at age 20-29 years. Adjusted incidence was marginally lower in females compared with males. People with recorded White ethnicity had a higher adjusted incidence compared with all other ethnicity groups; people with Black or unknown ethnicity recorded had the lowest incidence. Incidence did not vary by socioeconomic deprivation nor between those living in rural and urban areas. Within England, there was variation between regions; adjusted incidence was lowest in the West Midlands highest in the North East and the East of England.

Table 5-2 Incidence of inflammatory bowel disease (England HES-linked sub-population 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	2576	32998517	7.81	7.51 - 8.11	1.00	-	1.00	-
15-19	3698	10890163	33.96	32.88 - 35.07	4.35	4.14 - 4.57	4.60	4.38 - 4.84
20-24	5633	12591187	44.74	43.58 - 45.92	5.73	5.47 - 6.00	6.01	5.73 - 6.29
25-29	6180	13702323	45.10	43.99 - 46.24	5.78	5.52 - 6.05	6.00	5.73 - 6.28
30-34	6387	15150977	42.16	41.13 - 43.20	5.40	5.16 - 5.65	5.52	5.27 - 5.78
35-39	6622	16034410	41.30	40.32 - 42.31	5.29	5.05 - 5.54	5.34	5.10 - 5.59
40-44	6371	16143622	39.46	38.51 - 40.45	5.06	4.83 - 5.29	5.06	4.83 - 5.30
45-49	6099	15692932	38.86	37.90 - 39.85	4.98	4.75 - 5.21	4.94	4.72 - 5.17
50-54	5903	14725521	40.09	39.08 - 41.12	5.14	4.90 - 5.38	5.00	4.77 - 5.23
55-59	5612	13462888	41.68	40.61 - 42.79	5.34	5.10 - 5.59	5.07	4.84 - 5.31
60-64	5383	11832691	45.49	44.29 - 46.72	5.83	5.56 - 6.11	5.42	5.17 - 5.68
65-69	4710	10395201	45.31	44.03 - 46.62	5.80	5.53 - 6.09	5.27	5.02 - 5.53
70-74	3960	8912674	44.43	43.07 - 45.84	5.69	5.42 - 5.98	5.08	4.83 - 5.34
75-79	3122	7156667	43.62	42.12 - 45.18	5.59	5.30 - 5.89	4.94	4.69 - 5.20
80&over	3423	10457341	32.73	31.65 - 33.85	4.19	3.98 - 4.41	3.75	3.56 - 3.95
Gender								
Male	37196	105868295	35.13	34.78 - 35.49	1.00		1	
Female	38483	104278820	36.90	36.54 - 37.27	1.05	1.04 - 1.07	0.96	0.95 - 0.98
Calender period								
2000 - 2004	18656	45735953	40.79	40.21 - 41.38	1.00	-	1.00	-
2005 - 2009	17848	50925196	35.05	34.54 - 35.57	0.86	0.84 - 0.88	0.84	0.83 - 0.86
2010 - 2014	18284	53160179	34.39	33.90 - 34.90	0.84	0.83 - 0.86	0.81	0.80 - 0.83
2015 - 2020	20891	60325787	34.63	34.16 - 35.10	0.85	0.83 - 0.87	0.81	0.80 - 0.83
Ethnicity* **								
White	65474	151630918	43.18	42.85 - 43.51	1.00		1.00	
Mixed	653	2306641	28.31	26.22 - 30.57	0.66	0.61 - 0.71	0.84	0.77 - 0.90
Asian	4115	11150991	36.90	35.79 - 38.05	0.85	0.83 - 0.88	0.90	0.87 - 0.93
Black	1335	6603962	20.22	19.16 - 21.33	0.47	0.44 - 0.49	0.50	0.47 - 0.53
Other ethnicity	1061	3466104	30.61	28.82 - 32.51	0.71	0.67 - 0.75	0.74	0.70 - 0.79
Unknown	3041	34988499	8.69	8.39 - 9.01	0.20	0.19 - 0.21	0.20	0.19 - 0.20
Socioeconomic deprivation quintile (household-level)								
1-least deprived	16450	45635922	36.05	35.50 - 36.60	1.00	-	1.00	-
2	15795	42511554	37.15	36.58 - 37.74	1.03	1.01 - 1.05	1.02	0.99 - 1.04
3	15100	41288728	36.57	35.99 - 37.16	1.01	0.99 - 1.04	1.01	0.98 - 1.03
4	14978	41501509	36.09	35.52 - 36.67	1.00	0.98 - 1.02	1.01	0.98 - 1.03
5-most deprived	13257	38886454	34.09	33.52 - 34.68	0.95	0.92 - 0.97	0.97	0.95 - 1.00
	99	322948	30.66	25.17 37.33	0.85	0.70 1.04	0.87	0.72 1.07
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	12790	35118332	36.42	35.79 - 37.06	1.00	-	1.00	-
2	13633	37571864	36.29	35.68 - 36.90	1.00	0.97 - 1.02	0.98	0.95 - 1.00
3	14663	40784609	35.95	35.38 - 36.54	0.99	0.96 - 1.01	0.99	0.96 - 1.01
4	17297	48093300	35.97	35.43 - 36.51	0.99	0.97 - 1.01	0.99	0.96 - 1.01
5-most deprived	17296	48579011	35.60	35.08 - 36.14	0.98	0.96 - 1.00	0.99	0.96 - 1.01
Urban-rural household location								
Urban	65840	183261153	35.93	35.65 - 36.20	1.00		1.00	
Rural	9839	26885962	36.60	35.88 - 37.33	1.02	1.00 - 1.04	0.97	0.95 - 1.00
Region of England								
North East	3443	7894621	43.61	42.18 - 45.09	1.00	-	1.00	-
North West	13266	35494560	37.37	36.74 - 38.02	0.86	0.83 - 0.89	0.89	0.86 - 0.92
Yorkshire & The Humber	3126	8376977	37.32	36.03 - 38.65	0.86	0.82 - 0.90	0.90	0.86 - 0.95
East Midlands	2163	5729497	37.75	36.19 - 39.38	0.87	0.82 - 0.91	0.91	0.86 - 0.96
West Midlands	11547	33085251	34.90	34.27 - 35.54	0.80	0.77 - 0.83	0.85	0.81 - 0.88
East of England	4452	11521169	38.64	37.52 - 39.79	0.89	0.85 - 0.93	0.98	0.94 - 1.03
South West	10057	27192999	36.98	36.27 - 37.71	0.85	0.82 - 0.88	0.91	0.87 - 0.94
South Central	9088	26186719	34.70	34.00 - 35.43	0.80	0.77 - 0.83	0.88	0.84 - 0.91
London	11881	35820609	33.17	32.58 - 33.77	0.76	0.73 - 0.79	0.90	0.87 - 0.94
South East Coast	6656	18844713	35.32	34.48 - 36.18	0.81	0.78 - 0.84	0.91	0.87 - 0.95
Total population	75679	210147115	36.01	35.76 - 36.27				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

***The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics (hospital inpatient and outpatient admissions)

5.1 Incidence of ulcerative colitis in the United Kingdom (2000-2020)

Between 2000 and 2020, 54,467 people received a new diagnosis of UC during 286,673,368 person-years of active general practice registration in the population, representing a population incidence rate of 19.00 new cases per 100,000 person-years (i.e., 1 new case of UC identified among every 5,263 people if they were each followed for 1 year) (Table 5-3).

Table 5-3 shows incidence rates stratified by different population characteristics with unadjusted and adjusted incidence rate ratios. Incidence in females was marginally lower than in males. Incidence was 2.5 for young people under age 15 years, after which it increased sharply to age 20-24 and then modestly up to age 65-69, decreasing slightly at age 70 and older. Incidence was highest in 2000-2004 after which it decreased over time. Incidence was similar across socioeconomic groups, however, adjusted incidence decreased marginally with increasing socioeconomic deprivation; those in the most deprived socioeconomic quintile had a lower incidence compared with those in the least deprived quintile which was statistically significant.

The overall incidence rates for England, Scotland, Wales and Northern Ireland were 19.5, 16.0, 15.8, and 16.7 new cases per 100,000 person-years respectively. Adjusted incidence was similar across all devolved nations. Incidence patterns within devolved nations were generally similar to those in the UK overall, however, adjusted incidence was not different between females and males in Northern Ireland and changes in incidence with age were more stable in Scotland and Northern Ireland.

In Scotland, incidence did not decrease sharply after 2004; instead, incidence in Scotland was lowest in 2015-2020. In Wales and Northern Ireland adjusted incidence was similar across socioeconomic quintiles.

Within England, there was variation between regions; South Central had the lowest incidence and The North East had the highest incidence (Table in data supplement).

Table 5-3 Incidence of ulcerative colitis (United Kingdom 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	1104	44518514	2.48	2.34 - 2.63	1.00		1.00	
15-19	1890	15060052	12.55	12.00 - 13.13	5.06	4.70 - 5.45	5.05	4.69 - 5.44
20-24	3307	17074960	19.37	18.72 - 20.04	7.81	7.30 - 8.36	7.77	7.26 - 8.32
25-29	4070	18586007	21.90	21.24 - 22.58	8.83	8.26 - 9.44	8.79	8.23 - 9.40
30-34	4657	20534880	22.68	22.04 - 23.34	9.15	8.56 - 9.77	9.02	8.45 - 9.63
35-39	4981	21824402	22.82	22.20 - 23.47	9.20	8.62 - 9.82	9.03	8.46 - 9.64
40-44	4871	22055948	22.08	21.47 - 22.71	8.91	8.34 - 9.51	8.79	8.23 - 9.38
45-49	4581	21472570	21.33	20.73 - 21.96	8.60	8.06 - 9.19	8.58	8.04 - 9.17
50-54	4500	20136077	22.35	21.70 - 23.01	9.01	8.44 - 9.62	9.00	8.42 - 9.61
55-59	4376	18442422	23.73	23.04 - 24.44	9.57	8.96 - 10.22	9.52	8.91 - 10.17
60-64	4189	16236448	25.80	25.03 - 26.59	10.40	9.74 - 11.12	10.41	9.74 - 11.12
65-69	3771	14250600	26.46	25.63 - 27.32	10.67	9.98 - 11.41	10.70	10.00 - 11.44
70-74	3149	12180228	25.85	24.97 - 26.77	10.43	9.73 - 11.17	10.43	9.73 - 11.17
75-79	2379	9754619	24.39	23.43 - 25.39	9.83	9.16 - 10.56	9.79	9.12 - 10.52
80&over	2642	14545642	18.16	17.48 - 18.87	7.32	6.83 - 7.86	7.34	6.84 - 7.87
Gender								
Male	28093	143935069	19.52	19.29 - 19.75	1.00	-	1.00	-
Female	26374	142738299	18.48	18.26 - 18.70	0.95	0.93 - 0.96	0.94	0.92 - 0.95
Calender period								
2000 - 2004	14392	60862947	23.65	23.26 - 24.04	1.00	-	1.00	-
2005 - 2009	13635	70878250	19.24	18.92 - 19.56	0.81	0.79 - 0.83	0.82	0.80 - 0.84
2010 - 2014	12735	73314589	17.37	17.07 - 17.67	0.73	0.72 - 0.75	0.75	0.73 - 0.76
2015 - 2020	13705	81617583	16.79	16.51 - 17.08	0.71	0.69 - 0.73	0.72	0.70 - 0.74
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	9520	48806977	19.51	19.12 - 19.90	1.00	-	1.00	-
2	9924	50055578	19.83	19.44 - 20.22	1.02	0.99 - 1.05	1.01	0.98 - 1.04
3	10440	54283859	19.23	18.87 - 19.60	0.99	0.96 - 1.01	0.99	0.96 - 1.02
4	12373	65485221	18.89	18.56 - 19.23	0.97	0.94 - 0.99	0.97	0.95 - 1.00
5-most deprived	12210	68041733	17.94	17.63 - 18.27	0.92	0.90 - 0.94	0.94	0.92 - 0.97
Country								
England	48044	246652536	19.48	19.31 - 19.65	1.00	-	1.00	-
Scotland	3244	20266082	16.01	15.47 - 16.57	0.82	0.79 - 0.85	0.97	0.93 - 1.01
Wales	2204	13919497	15.83	15.19 - 16.51	0.81	0.78 - 0.85	0.96	0.91 - 1.00
Northern Ireland	975	5835254	16.71	15.69 - 17.79	0.86	0.81 - 0.91	1.02	0.96 - 1.09
Total population	54467	286673368	19.00	18.84 - 19.16				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

For the English sub-group population with HES-linked records (Table 5-4), the incidence rate was 19.87 new cases per 100,000 person-years (i.e., 1 new case of UC identified among every 5,033 people if they were each followed for 1 year). This was only marginally higher than the incidence estimated in the overall English population and in the UK overall.

Compared with the UK population and the overall English population, patterns of incidence were similar across calendar time and gender, however, they were more stable with increasing age. People with recorded White ethnicity or Asian ethnicity had a higher adjusted incidence compared with all other ethnicity groups; people with Black or unknown ethnicity recorded had the lowest incidence. Incidence decreased with increasing socioeconomic deprivation at the household-level and adjusted incidence was significantly lower in the 4th and 5th deprivation quintiles compared with the least deprived quintile. Differences in adjusted incidence across socioeconomic deprivation quintiles at GP-level were not statistically significant, nor were differences between rural and urban areas. Within England, there was variation between regions; adjusted incidence was lowest in the West Midlands highest in the North East and East of England.

Table 5-4 Incidence of ulcerative colitis (England HES-linked sub-population 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	879	32998517	2.66	2.49 - 2.85	1.00	-	1.00	-
15-19	1444	10890163	13.26	12.59 - 13.96	4.98	4.58 - 5.41	5.25	4.82 - 5.71
20-24	2522	12591187	20.03	19.26 - 20.83	7.52	6.96 - 8.12	7.87	7.29 - 8.50
25-29	3096	13702323	22.59	21.81 - 23.40	8.48	7.87 - 9.14	8.81	8.17 - 9.49
30-34	3562	15150977	23.51	22.75 - 24.29	8.83	8.20 - 9.50	8.98	8.34 - 9.66
35-39	3780	16034410	23.57	22.83 - 24.34	8.85	8.22 - 9.52	8.85	8.22 - 9.53
40-44	3712	16143622	22.99	22.27 - 23.75	8.63	8.02 - 9.29	8.56	7.95 - 9.21
45-49	3501	15692932	22.31	21.58 - 23.06	8.38	7.78 - 9.02	8.27	7.68 - 8.90
50-54	3435	14725521	23.33	22.56 - 24.12	8.76	8.13 - 9.43	8.49	7.89 - 9.15
55-59	3320	13462888	24.66	23.84 - 25.51	9.26	8.59 - 9.97	8.73	8.11 - 9.41
60-64	3204	11832691	27.08	26.16 - 28.03	10.17	9.43 - 10.95	9.41	8.73 - 10.14
65-69	2860	10395201	27.51	26.52 - 28.54	10.33	9.58 - 11.14	9.37	8.69 - 10.11
70-74	2422	8912674	27.17	26.11 - 28.28	10.20	9.44 - 11.02	9.12	8.44 - 9.85
75-79	1897	7156667	26.51	25.34 - 27.73	9.95	9.19 - 10.78	8.81	8.13 - 9.54
80&over	2113	10457341	20.21	19.36 - 21.09	7.59	7.01 - 8.21	6.88	6.35 - 7.44
Gender								
Male	21405	105868295	20.22	19.95 - 20.49	1.00	-	1	-
Female	20342	104278820	19.51	19.24 - 19.78	0.96	0.95 - 0.98	0.88	0.86 - 0.90
Calender period								
2000 - 2004	11023	45735953	24.10	23.66 - 24.56	1.00	-	1.00	-
2005 - 2009	10291	50925196	20.21	19.82 - 20.60	0.84	0.82 - 0.86	0.83	0.80 - 0.85
2010 - 2014	9874	53160179	18.57	18.21 - 18.94	0.77	0.75 - 0.79	0.75	0.73 - 0.77
2015 - 2020	10559	60325787	17.50	17.17 - 17.84	0.73	0.71 - 0.75	0.70	0.68 - 0.72
Ethnicity* **								
White	35955	151630918	23.71	23.47 - 23.96	1.00		1.00	
Mixed	313	2306641	13.57	12.15 - 15.16	0.57	0.51 - 0.64	0.82	0.74 - 0.92
Asian	2439	11150991	21.87	21.02 - 22.76	0.92	0.89 - 0.96	1.04	1.00 - 1.09
Black	664	6603962	10.05	9.32 - 10.85	0.42	0.39 - 0.46	0.49	0.45 - 0.53
Other ethnicity	595	3466104	17.17	15.84 - 18.60	0.72	0.67 - 0.79	0.80	0.74 - 0.87
Unknown	1781	34988499	5.09	4.86 - 5.33	0.21	0.20 0.23	0.21	0.20 0.22
Socioeconomic deprivation quintile (household-level)								
1-least deprived	9482	45635922	20.78	20.36 - 21.20	1.00		1.00	
2	8953	42511554	21.06	20.63 - 21.50	1.01	0.98 - 1.04	1.00	0.97 - 1.03
3	8437	41288728	20.43	20.00 - 20.87	0.98	0.96 - 1.01	0.98	0.95 - 1.01
4	8045	41501509	19.38	18.97 - 19.81	0.93	0.91 - 0.96	0.95	0.92 - 0.98
5-most deprived	6770	38886454	17.41	17.00 - 17.83	0.84	0.81 - 0.86	0.89	0.86 - 0.92
	60	322948	18.58	14.43 - 23.93	0.89	0.69 - 1.15	0.91	0.71 - 1.18
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	7230	35118332	20.59	20.12 - 21.07	1.00		1.00	
2	7747	37571864	20.62	20.17 - 21.08	1.00	0.97 - 1.03	1.00	0.96 - 1.03
3	8171	40784609	20.03	19.60 - 20.47	0.97	0.94 - 1.00	0.99	0.96 - 1.02
4	9406	48093300	19.56	19.17 - 19.96	0.95	0.92 - 0.98	0.98	0.95 - 1.02
5-most deprived	9193	48579011	18.92	18.54 - 19.31	0.92	0.89 - 0.95	0.98	0.94 - 1.01
Urban-rural household location								
Urban	36191	183261153	19.75	19.55 - 19.95	1	-	1.00	-
Rural	5556	26885962	20.67	20.13 - 21.22	1.05	1.02 - 1.08	0.97	0.94 - 1.00
Region of England								
North East	1939	7894621	24.56	23.49 - 25.68	1.00	-	1.00	-
North West	7092	35494560	19.98	19.52 - 20.45	0.81	0.77 - 0.86	0.84	0.79 - 0.88
Yorkshire & The Humber	1678	8376977	20.03	19.10 - 21.01	0.82	0.76 - 0.87	0.85	0.79 - 0.90
East Midlands	1241	5729497	21.66	20.49 - 22.90	0.88	0.82 - 0.95	0.90	0.84 - 0.97
West Midlands	6361	33085251	19.23	18.76 - 19.70	0.78	0.74 - 0.82	0.81	0.77 - 0.85
East of England	2552	11521169	22.15	21.31 - 23.03	0.90	0.85 - 0.96	0.96	0.90 - 1.02
South West	5598	27192999	20.59	20.05 - 21.13	0.84	0.80 - 0.88	0.87	0.83 - 0.92
South Central	5021	26186719	19.17	18.65 - 19.71	0.78	0.74 - 0.82	0.82	0.78 - 0.87
London	6574	35820609	18.35	17.91 - 18.80	0.75	0.71 - 0.79	0.87	0.83 - 0.92
South East Coast	3691	18844713	19.59	18.96 - 20.23	0.80	0.75 - 0.84	0.86	0.81 - 0.91
Total population	41747	210147115	19.87	19.68 - 20.06				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

***The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics (hospital inpatient and outpatient admissions)

5.2 Incidence of Crohn's disease in the United Kingdom (2000-2020)

Between 2000 and 2020, 38,224 people received a new diagnosis of Crohn's disease during 286,673,368 person-years of active general practice registration in the population, representing a population incidence rate of 13.33 new cases per 100,000 person-years (i.e., 1 new case of Crohn's disease identified among every 7,502 people if they were each followed for 1 year) (Table 5-5).

Table 5-5 shows incidence rates stratified by different population characteristics with unadjusted and adjusted incidence rate ratios. Incidence in females was marginally higher than in males. Incidence was 4.5 for young people under age 15 years, after which it increased until age 20-24 and then decreased slightly and remained stable until age 75-79, decreasing at age 80 and older. Incidence was highest in 2000-2004 after which it decreased but then remained stable between 2005-2020. Incidence was similar across socioeconomic groups, however, adjusted incidence was higher in the 3rd to 5th socioeconomic deprivation quintile compared with the least deprived quintile.

The overall incidence rates for England, Scotland, Wales and Northern Ireland were 13.3, 14.5, 11.7, and 14.2 new cases per 100,000 person-years respectively. Adjusted incidence was higher in Scotland and Northern Ireland compared with England and Wales. Incidence patterns within devolved nations were generally similar to those in the UK overall, however, adjusted incidence was not different between females and males in Northern Ireland. In Scotland and Wales, the decrease in adjusted incidence over time was not statistically significant. In Wales and Northern Ireland adjusted incidence was similar across socioeconomic quintiles.

Within England, there was variation between regions; London had the lowest incidence and The North East had the highest incidence (Table in data supplement).

Table 5-5 Incidence of Crohn's disease (United Kingdom 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	2026	44518514	4.55	4.36 - 4.75	1.00		1.00	
15-19	2814	15060052	18.69	18.01 - 19.39	4.11	3.88 - 4.35	4.12	3.89 - 4.36
20-24	3718	17074960	21.77	21.09 - 22.49	4.78	4.53 - 5.05	4.77	4.52 - 5.04
25-29	3561	18586007	19.16	18.54 - 19.80	4.21	3.99 - 4.45	4.19	3.97 - 4.43
30-34	3270	20534880	15.92	15.39 - 16.48	3.50	3.31 - 3.70	3.47	3.28 - 3.67
35-39	3141	21824402	14.39	13.90 - 14.90	3.16	2.99 - 3.34	3.14	2.97 - 3.33
40-44	2995	22055948	13.58	13.10 - 14.07	2.98	2.82 - 3.16	2.98	2.82 - 3.16
45-49	2807	21472570	13.07	12.60 - 13.57	2.87	2.71 - 3.04	2.88	2.72 - 3.05
50-54	2744	20136077	13.63	13.13 - 14.15	2.99	2.83 - 3.17	2.99	2.83 - 3.17
55-59	2543	18442422	13.79	13.26 - 14.34	3.03	2.86 - 3.21	3.03	2.86 - 3.21
60-64	2355	16236448	14.50	13.93 - 15.10	3.19	3.00 - 3.38	3.19	3.01 - 3.39
65-69	1999	14250600	14.03	13.43 - 14.66	3.08	2.90 - 3.28	3.08	2.89 - 3.27
70-74	1679	12180228	13.78	13.14 - 14.46	3.03	2.84 - 3.23	3.01	2.82 - 3.21
75-79	1278	9754619	13.10	12.40 - 13.84	2.88	2.68 - 3.09	2.85	2.66 - 3.06
80&over	1294	14545642	8.90	8.42 - 9.39	1.95	1.82 - 2.10	1.92	1.79 - 2.06
Gender								
Male	17769	143935069	12.35	12.16 - 12.53	1.00	-	1.00	-
Female	20455	142738299	14.33	14.14 - 14.53	1.16	1.14 - 1.18	1.17	1.15 - 1.20
Calender period								
2000 - 2004	9016	60862947	14.81	14.51 - 15.12	1.00	-	1.00	-
2005 - 2009	8918	70878250	12.58	12.32 - 12.85	0.85	0.82 - 0.87	0.85	0.82 - 0.87
2010 - 2014	9455	73314589	12.90	12.64 - 13.16	0.87	0.85 - 0.90	0.87	0.85 - 0.90
2015 - 2020	10835	81617583	13.28	13.03 - 13.53	0.90	0.87 - 0.92	0.89	0.87 - 0.92
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	6202	48806977	12.71	12.39 - 13.03	1.00	-	1.00	-
2	6598	50055578	13.18	12.87 - 13.50	1.04	1.00 - 1.07	1.02	0.98 - 1.05
3	7274	54283859	13.40	13.10 - 13.71	1.05	1.02 - 1.09	1.04	1.01 - 1.08
4	8899	65485221	13.59	13.31 - 13.87	1.07	1.04 - 1.10	1.05	1.01 - 1.08
5-most deprived	9251	68041733	13.60	13.32 - 13.88	1.07	1.04 - 1.10	1.06	1.02 - 1.09
Country								
England	32837	246652536	13.31	13.17 - 13.46	1.00	-	1.00	-
Scotland	2929	20266082	14.45	13.94 - 14.99	1.09	1.05 - 1.13	1.24	1.18 - 1.30
Wales	1632	13919497	11.72	11.17 - 12.31	0.88	0.84 - 0.93	1.01	0.95 - 1.07
Northern Ireland	826	5835254	14.16	13.22 - 15.15	1.06	0.99 - 1.14	1.19	1.10 - 1.28
Total population	38224	286673368	13.33	13.20 - 13.47				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

For the English sub-group population with HES-linked records (Table 5-6), the incidence rate was 13.35 new cases per 100,000 person-years (i.e., 1 new case of Crohn's disease identified among every 7,491 people if they were each followed for 1 year). This was the same as the incidence estimated in the overall English population and in the UK overall.

Compared with the UK population and the overall English population, patterns of incidence were similar across calendar time, age, and gender. People with recorded White ethnicity had a higher adjusted incidence compared with all other ethnicity groups; people with Black or unknown ethnicity recorded had the lowest incidence. At the household-level, adjusted incidence was lower in the least deprived socioeconomic quintile compared with more deprived quintiles, however there were no statistically significant associations with socioeconomic deprivation at the GP-level nor between those living in rural and urban areas. Within England, there was variation between regions; adjusted incidence was lowest in the West Midlands highest in the North East, however, confidence intervals in several regions overlapped with the North East.

Table 5-6 Incidence of Crohn's disease (England HES-linked sub-population 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	1508	32998517	4.57	4.34 - 4.81	1.00	-	1.00	-
15-19	2061	10890163	18.93	18.13 - 19.76	4.14	3.88 - 4.43	4.39	4.11 - 4.69
20-24	2721	12591187	21.61	20.81 - 22.44	4.73	4.44 - 5.04	4.95	4.65 - 5.27
25-29	2619	13702323	19.11	18.40 - 19.86	4.18	3.93 - 4.46	4.34	4.08 - 4.63
30-34	2334	15150977	15.40	14.79 - 16.04	3.37	3.16 - 3.60	3.45	3.24 - 3.68
35-39	2339	16034410	14.59	14.01 - 15.19	3.19	2.99 - 3.41	3.24	3.04 - 3.46
40-44	2185	16143622	13.53	12.98 - 14.11	2.96	2.77 - 3.16	2.97	2.79 - 3.18
45-49	2099	15692932	13.38	12.82 - 13.96	2.93	2.74 - 3.13	2.90	2.72 - 3.10
50-54	2011	14725521	13.66	13.07 - 14.27	2.99	2.80 - 3.19	2.90	2.72 - 3.10
55-59	1848	13462888	13.73	13.11 - 14.37	3.00	2.81 - 3.22	2.85	2.66 - 3.05
60-64	1749	11832691	14.78	14.10 - 15.49	3.23	3.02 - 3.47	3.00	2.80 - 3.21
65-69	1467	10395201	14.11	13.41 - 14.85	3.09	2.87 - 3.32	2.78	2.59 - 2.99
70-74	1203	8912674	13.50	12.76 - 14.28	2.95	2.74 - 3.19	2.61	2.42 - 2.81
75-79	944	7156667	13.19	12.38 - 14.06	2.89	2.66 - 3.13	2.52	2.32 - 2.73
80&over	957	10457341	9.15	8.59 - 9.75	2.00	1.85 - 2.17	1.75	1.61 - 1.90
Gender								
Male	13144	105868295	12.42	12.20 - 12.63	1.00		1	
Female	14901	104278820	14.29	14.06 - 14.52	1.15	1.12 - 1.18	1.06	1.04 - 1.09
Calender period								
2000 - 2004	6666	45735953	14.57	14.23 - 14.93	1.00	-	1.00	-
2005 - 2009	6406	50925196	12.58	12.27 - 12.89	0.86	0.83 - 0.89	0.85	0.82 - 0.88
2010 - 2014	7063	53160179	13.29	12.98 - 13.60	0.91	0.88 - 0.94	0.87	0.85 - 0.90
2015 - 2020	7910	60325787	13.11	12.83 - 13.40	0.90	0.87 - 0.93	0.86	0.83 - 0.89
Ethnicity* **								
White	24527	151630918	16.18	15.97 - 16.38	1.00	-	1.00	-
Mixed	284	2306641	12.31	10.96 - 13.83	0.76	0.68 - 0.86	0.84	0.74 - 0.94
Asian	1350	11150991	12.11	11.48 - 12.77	0.75	0.71 - 0.79	0.73	0.69 - 0.77
Black	518	6603962	7.84	7.20 - 8.55	0.48	0.44 - 0.53	0.48	0.44 - 0.53
Other ethnicity	385	3466104	11.11	10.05 - 12.27	0.69	0.62 - 0.76	0.68	0.61 - 0.75
Unknown	981	34988499	2.80	2.63 - 2.98	0.17	0.16 - 0.18	0.16	0.15 - 0.17
Socioeconomic deprivation quintile (household-level)								
1-least deprived	5741	45635922	12.58	12.26 - 12.91	1.00	-	1.00	-
2	5667	42511554	13.33	12.99 - 13.68	1.06	1.02 - 1.10	1.04	1.01 - 1.08
3	5513	41288728	13.35	13.00 - 13.71	1.06	1.02 - 1.10	1.05	1.01 - 1.09
4	5752	41501509	13.86	13.51 - 14.22	1.10	1.06 - 1.14	1.09	1.05 - 1.14
5-most deprived	5340	38886454	13.73	13.37 - 14.11	1.09	1.05 - 1.13	1.09	1.04 - 1.14
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	4581	35118332	13.04	12.67 - 13.43	1.00	-	1.00	-
2	4892	37571864	13.02	12.66 - 13.39	1.00	0.96 - 1.04	0.96	0.92 - 1.00
3	5396	40784609	13.23	12.88 - 13.59	1.01	0.98 - 1.05	0.99	0.95 - 1.03
4	6494	48093300	13.50	13.18 - 13.84	1.04	1.00 - 1.08	0.99	0.95 - 1.03
5-most deprived	6682	48579011	13.75	13.43 - 14.09	1.05	1.02 - 1.09	0.99	0.95 - 1.04
Urban-rural household location								
Urban	24560	183261153	13.40	13.24 - 13.57	1	-	1.00	-
Rural	3485	26885962	12.96	12.54 - 13.40	0.97	0.93 - 1.00	0.96	0.92 - 1.00
Region of England								
North East	1291	7894621	16.35	15.48 - 17.27	1.00	-	1.00	-
North West	4998	35494560	14.08	13.70 - 14.48	0.86	0.81 - 0.92	0.91	0.86 - 0.97
Yorkshire & The Humber	1215	8376977	14.50	13.71 - 15.34	0.89	0.82 - 0.96	0.95	0.88 - 1.03
East Midlands	764	5729497	13.33	12.42 - 14.31	0.82	0.75 - 0.89	0.88	0.80 - 0.96
West Midlands	4255	33085251	12.86	12.48 - 13.25	0.79	0.74 - 0.84	0.86	0.81 - 0.92
East of England	1573	11521169	13.65	12.99 - 14.34	0.83	0.78 - 0.90	0.99	0.92 - 1.07
South West	3837	27192999	14.11	13.67 - 14.56	0.86	0.81 - 0.92	0.96	0.90 - 1.02
South Central	3400	26186719	12.98	12.55 - 13.43	0.79	0.74 - 0.85	0.93	0.87 - 0.99
London	4255	35820609	11.88	11.53 - 12.24	0.73	0.68 - 0.77	0.89	0.83 - 0.94
South East Coast	2457	18844713	13.04	12.53 - 13.56	0.80	0.75 - 0.85	0.95	0.88 - 1.02
Total population	28045	210147115	13.35	13.19 - 13.50				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

***The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics (hospital inpatient and outpatient admissions)

5.3 Incidence of unclassified inflammatory bowel disease in the United Kingdom (2000-2020)

Between 2000 and 2020, 10,918 people received a new diagnosis of IBD unclassified during 286,673,368 person-years of active general practice registration in the population, representing a population incidence rate of 3.81 new cases per 100,000 person-years (i.e., 1 new case of IBD unclassified identified among every 26,247 people if they were each followed for 1 year) (Table 5-7).

Table 5-7 shows incidence rates stratified by different population characteristics with unadjusted and adjusted incidence rate ratios. Incidence in females was marginally higher than in males. Incidence was 0.8 for young people under age 15 years, after which it increased until age 20-24 and remained stable. Incidence increased over time; in 2015-2020 the adjusted incidence was almost twice as high as in 2000-2004. Adjusted incidence increased modestly with increasing socioeconomic deprivation.

The overall incidence rates for England, Scotland, Wales and Northern Ireland were 3.6, 6.8, 3.3, and 4.7 new cases per 100,000 person-years respectively. Adjusted incidence was higher in Scotland and Northern Ireland compared with England and Wales. Incidence patterns within devolved nations were generally similar to those in the UK overall, however, adjusted incidence was not different between females and males in Scotland, Wales and Northern Ireland. In Northern Ireland adjusted incidence did not increase over time. Within each devolved nation, adjusted incidence across socioeconomic groups were not statistically significant.

Within England, there was very little variation between regions, however adjusted incidence was lower in the South West (Table in data supplement).

Table 5-7 Incidence of unclassified inflammatory bowel disease (United Kingdom 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	351	44518514	0.79	0.71 - 0.88	1.00		1.00	
15-19	396	15060052	2.63	2.38 - 2.90	3.34	2.89 - 3.85	3.37	2.92 - 3.89
20-24	740	17074960	4.33	4.03 - 4.66	5.50	4.84 - 6.24	5.54	4.88 - 6.29
25-29	824	18586007	4.43	4.14 - 4.75	5.62	4.96 - 6.37	5.65	4.99 - 6.40
30-34	905	20534880	4.41	4.13 - 4.70	5.59	4.94 - 6.32	5.69	5.03 - 6.44
35-39	926	21824402	4.24	3.98 - 4.53	5.38	4.76 - 6.08	5.56	4.92 - 6.28
40-44	845	22055948	3.83	3.58 - 4.10	4.86	4.29 - 5.50	5.03	4.44 - 5.70
45-49	864	21472570	4.02	3.76 - 4.30	5.10	4.51 - 5.78	5.17	4.56 - 5.85
50-54	853	20136077	4.24	3.96 - 4.53	5.37	4.74 - 6.08	5.37	4.75 - 6.09
55-59	840	18442422	4.55	4.26 - 4.87	5.78	5.10 - 6.54	5.81	5.13 - 6.58
60-64	817	16236448	5.03	4.70 - 5.39	6.38	5.63 - 7.23	6.44	5.68 - 7.30
65-69	739	14250600	5.19	4.83 - 5.57	6.58	5.79 - 7.47	6.58	5.79 - 7.47
70-74	637	12180228	5.23	4.84 - 5.65	6.63	5.82 - 7.56	6.61	5.80 - 7.53
75-79	539	9754619	5.53	5.08 - 6.01	7.01	6.13 - 8.02	7.10	6.20 - 8.12
80&over	642	14545642	4.41	4.09 - 4.77	5.60	4.92 - 6.38	5.65	4.96 - 6.44
Gender								
Male	5104	143935069	3.55	3.45 - 3.64	1.00	-	1.00	-
Female	5814	142738299	4.07	3.97 - 4.18	1.15	1.11 - 1.19	1.13	1.09 - 1.17
Calender period								
2000 - 2004	1655	60862947	2.72	2.59 - 2.85	1.00	-	1.00	-
2005 - 2009	2190	70878250	3.09	2.96 - 3.22	1.14	1.07 - 1.21	1.11	1.04 - 1.19
2010 - 2014	2692	73314589	3.67	3.54 - 3.81	1.35	1.27 - 1.44	1.33	1.25 - 1.41
2015 - 2020	4381	81617583	5.37	5.21 - 5.53	1.97	1.87 - 2.09	1.94	1.83 - 2.05
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	1818	48806977	3.72	3.56 - 3.90	1.00	-	1.00	-
2	1850	50055578	3.70	3.53 - 3.87	0.99	0.93 - 1.06	0.98	0.92 - 1.04
3	2034	54283859	3.75	3.59 - 3.91	1.01	0.94 - 1.07	1.00	0.94 - 1.07
4	2561	65485221	3.91	3.76 - 4.07	1.05	0.99 - 1.11	1.07	1.00 - 1.13
5-most deprived	2655	68041733	3.90	3.76 - 4.05	1.05	0.99 - 1.11	1.10	1.04 - 1.17
Country								
England	8799	246652536	3.57	3.49 - 3.64	1.00	-	1.00	-
Scotland	1384	20266082	6.83	6.48 - 7.20	1.91	1.81 - 2.03	1.93	1.78 - 2.09
Wales	461	13919497	3.31	3.02 - 3.63	0.93	0.85 - 1.02	0.92	0.83 - 1.03
Northern Ireland	274	5835254	4.70	4.17 - 5.29	1.32	1.17 - 1.48	1.37	1.21 - 1.56
Total population	10918	286673368	3.81	3.74 - 3.88				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

For the English sub-group population with HES-linked records (Table 5-8), the incidence rate was 2.80 new cases per 100,000 person-years (i.e., 1 new case of IBD unclassified identified among every 35,714 people if they were each followed for 1 year). This was lower than the incidence estimated in the overall English population and in the UK overall.

Compared with the UK population and the overall English population, patterns of incidence were similar across calendar time, age, and gender. People with recorded White ethnicity had a higher adjusted incidence compared with other ethnicity groups, except for Mixed ethnicity. People with unknown ethnicity recorded had the lowest incidence. Incidence did not vary by socioeconomic deprivation, but was marginally higher in rural areas compared with urban areas. Within England, there was very little variation between regions although adjusted incidence was higher in the North West, the East of England and London, compared with other regions.

Table 5-8 Incidence of unclassified inflammatory bowel disease (England HES-linked sub-population 2000-2020)

Characteristic	Cases	Person-years	Incidence rate*	95% confidence interval	Unadjusted incidence rate ratio	95% confidence interval	Adjusted** incidence rate ratio	95% confidence interval
Age (years)								
<15	189	32998517	0.57	0.50 - 0.66	1.00	-	1.00	-
15-19	193	10890163	1.77	1.54 - 2.04	3.09	2.53 - 3.78	3.33	2.73 - 4.07
20-24	390	12591187	3.10	2.80 - 3.42	5.41	4.55 - 6.43	5.75	4.83 - 6.84
25-29	465	13702323	3.39	3.10 - 3.72	5.93	5.00 - 7.02	6.15	5.19 - 7.29
30-34	491	15150977	3.24	2.97 - 3.54	5.66	4.78 - 6.69	5.87	4.96 - 6.94
35-39	503	16034410	3.14	2.87 - 3.42	5.48	4.63 - 6.47	5.74	4.85 - 6.79
40-44	474	16143622	2.94	2.68 - 3.21	5.13	4.33 - 6.07	5.38	4.55 - 6.37
45-49	499	15692932	3.18	2.91 - 3.47	5.55	4.70 - 6.56	5.68	4.80 - 6.71
50-54	457	14725521	3.10	2.83 - 3.40	5.42	4.57 - 6.42	5.42	4.58 - 6.43
55-59	444	13462888	3.30	3.01 - 3.62	5.76	4.86 - 6.83	5.71	4.82 - 6.78
60-64	430	11832691	3.63	3.31 - 3.99	6.34	5.35 - 7.53	6.22	5.24 - 7.38
65-69	383	10395201	3.68	3.33 - 4.07	6.43	5.40 - 7.66	6.12	5.14 - 7.29
70-74	335	8912674	3.76	3.38 - 4.18	6.56	5.49 - 7.84	6.10	5.10 - 7.29
75-79	281	7156667	3.93	3.49 - 4.41	6.86	5.70 - 8.24	6.41	5.33 - 7.71
80&over	353	10457341	3.38	3.04 - 3.75	5.89	4.94 - 7.03	5.44	4.55 - 6.49
Gender								
Male	2647	105868295	2.50	2.41 - 2.60	1.00	-	1	-
Female	3240	104278820	3.11	3.00 - 3.22	1.24	1.18 - 1.31	1.14	1.09 - 1.20
Calender period								
2000 - 2004	967	45735953	2.11	1.99 - 2.25	1.00	-	1.00	-
2005 - 2009	1151	50925196	2.26	2.13 - 2.39	1.07	0.98 - 1.16	1.05	0.97 - 1.15
2010 - 2014	1347	53160179	2.53	2.40 - 2.67	1.20	1.10 - 1.30	1.16	1.07 - 1.27
2015 - 2020	2422	60325787	4.01	3.86 - 4.18	1.90	1.76 - 2.05	1.84	1.71 - 1.98
Ethnicity* **								
White	4992	151630918	3.29	3.20 - 3.38	1.00	-	1.00	-
Mixed	56	2306641	2.43	1.87 - 3.15	0.74	0.57 - 0.96	0.86	0.66 - 1.13
Asian	326	11150991	2.92	2.62 - 3.26	0.89	0.79 - 0.99	0.84	0.75 - 0.94
Black	153	6603962	2.32	1.98 - 2.71	0.70	0.60 - 0.83	0.65	0.55 - 0.77
Other ethnicity	81	3466104	2.34	1.88 - 2.91	0.71	0.57 - 0.88	0.66	0.53 - 0.82
Unknown	279	34988499	0.80	0.71 - 0.90	0.24	0.21 - 0.27	0.26	0.23 - 0.30
Socioeconomic deprivation quintile (household-level)								
1-least deprived	1227	45635922	2.69	2.54 - 2.84	1.00	-	1.00	-
2	1175	42511554	2.76	2.61 - 2.93	1.03	0.95 - 1.11	1.01	0.93 - 1.10
3	1150	41288728	2.79	2.63 - 2.95	1.04	0.96 - 1.12	1.01	0.93 - 1.10
4	1181	41501509	2.85	2.69 - 3.01	1.06	0.98 - 1.15	1.03	0.94 - 1.13
5-most deprived	1147	38886454	2.95	2.78 - 3.13	1.10	1.01 - 1.19	1.09	0.99 - 1.20
Socioeconomic deprivation quintile (general practice-level)								
1-least deprived	979	35118332	2.79	2.62 - 2.97	1.00	-	1.00	-
2	994	37571864	2.65	2.49 - 2.82	0.95	0.87 - 1.04	0.92	0.84 - 1.01
3	1096	40784609	2.69	2.53 - 2.85	0.96	0.88 - 1.05	0.97	0.88 - 1.06
4	1397	48093300	2.90	2.76 - 3.06	1.04	0.96 - 1.13	1.02	0.93 - 1.12
5-most deprived	1421	48579011	2.93	2.78 - 3.08	1.05	0.97 - 1.14	1.03	0.93 - 1.14
Urban-rural household location								
Urban	5089	183261153	2.78	2.70 - 2.85	1	-	1.00	-
Rural	798	26885962	2.97	2.77 - 3.18	1.07	0.99 - 1.15	1.11	1.02 - 1.20
Region of England								
North East	213	7894621	2.70	2.36 - 3.09	1.00	-	1.00	-
North West	1176	35494560	3.31	3.13 - 3.51	1.23	1.06 - 1.42	1.27	1.09 - 1.47
Yorkshire & The Humber	233	8376977	2.78	2.45 - 3.16	1.03	0.86 - 1.24	1.09	0.90 - 1.31
East Midlands	158	5729497	2.76	2.36 - 3.22	1.02	0.83 - 1.26	1.12	0.91 - 1.37
West Midlands	931	33085251	2.81	2.64 - 3.00	1.04	0.90 - 1.21	1.10	0.95 - 1.28
East of England	327	11521169	2.84	2.55 - 3.16	1.05	0.89 - 1.25	1.20	1.01 - 1.43
South West	622	27192999	2.29	2.11 - 2.47	0.85	0.73 - 0.99	0.91	0.78 - 1.07
South Central	667	26186719	2.55	2.36 - 2.75	0.94	0.81 - 1.10	1.07	0.91 - 1.26
London	1052	35820609	2.94	2.76 - 3.12	1.09	0.94 - 1.26	1.27	1.09 - 1.48
South East Coast	508	18844713	2.70	2.47 - 2.94	1.00	0.85 - 1.17	1.12	0.95 - 1.32
Total population	5887	210147115	2.80	2.73 - 2.87				

*Incidence rate = newly diagnosed cases per 100,000 person-years contributed by the baseline population

**Incidence rate ratio adjusted for all varibles in the table and whether people's health records were from CPRD GOLD or CPRD Aurum

***The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics (hospital inpatient and outpatient admissions)

6 Prevalence of inflammatory bowel disease in the United Kingdom (2020)

We identified 131,074 individuals with a diagnosis of IBD among a baseline population of 16,087,994, which represented a prevalence of 0.81%, equating to one in every 123 people with a diagnosis of IBD in the UK (Table 6-1).

Prevalence was marginally higher in females (0.83%) compared with males (0.80%) and increased with age for both groups. Prevalence figures for England, Scotland, Wales and Northern Ireland were 0.80%, 0.97%, 0.83%, and 0.88% respectively. After standardising for age, there was marginal change in these figures and age-standardised prevalence was similar between England and Wales, and slightly higher in Scotland and Northern Ireland (Table in data supplement). Within England there was also variation between regions, with London having the lowest prevalence (0.64%) and the East of England having the highest (0.92%); age-standardised prevalence remained lowest in London and highest in the East of England, although confidence intervals for the North East, Yorkshire & The Humber and the South West overlapped with the East of England. The variation in age-standardised prevalence between devolved nations and between regions affected men and women similarly.

In the UK overall, prevalence decreased with increasing socioeconomic deprivation; this pattern was similar in England, Scotland and Northern Ireland, but not in Wales.

Table 6-1 Prevalence of inflammatory bowel disease per 100 population (United Kingdom 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	0.01	(0.01-0.01)	0.01	(0.01-0.01)	0.01	(0.01-0.01)
10-19	0.13	(0.13-0.14)	0.11	(0.11-0.12)	0.15	(0.14-0.16)
20-29	0.51	(0.50-0.52)	0.47	(0.46-0.49)	0.55	(0.54-0.57)
30-39	0.83	(0.82-0.84)	0.85	(0.83-0.86)	0.81	(0.80-0.83)
40-49	1.01	(1.00-1.02)	1.09	(1.07-1.11)	0.94	(0.92-0.96)
50-59	1.18	(1.16-1.19)	1.25	(1.23-1.27)	1.11	(1.09-1.13)
60-69	1.34	(1.32-1.35)	1.35	(1.33-1.38)	1.32	(1.29-1.34)
70-79	1.50	(1.48-1.52)	1.46	(1.43-1.49)	1.54	(1.51-1.58)
80&over	1.28	(1.25-1.30)	1.26	(1.23-1.29)	1.31	(1.27-1.35)
Gender						
Male	0.80	(0.79-0.80)				
Female	0.83	(0.83-0.84)				
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	0.91	(0.90-0.92)	0.93	(0.91-0.95)	0.89	(0.88-0.91)
2	0.86	(0.85-0.87)	0.88	(0.86-0.89)	0.84	(0.82-0.85)
3	0.86	(0.85-0.87)	0.88	(0.87-0.90)	0.83	(0.82-0.85)
4	0.77	(0.76-0.78)	0.78	(0.77-0.80)	0.75	(0.74-0.76)
5-most deprived	0.72	(0.71-0.73)	0.74	(0.73-0.75)	0.70	(0.69-0.71)
Country						
England	0.80	(0.79-0.80)	0.82	(0.81-0.82)	0.78	(0.77-0.78)
Scotland	0.97	(0.95-0.99)	0.99	(0.97-1.01)	0.95	(0.92-0.97)
Wales	0.83	(0.81-0.85)	0.85	(0.82-0.88)	0.81	(0.78-0.83)
Northern Ireland	0.88	(0.85-0.92)	0.89	(0.84-0.93)	0.88	(0.84-0.92)
Total population	0.81	(0.81-0.82)	0.83	(0.83-0.84)	0.80	(0.79-0.80)

The prevalence of IBD in the English sub-group population with HES-linked records was 0.92%, equating to one in every 109 people with a diagnosis of IBD (Table 6-2). This was higher than the prevalence estimated in the overall English population and in the UK overall. Compared with the UK population and the overall English population, patterns of prevalence were similar across age and gender. Prevalence was higher in people with recorded White ethnicity compared with all other ethnicity groups; people with Black, Mixed or Unknown ethnicity recorded had the lowest prevalence.

Prevalence decreased with increasing socioeconomic deprivation at the household-level and general practice-level, however, there was greater variation across quintiles at the household-level. Prevalence was higher in rural compared with urban areas. Prevalence varied across regions, however London had considerably lower prevalence (0.77%) compared with all other regions.

Table 6-2 Prevalence of inflammatory bowel disease per 100 population (England HES-linked sub-population 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	0.02	(0.01-0.02)	0.01	(0.01-0.02)	0.02	(0.02-0.02)
10-19	0.15	(0.14-0.16)	0.13	(0.12-0.14)	0.17	(0.16-0.18)
20-29	0.56	(0.55-0.57)	0.53	(0.51-0.55)	0.59	(0.57-0.60)
30-39	0.91	(0.90-0.93)	0.95	(0.93-0.97)	0.87	(0.86-0.89)
40-49	1.11	(1.10-1.13)	1.20	(1.18-1.23)	1.03	(1.01-1.06)
50-59	1.33	(1.32-1.35)	1.41	(1.39-1.44)	1.26	(1.23-1.28)
60-69	1.55	(1.53-1.57)	1.57	(1.54-1.61)	1.52	(1.49-1.55)
70-79	1.76	(1.74-1.79)	1.72	(1.68-1.75)	1.82	(1.78-1.86)
80&over	1.59	(1.55-1.62)	1.57	(1.53-1.62)	1.60	(1.55-1.66)
Gender						
Male	0.89	(0.89-0.90)				
Female	0.95	(0.94-0.96)				
Ethnicity*						
White	1.13	(1.12-1.13)	1.15	(1.14-1.16)	1.10	(1.09-1.11)
Mixed	0.47	(0.44-0.50)	0.52	(0.48-0.56)	0.42	(0.38-0.46)
Asian	0.66	(0.65-0.68)	0.61	(0.59-0.63)	0.72	(0.70-0.74)
Black	0.43	(0.41-0.44)	0.46	(0.43-0.49)	0.39	(0.36-0.41)
Other ethnicity	0.55	(0.53-0.58)	0.49	(0.45-0.52)	0.61	(0.58-0.65)
Unknown	0.26	(0.26-0.27)	0.25	(0.23-0.26)	0.28	(0.27-0.29)
Socioeconomic deprivation quintile (household-level)						
1-least deprived	1.05	(1.04-1.06)	1.07	(1.05-1.08)	1.03	(1.02-1.05)
2	1.01	(1.00-1.03)	1.03	(1.02-1.05)	1.00	(0.98-1.01)
3	0.96	(0.95-0.98)	0.99	(0.98-1.01)	0.93	(0.92-0.95)
4	0.83	(0.82-0.85)	0.86	(0.85-0.88)	0.81	(0.79-0.82)
5-most deprived	0.75	(0.73-0.76)	0.80	(0.78-0.81)	0.70	(0.68-0.71)
	0.65	(0.51-0.82)	0.64	(0.45-0.89)	0.66	(0.48-0.90)
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	1.03	(1.02-1.05)	1.06	(1.04-1.08)	1.01	(0.99-1.03)
2	0.97	(0.95-0.98)	0.99	(0.97-1.01)	0.94	(0.93-0.96)
3	0.97	(0.95-0.98)	1.00	(0.98-1.01)	0.94	(0.92-0.96)
4	0.86	(0.85-0.87)	0.88	(0.87-0.90)	0.83	(0.82-0.85)
5-most deprived	0.83	(0.82-0.84)	0.87	(0.85-0.88)	0.79	(0.77-0.80)
Urban-rural household location						
Urban	0.90	(0.89-0.91)	0.93	(0.92-0.94)	0.87	(0.86-0.88)
Rural	1.09	(1.07-1.11)	1.13	(1.10-1.15)	1.05	(1.02-1.07)
Region of England						
North East	1.04	(1.01-1.07)	1.09	(1.04-1.14)	0.98	(0.94-1.03)
North West	0.96	(0.95-0.98)	1.02	(1.00-1.04)	0.91	(0.89-0.93)
Yorkshire & The Humber	0.94	(0.91-0.97)	0.99	(0.95-1.04)	0.89	(0.84-0.93)
East Midlands	0.86	(0.82-0.90)	0.92	(0.87-0.98)	0.80	(0.76-0.85)
West Midlands	0.89	(0.88-0.91)	0.93	(0.91-0.95)	0.86	(0.84-0.88)
East of England	1.05	(1.02-1.08)	1.06	(1.02-1.11)	1.03	(0.99-1.07)
South West	1.03	(1.01-1.04)	1.03	(1.01-1.05)	1.02	(1.00-1.05)
South Central	0.95	(0.93-0.96)	0.99	(0.97-1.02)	0.90	(0.88-0.92)
London	0.77	(0.76-0.78)	0.76	(0.74-0.78)	0.77	(0.76-0.79)
South East Coast	0.99	(0.97-1.01)	1.04	(1.01-1.06)	0.95	(0.92-0.97)
Total population	0.92	(0.92-0.93)	0.95	(0.94-0.96)	0.89	(0.89-0.90)

*The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics

6.1 Prevalence of ulcerative colitis in the United Kingdom (2020)

We identified 70,155 individuals with a diagnosis of UC among a baseline population of 16,087,994, which represented a prevalence of 0.44%, equating to one in every 227 people with a diagnosis of UC in the UK (Table 6-3).

Prevalence was marginally lower in females (0.43%) compared with males (0.44%) and increased with age for both groups. Prevalence figures for England, Scotland, Wales and Northern Ireland were 0.43%, 0.46%, 0.43%, and 0.45% respectively. After standardising for age, there was marginal change in these figures and age-standardised prevalence was similar between England, Scotland and Northern Ireland, and slightly lower in Wales (Table in data supplement). Within England there was also variation between regions, with London having the lowest prevalence (0.35%) and the North East and South West having the highest (0.49%); age-standardised prevalence remained lowest in London but was highest in the East of England. The variation in age-standardised prevalence between devolved nations and between regions affected men and women similarly.

In the UK overall, prevalence decreased with increasing socioeconomic deprivation; this pattern was similar within each devolved nation.

Table 6-3 Prevalence of ulcerative colitis per 100 population (United Kingdom 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	<0.01	(<0.01-<0.01)	<0.01	(<0.01-<0.01)	<0.01	(<0.01-<0.01)
10-19	0.04	(0.04-0.05)	0.04	(0.04-0.04)	0.05	(0.04-0.05)
20-29	0.22	(0.21-0.22)	0.20	(0.19-0.21)	0.23	(0.22-0.24)
30-39	0.40	(0.39-0.41)	0.39	(0.38-0.40)	0.40	(0.39-0.42)
40-49	0.52	(0.51-0.53)	0.53	(0.52-0.54)	0.51	(0.49-0.52)
50-59	0.63	(0.62-0.64)	0.63	(0.62-0.65)	0.62	(0.61-0.64)
60-69	0.77	(0.76-0.78)	0.73	(0.71-0.75)	0.81	(0.79-0.83)
70-79	0.92	(0.90-0.94)	0.84	(0.82-0.87)	1.01	(0.98-1.03)
80&over	0.83	(0.81-0.85)	0.79	(0.76-0.81)	0.89	(0.85-0.92)
Gender						
Male	0.44	(0.44-0.45)				
Female	0.43	(0.42-0.43)				
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	0.51	(0.50-0.51)	0.50	(0.49-0.51)	0.51	(0.50-0.52)
2	0.47	(0.46-0.48)	0.47	(0.46-0.48)	0.48	(0.46-0.49)
3	0.46	(0.45-0.47)	0.45	(0.44-0.46)	0.47	(0.46-0.48)
4	0.40	(0.39-0.40)	0.39	(0.38-0.40)	0.41	(0.40-0.42)
5-most deprived	0.37	(0.37-0.38)	0.36	(0.36-0.37)	0.38	(0.37-0.39)
Country						
England	0.43	(0.43-0.44)	0.43	(0.42-0.43)	0.44	(0.43-0.44)
Scotland	0.46	(0.45-0.47)	0.44	(0.42-0.46)	0.48	(0.46-0.50)
Wales	0.43	(0.42-0.45)	0.42	(0.40-0.44)	0.45	(0.43-0.47)
Northern Ireland	0.45	(0.43-0.47)	0.43	(0.40-0.47)	0.46	(0.43-0.49)
Total population	0.44	(0.43-0.44)	0.43	(0.42-0.43)	0.44	(0.44-0.45)

... no cases available for prevalence calculation

The prevalence of UC in the English sub-group population with HES-linked records was 0.51%, equating to one in every 196 people with a diagnosis of UC (Table 6-4). This was higher than the prevalence estimated in the overall English population and in the UK overall. Compared with the UK population and the overall English population, patterns of prevalence were similar across age and there was no difference between females and males. Prevalence was higher in people with recorded White ethnicity compared with all other ethnicity groups; people with Black, Mixed or Unknown ethnicity recorded had the lowest prevalence.

Prevalence decreased with increasing socioeconomic deprivation at the household-level and general practice-level, however, there was greater variation across quintiles at the household-level. Prevalence was higher in rural compared with urban areas. Prevalence varied across regions, however London (0.44%) and the East Midlands (0.47%) had lower prevalence compared with other regions.

Table 6-4 Prevalence of ulcerative colitis per 100 population (England HES-linked sub-population 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	0.01	(0.00-0.01)	0.01	(0.00-0.01)	0.01	(0.00-0.01)
10-19	0.05	(0.05-0.06)	0.05	(0.05-0.06)	0.06	(0.05-0.06)
20-29	0.24	(0.24-0.25)	0.23	(0.22-0.24)	0.26	(0.25-0.27)
30-39	0.45	(0.44-0.46)	0.46	(0.44-0.47)	0.45	(0.44-0.46)
40-49	0.59	(0.58-0.60)	0.61	(0.59-0.63)	0.57	(0.56-0.59)
50-59	0.74	(0.73-0.76)	0.75	(0.73-0.77)	0.73	(0.71-0.75)
60-69	0.93	(0.91-0.94)	0.89	(0.86-0.91)	0.96	(0.94-0.99)
70-79	1.12	(1.10-1.15)	1.04	(1.01-1.07)	1.21	(1.18-1.25)
80&over	1.05	(1.02-1.07)	1.01	(0.97-1.04)	1.11	(1.06-1.15)
Gender						
Male	0.52	(0.51-0.52)				
Female	0.51	(0.51-0.52)				
Ethnicity*						
White	0.62	(0.62-0.63)	0.61	(0.60-0.62)	0.63	(0.63-0.64)
Mixed	0.24	(0.22-0.26)	0.26	(0.23-0.29)	0.22	(0.19-0.24)
Asian	0.41	(0.39-0.42)	0.36	(0.35-0.38)	0.45	(0.43-0.47)
Black	0.22	(0.21-0.24)	0.24	(0.22-0.26)	0.21	(0.19-0.23)
Other ethnicity	0.31	(0.29-0.33)	0.27	(0.25-0.30)	0.35	(0.32-0.38)
Unknown	0.16	(0.15-0.16)	0.15	(0.14-0.16)	0.16	(0.16-0.17)
Socioeconomic deprivation quintile (household-level)						
1-least deprived	0.61	(0.60-0.62)	0.61	(0.59-0.62)	0.62	(0.60-0.63)
2	0.58	(0.57-0.59)	0.58	(0.56-0.59)	0.58	(0.57-0.60)
3	0.54	(0.53-0.55)	0.54	(0.53-0.55)	0.55	(0.53-0.56)
4	0.45	(0.44-0.46)	0.44	(0.43-0.46)	0.46	(0.45-0.47)
5-most deprived	0.38	(0.37-0.39)	0.39	(0.37-0.40)	0.37	(0.36-0.38)
	0.35	(0.26-0.48)	0.31	(0.19-0.50)	0.39	(0.26-0.59)
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	0.59	(0.58-0.61)	0.59	(0.58-0.61)	0.60	(0.58-0.61)
2	0.55	(0.54-0.56)	0.55	(0.54-0.56)	0.55	(0.54-0.57)
3	0.54	(0.53-0.55)	0.54	(0.53-0.55)	0.55	(0.53-0.56)
4	0.47	(0.46-0.48)	0.46	(0.45-0.47)	0.48	(0.46-0.49)
5-most deprived	0.44	(0.43-0.45)	0.44	(0.43-0.45)	0.44	(0.43-0.45)
Urban-rural household location						
Urban	0.50	(0.49-0.50)	0.49	(0.49-0.50)	0.50	(0.49-0.51)
Rural	0.64	(0.62-0.65)	0.64	(0.62-0.66)	0.64	(0.62-0.66)
Region of England						
North East	0.59	(0.57-0.61)	0.58	(0.55-0.62)	0.60	(0.56-0.63)
North West	0.52	(0.51-0.53)	0.53	(0.52-0.54)	0.52	(0.50-0.53)
Yorkshire & The Humber	0.51	(0.49-0.54)	0.51	(0.48-0.54)	0.51	(0.48-0.55)
East Midlands	0.47	(0.45-0.50)	0.49	(0.45-0.53)	0.46	(0.42-0.49)
West Midlands	0.50	(0.49-0.51)	0.50	(0.48-0.51)	0.49	(0.48-0.51)
East of England	0.61	(0.59-0.63)	0.59	(0.56-0.62)	0.63	(0.60-0.66)
South West	0.55	(0.54-0.57)	0.54	(0.53-0.56)	0.57	(0.55-0.58)
South Central	0.52	(0.51-0.53)	0.54	(0.52-0.55)	0.51	(0.49-0.53)
London	0.44	(0.43-0.45)	0.42	(0.41-0.43)	0.46	(0.45-0.47)
South East Coast	0.57	(0.56-0.58)	0.57	(0.55-0.59)	0.56	(0.55-0.59)
Total population	0.51	(0.51-0.52)	0.51	(0.51-0.52)	0.52	(0.51-0.52)

*The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics

6.2 Prevalence of Crohn's disease in the United Kingdom (2020)

We identified 50,158 individuals with a diagnosis of Crohn's disease among a baseline population of 16,087,994, which represented a prevalence of 0.31%, equating to one in every 323 people with a diagnosis of Crohn's disease in the UK (Table 6-5).

Prevalence was higher in females (0.33%) compared with males (0.29%) and increased with age for both groups. Prevalence figures for England, Scotland, Wales and Northern Ireland were 0.30%, 0.39%, 0.34%, and 0.35% respectively. After standardising for age, there was marginal change in these figures and age-standardised prevalence was slightly lower in England compared with the other devolved nations (Table in data supplement). Within England there was also variation between regions, with London having the lowest prevalence (0.24%) and the South West having the highest (0.35%); age-standardised prevalence remained lowest in London and highest in the South West, although confidence intervals for Yorkshire & The Humber overlapped with the South West. The variation in age-standardised prevalence between devolved nations and between regions affected men and women similarly.

In the UK overall, prevalence decreased with increasing socioeconomic deprivation; this pattern was similar in England and Scotland but not in Wales and Northern Ireland.

Table 6-5 Prevalence of Crohn's disease per 100 population (United Kingdom 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	<0.01	(<0.01-<0.01)	<0.01	(<0.01-<0.01)	0.01	(0.00-0.01)
10-19	0.07	(0.07-0.08)	0.06	(0.05-0.07)	0.09	(0.08-0.09)
20-29	0.25	(0.24-0.26)	0.22	(0.21-0.23)	0.28	(0.27-0.29)
30-39	0.36	(0.35-0.37)	0.38	(0.37-0.39)	0.34	(0.33-0.35)
40-49	0.41	(0.40-0.42)	0.46	(0.45-0.48)	0.36	(0.35-0.37)
50-59	0.46	(0.45-0.46)	0.52	(0.51-0.53)	0.39	(0.38-0.41)
60-69	0.46	(0.45-0.47)	0.52	(0.50-0.53)	0.41	(0.39-0.42)
70-79	0.46	(0.45-0.47)	0.49	(0.48-0.51)	0.43	(0.41-0.44)
80&over	0.36	(0.35-0.37)	0.38	(0.36-0.40)	0.33	(0.31-0.35)
Gender						
Male	0.29	(0.29-0.29)				
Female	0.33	(0.33-0.34)				
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	0.34	(0.33-0.34)	0.36	(0.35-0.37)	0.31	(0.30-0.32)
2	0.32	(0.31-0.33)	0.34	(0.33-0.35)	0.30	(0.29-0.31)
3	0.33	(0.32-0.34)	0.36	(0.35-0.37)	0.30	(0.29-0.31)
4	0.30	(0.30-0.31)	0.32	(0.32-0.33)	0.28	(0.27-0.29)
5-most deprived	0.28	(0.28-0.29)	0.31	(0.30-0.32)	0.26	(0.25-0.27)
Country						
England	0.30	(0.30-0.30)	0.32	(0.32-0.33)	0.28	(0.28-0.28)
Scotland	0.39	(0.38-0.41)	0.43	(0.42-0.45)	0.35	(0.34-0.37)
Wales	0.34	(0.33-0.35)	0.38	(0.36-0.39)	0.30	(0.29-0.32)
Northern Ireland	0.35	(0.33-0.37)	0.37	(0.34-0.40)	0.33	(0.31-0.36)
Total population	0.31	(0.31-0.31)	0.33	(0.33-0.34)	0.29	(0.29-0.29)

The prevalence of Crohn's disease in the English sub-group population with HES-linked records was 0.35%, equating to one in every 286 people with a diagnosis of IBD (Table 6-6). This was higher than the prevalence estimated in the overall English population and in the UK overall. Compared with the UK population and the overall English population, patterns of prevalence were similar across age and gender. Prevalence was higher in people with recorded White ethnicity compared with all other ethnicity groups; people with Black, Mixed or Unknown ethnicity recorded had the lowest prevalence.

Prevalence decreased with increasing socioeconomic deprivation at the household-level and general practice-level, however, there was greater variation across quintiles at the household-level. Prevalence was higher in rural compared with urban areas. Prevalence varied across regions, however London (0.27%) had lower prevalence compared with other regions.

Table 6-6 Prevalence of Crohn's disease per 100 population (England HES-linked sub-population 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	0.01	(0.01-0.01)	0.01	(0.01-0.01)	0.01	(0.01-0.01)
10-19	0.08	(0.08-0.09)	0.07	(0.06-0.08)	0.10	(0.09-0.11)
20-29	0.27	(0.26-0.28)	0.25	(0.24-0.27)	0.29	(0.28-0.30)
30-39	0.40	(0.39-0.41)	0.43	(0.41-0.44)	0.37	(0.36-0.38)
40-49	0.44	(0.43-0.45)	0.50	(0.49-0.52)	0.39	(0.37-0.40)
50-59	0.50	(0.49-0.51)	0.57	(0.55-0.58)	0.44	(0.43-0.46)
60-69	0.52	(0.51-0.54)	0.58	(0.56-0.60)	0.47	(0.45-0.48)
70-79	0.53	(0.52-0.55)	0.56	(0.54-0.58)	0.50	(0.48-0.52)
80&over	0.45	(0.43-0.47)	0.48	(0.45-0.50)	0.41	(0.38-0.43)
Gender						
Male	0.32	(0.32-0.32)				
Female	0.37	(0.37-0.38)				
Ethnicity*						
White	0.43	(0.43-0.44)	0.46	(0.45-0.47)	0.40	(0.39-0.41)
Mixed	0.19	(0.18-0.21)	0.21	(0.19-0.24)	0.17	(0.15-0.20)
Asian	0.21	(0.20-0.22)	0.20	(0.18-0.21)	0.22	(0.21-0.24)
Black	0.17	(0.15-0.18)	0.18	(0.16-0.20)	0.15	(0.14-0.17)
Other ethnicity	0.20	(0.19-0.22)	0.18	(0.16-0.20)	0.23	(0.21-0.26)
Unknown	0.09	(0.08-0.09)	0.08	(0.07-0.09)	0.09	(0.09-0.10)
Socioeconomic deprivation quintile (household-level)						
1-least deprived	0.37	(0.37-0.38)	0.39	(0.38-0.40)	0.35	(0.34-0.36)
2	0.37	(0.36-0.38)	0.39	(0.38-0.40)	0.35	(0.34-0.36)
3	0.36	(0.35-0.37)	0.39	(0.38-0.40)	0.33	(0.32-0.34)
4	0.33	(0.32-0.33)	0.35	(0.34-0.37)	0.30	(0.29-0.31)
5-most deprived	0.31	(0.30-0.32)	0.35	(0.34-0.36)	0.27	(0.26-0.28)
	0.26	(0.18-0.37)	0.31	(0.19-0.50)	0.21	(0.12-0.37)
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	0.37	(0.37-0.38)	0.40	(0.39-0.41)	0.35	(0.34-0.36)
2	0.35	(0.34-0.36)	0.37	(0.36-0.38)	0.33	(0.32-0.34)
3	0.36	(0.36-0.37)	0.39	(0.38-0.40)	0.33	(0.32-0.34)
4	0.33	(0.32-0.34)	0.36	(0.35-0.37)	0.30	(0.29-0.31)
5-most deprived	0.33	(0.32-0.33)	0.36	(0.35-0.37)	0.30	(0.29-0.31)
Urban-rural household location						
Urban	0.34	(0.34-0.35)	0.37	(0.37-0.38)	0.32	(0.31-0.32)
Rural	0.37	(0.36-0.38)	0.41	(0.39-0.42)	0.34	(0.33-0.36)
Region of England						
North East	0.40	(0.38-0.42)	0.45	(0.42-0.48)	0.34	(0.32-0.37)
North West	0.37	(0.36-0.38)	0.41	(0.40-0.43)	0.33	(0.32-0.34)
Yorkshire & The Humber	0.37	(0.35-0.39)	0.42	(0.39-0.45)	0.32	(0.29-0.34)
East Midlands	0.33	(0.30-0.35)	0.36	(0.32-0.39)	0.30	(0.27-0.33)
West Midlands	0.34	(0.33-0.35)	0.37	(0.35-0.38)	0.31	(0.30-0.32)
East of England	0.37	(0.36-0.39)	0.41	(0.38-0.44)	0.34	(0.32-0.37)
South West	0.40	(0.39-0.42)	0.42	(0.40-0.43)	0.39	(0.38-0.41)
South Central	0.36	(0.35-0.37)	0.39	(0.37-0.40)	0.32	(0.31-0.34)
London	0.27	(0.27-0.28)	0.28	(0.27-0.29)	0.26	(0.25-0.27)
South East Coast	0.37	(0.36-0.38)	0.40	(0.38-0.42)	0.33	(0.32-0.35)
Total population	0.35	(0.34-0.35)	0.37	(0.37-0.38)	0.32	(0.32-0.32)

*The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics

6.3 Prevalence of unclassified inflammatory bowel disease in the United Kingdom (2020)

We identified 10,761 individuals with a diagnosis of IBD unclassified among a baseline population of 16,087,994, which represented a prevalence of 0.07%, equating to one in every 1,429 people with a diagnosis of IBD unclassified in the UK (Table 6-7).

Prevalence was similar between females (0.07%) and males (0.06%) and increased with age for both groups. Prevalence figures for England, Scotland, Wales and Northern Ireland were 0.06%, 0.11%, 0.05%, and 0.08% respectively. After standardising for age, there was marginal change in these figures and age-standardised prevalence was slightly lower in England and Wales compared with Scotland and Northern Ireland (Table in data supplement). Within England there was little variation between regions; age-standardised prevalence also showed little variation. The variation in age-standardised prevalence between devolved nations and between regions affected men and women similarly.

In the UK overall and within devolved nations, prevalence was similar across socioeconomic groups.

Table 6-7 Prevalence of unclassified inflammatory bowel disease per 100 population (United Kingdom 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	<0.01	(<0.01-<0.01)	<0.01	(<0.01-<0.01)	<0.01	(<0.01-<0.01)
10-19	0.02	(0.01-0.02)	0.01	(0.01-0.02)	0.02	(0.01-0.02)
20-29	0.05	(0.04-0.05)	0.05	(0.05-0.05)	0.05	(0.04-0.05)
30-39	0.07	(0.07-0.07)	0.08	(0.07-0.08)	0.07	(0.06-0.07)
40-49	0.08	(0.08-0.09)	0.09	(0.09-0.10)	0.08	(0.07-0.08)
50-59	0.09	(0.09-0.10)	0.10	(0.09-0.11)	0.09	(0.08-0.09)
60-69	0.10	(0.10-0.11)	0.11	(0.10-0.12)	0.10	(0.09-0.10)
70-79	0.12	(0.11-0.12)	0.12	(0.11-0.13)	0.11	(0.11-0.12)
80&over	0.09	(0.09-0.10)	0.09	(0.09-0.10)	0.09	(0.08-0.10)
Gender						
Male	0.06	(0.06-0.06)				
Female	0.07	(0.07-0.07)				
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	0.07	(0.07-0.07)	0.07	(0.07-0.08)	0.07	(0.06-0.07)
2	0.07	(0.06-0.07)	0.07	(0.07-0.08)	0.06	(0.06-0.07)
3	0.07	(0.06-0.07)	0.07	(0.07-0.08)	0.06	(0.06-0.07)
4	0.07	(0.06-0.07)	0.07	(0.07-0.08)	0.06	(0.06-0.07)
5-most deprived	0.06	(0.06-0.07)	0.07	(0.06-0.07)	0.06	(0.06-0.06)
Country						
England	0.06	(0.06-0.06)	0.07	(0.07-0.07)	0.06	(0.06-0.06)
Scotland	0.11	(0.11-0.12)	0.11	(0.11-0.12)	0.11	(0.11-0.12)
Wales	0.05	(0.05-0.06)	0.05	(0.05-0.06)	0.05	(0.05-0.06)
Northern Ireland	0.08	(0.08-0.10)	0.08	(0.07-0.10)	0.09	(0.07-0.10)
Total population	0.07	(0.07-0.07)	0.07	(0.07-0.07)	0.06	(0.06-0.06)

The prevalence of IBD unclassified in the English sub-group population with HES-linked records was 0.06%, equating to one in every 1,667 people with a diagnosis of IBD unclassified (Table 6-8). This was similar to the prevalence estimated in the overall English population and in the UK overall. Compared with the UK population and the overall English population, patterns of prevalence were similar across age and gender. Prevalence was higher in people with recorded White ethnicity compared with all other ethnicity groups; people with Unknown ethnicity recorded had the lowest prevalence.

Prevalence was similar across socioeconomic groups deprivation at the household-level and general practice-level. Prevalence was slightly higher in rural compared with urban areas. Prevalence showed little variation across regions.

Table 6-8 Prevalence of unclassified inflammatory bowel disease per 100 population (England HES-linked sub-population 2020)

	Whole population		Females		Males	
Characteristic	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**	**Prevalence**	**(95% confidence interval)**
Age at midyear (years)						
0-9	<0.01	(<0.01-<0.01)	<0.01	(<0.01-<0.01)	<0.01	(<0.01-<0.01)
10-19	0.01	(0.01-0.01)	0.01	(0.01-0.01)	0.01	(0.01-0.01)
20-29	0.04	(0.04-0.04)	0.04	(0.04-0.05)	0.04	(0.03-0.04)
30-39	0.06	(0.06-0.07)	0.07	(0.06-0.07)	0.06	(0.05-0.06)
40-49	0.08	(0.07-0.08)	0.08	(0.08-0.09)	0.07	(0.07-0.08)
50-59	0.09	(0.08-0.09)	0.09	(0.09-0.10)	0.08	(0.08-0.09)
60-69	0.10	(0.10-0.11)	0.11	(0.10-0.12)	0.09	(0.09-0.10)
70-79	0.11	(0.10-0.12)	0.11	(0.10-0.12)	0.11	(0.10-0.12)
80&over	0.09	(0.08-0.10)	0.09	(0.08-0.10)	0.09	(0.08-0.10)
Gender						
Male	0.06	(0.06-0.06)				
Female	0.07	(0.06-0.07)				
Ethnicity*						
White	0.07	(0.07-0.08)	0.08	(0.07-0.08)	0.07	(0.07-0.07)
Mixed	0.04	(0.03-0.05)	0.04	(0.03-0.05)	0.03	(0.02-0.05)
Asian	0.05	(0.04-0.05)	0.05	(0.04-0.05)	0.05	(0.04-0.06)
Black	0.04	(0.03-0.04)	0.04	(0.04-0.05)	0.03	(0.02-0.04)
Other ethnicity	0.03	(0.03-0.04)	0.03	(0.03-0.05)	0.03	(0.03-0.04)
Unknown	0.02	(0.02-0.02)	0.02	(0.02-0.02)	0.02	(0.02-0.03)
Socioeconomic deprivation quintile (household-level)						
1-least deprived	0.07	(0.06-0.07)	0.07	(0.06-0.07)	0.06	(0.06-0.07)
2	0.07	(0.06-0.07)	0.07	(0.06-0.07)	0.06	(0.06-0.07)
3	0.06	(0.06-0.07)	0.06	(0.06-0.07)	0.06	(0.06-0.07)
4	0.06	(0.05-0.06)	0.06	(0.06-0.07)	0.05	(0.05-0.06)
5-most deprived	0.06	(0.05-0.06)	0.06	(0.06-0.07)	0.05	(0.05-0.05)
	0.04	(0.01-0.10)	0.02	(0.00-0.14)	0.05	(0.02-0.16)
Socioeconomic deprivation quintile (general practice-level)						
1-least deprived	0.07	(0.06-0.07)	0.07	(0.06-0.07)	0.06	(0.06-0.07)
2	0.06	(0.06-0.07)	0.07	(0.06-0.07)	0.06	(0.06-0.06)
3	0.06	(0.06-0.07)	0.06	(0.06-0.07)	0.06	(0.06-0.07)
4	0.06	(0.06-0.06)	0.06	(0.06-0.07)	0.06	(0.05-0.06)
5-most deprived	0.06	(0.05-0.06)	0.06	(0.06-0.07)	0.05	(0.05-0.05)
Urban-rural household location						
Urban	0.06	(0.06-0.06)	0.06	(0.06-0.07)	0.06	(0.05-0.06)
Rural	0.08	(0.07-0.08)	0.08	(0.07-0.09)	0.07	(0.07-0.08)
Region of England						
North East	0.05	(0.04-0.06)	0.06	(0.05-0.07)	0.04	(0.03-0.05)
North West	0.07	(0.06-0.07)	0.07	(0.07-0.08)	0.06	(0.06-0.06)
Yorkshire & The Humber	0.06	(0.05-0.07)	0.06	(0.05-0.07)	0.06	(0.05-0.07)
East Midlands	0.06	(0.05-0.07)	0.07	(0.06-0.09)	0.05	(0.04-0.07)
West Midlands	0.06	(0.06-0.06)	0.07	(0.06-0.07)	0.06	(0.05-0.06)
East of England	0.06	(0.06-0.07)	0.07	(0.06-0.08)	0.06	(0.05-0.07)
South West	0.07	(0.06-0.07)	0.07	(0.06-0.07)	0.07	(0.06-0.07)
South Central	0.07	(0.06-0.07)	0.07	(0.06-0.07)	0.07	(0.06-0.07)
London	0.05	(0.05-0.06)	0.06	(0.05-0.06)	0.05	(0.05-0.06)
South East Coast	0.06	(0.05-0.06)	0.06	(0.05-0.07)	0.05	(0.04-0.06)
Total population	0.06	(0.06-0.06)	0.07	(0.06-0.07)	0.06	(0.06-0.06)

*The option 'Other ethnicity' can be selected on government ethnicity data collection forms. 'Unknown' is where no ethnicity information was coded in the person's general practice record or in their hospital record

HES = Hospital Episode Statistics

7 Faecal calprotectin testing prior to inflammatory bowel disease diagnosis

Among people with incident IBD diagnosed between 2000 and 2008, none had recorded FCTs in their general practice record in the year prior to diagnosis. For those diagnosed between 2009 and 2019, 2.7% had a recorded FCT in their general practice record within the year before diagnosis (Table 7-1). The prevalence of FCT prior to diagnosis was low prior to 2014 and then increased in England and Scotland (4.0% and 9.6% respectively in 2019), with less consistent use in Wales and Northern Ireland.

Table 7-1 Faecal calprotectin testing within 1 year prior to inflammatory bowel disease diagnosis

Year of inflammatory bowel disease diagnosis	Incident inflammatory bowel disease cases age ≥ 15 years	United Kingdom	England	Scotland	Wales	Northern Ireland
	n (UK)	% with FCT	% with FCT	% with FCT	% with FCT	% with FCT
2009	4,755	<0.1	<0.1	<0.1	0	0
2010	4,609	0.2	0.2	0.5	0.5	0
2011	4,696	0.5	0.4	1.5	0	0
2012	4,866	1.0	1.0	1.6	0	0
2013	4,885	1.7	1.7	1.7	2.0	0
2014	4,985	4.2	4.4	3.6	3.4	0
2015	4,835	4.2	4.3	3.0	5.0	4.2
2016	5,021	4.3	4.6	4.3	1.6	0.8
2017	4,991	4.7	4.9	6.3	0.5	1.0
2018	5,001	3.9	3.9	7.3	0.4	0
2019	5,075	4.2	4.0	9.6	0.8	1.0
Total	53,719	2.7	2.7	3.4	1.4	0.6

8 Diagnosis of irritable bowel syndrome prior to inflammatory bowel disease

Among people with incident IBD, 13.2% had diagnostic IBS codes, 23.9% had been prescribed antispasmodic drugs and 28.6% had either or both of these prior to their initial IBD diagnosis (

Table 8-1). Apart from in young people under age 20 years, where this occurred much less commonly, the proportion of people with prior IBS diagnoses and antispasmodic drug prescriptions was similar for people diagnosed with IBD at different ages. By a modest amount, people diagnosed with IBD between age 30-39 were most likely to have prior IBS diagnosis and people between age 20-29 were most likely to have prior antispasmodic drug prescriptions.

Recording of functional abdominal pain was extremely rare prior to IBD diagnosis.

Table 8-1 Diagnoses of IBS and use of antispasmodic drugs prior to inflammatory bowel disease diagnosis

Age at inflammatory bowel disease diagnosis (years)	Incident coeliac disease case	Prior to incident inflammatory bowel disease diagnosis: ≥1 IBS code	≥1 antispasmodic drug prescription	≥1 functional abdominal pain code	≥1 IBS code or ≥1 antispasmodic drug prescription
	n	%	%	%	%
0-9	858	1.7	1.6	0	3.4
10-19	7,087	5.4	15.9	<0.1	18.2
20-29	15,929	13.9	27.6	<0.1	32.0
30-39	17,933	16.4	26.5	<0.1	32.5
40-49	17,002	15.1	24.9	<0.1	30.6
50-59	15,906	14.6	24.1	0	29.4
60-69	13,994	12.2	22.5	0	27.0
70-79	9,839	10.3	22.0	0	25.7
80&over	4,923	9.0	21.1	0	24.4
Total	103,471	13.2	23.9	<0.1	28.6

IBS=irritable bowel syndrome

Among incident IBD cases with a prior IBS diagnosis, there was a median of 5.5 years between the initial IBS code and the IBD diagnosis (Table 8-2). The median time between their first antispasmodic drug prescription and the IBD diagnosis was 2.6 years. These time intervals increased with later age at IBD diagnosis.

Table 8-2 Years between initial IBS recording and inflammatory bowel disease diagnosis

Age at inflammatory bowel disease diagnosis (years)	Years before inflammatory bowel disease diagnosis: earliest IBS code		earliest antispasmodic drug prescription		earliest IBS code or antispasmodic drug prescription	
	Median	IQR	Median	IQR	Median	IQR
0-9	0.6	(0.1-2.8)	0.2	(0.1-1.4)	0.2	(0.1-1.7)
10-19	0.7	(0.3-2.5)	0.4	(0.2-1.2)	0.5	(0.2-1.5)
20-29	1.7	(0.5-4.5)	1.0	(0.3-3.2)	1.1	(0.3-3.8)
30-39	4.0	(1.0-8.9)	2.0	(0.5-6.0)	2.8	(0.6-7.5)
40-49	6.7	(1.8-13.2)	3.0	(0.6-8.0)	4.3	(0.9-10.4)
50-59	8.7	(2.7-16.0)	4.1	(0.8-9.6)	5.8	(1.1-12.6)
60-69	10.2	(3.8-18.2)	5.0	(1.2-10.9)	6.6	(1.6-13.9)
70-79	10.6	(4.2-18.4)	5.4	(1.4-10.7)	6.9	(1.9-13.6)
80&over	12.1	(4.7-19.7)	6.7	(2.2-12.8)	8.0	(2.7-14.7)
Total	5.5	(1.3-12.5)	2.6	(0.5-7.5)	3.5	(0.6-9.5)

IBS=irritable bowel syndrome

Median=50th percentile, IQR (Interquartile range)=25th-75th percentile

9 Appendices

Appendix A Code lists for defining cases

Inflammatory bowel disease CPRD GOLD	Description	CPRD medcode	Read code
ulcerative colitis	H/O: ulcerative colitis	5749	14C4.11
	Ulcerative colitis and/or proctitis	1784	J41..12
	Ulcerative proctocolitis	6650	J410.00
	Ulcerative colitis	704	J410100
	Ulcerative rectosigmoiditis	24858	J410200
	Ulcerative proctitis	8347	J410300
	Exacerbation of ulcerative colitis	22516	J410400
	Ulcerative proctocolitis NOS	33456	J410z00
	Ulcerative pancolitis	104259	J413.00
	[X]Other ulcerative colitis	53743	Jyu4100
	Arthropathy in ulcerative colitis	17641	N031000
	Juvenile arthritis in ulcerative colitis	71083	N045400
Crohn's disease	Orofacial Crohn's disease	29616	J08z900
	Regional enteritis - Crohn's disease	11286	J40..00
	Crohn's disease	593	J40..11
	Granulomatous enteritis	51578	J40..12
	Regional enteritis of the small bowel	51576	J400.00
	Regional enteritis of the duodenum	71945	J400000
	Regional enteritis of the jejunum	63036	J400100
	Crohn's disease of the terminal ileum	28476	J400200
	Crohn's disease of the ileum unspecified	66238	J400300
	Crohn's disease of the ileum NOS	39278	J400400
	Exacerbation of Crohn's disease of small intestine	36913	J400500
	Crohn's disease of the small bowel NOS	9359	J400z00
	Regional enteritis of the large bowel	44426	J401.00

	Regional enteritis of the colon	62628	J401000
	Regional enteritis of the rectum	64773	J401100
	Exacerbation of Crohn's disease of large intestine	39037	J401200
	Crohn's disease of the large bowel NOS	20688	J401z00
	Crohn's colitis	6538	J401z11
	Regional ileocolitis	15773	J402.00
	Regional enteritis NOS	52449	J40z.00
	Crohn's disease NOS	59994	J40z.11
	[X]Other Crohn's disease	69959	Jyu4000
	Arthropathy in Crohn's disease	20480	N031100
	Juvenile arthritis in Crohn's disease	12575	N045300
	Crohn's disease activity index	11337	ZR3S.00
	CDAI - Crohn's disease activity index	11119	ZR3S.11
	Harvey and Bradshaw index	98437	ZRLY.00
IBD generic diagnosis	Dietary education for inflammatory bowel disease	108615	8CA4W00
	Management of inflammatory bowel disease	107313	8Cc5.00
	Management of IBD (inflammatory bowel disease)	110283	8Cc5.11
	Inflammatory bowel disease	1796	J4...12
			J435.00
IBD indeterminate diagnosis	Indeterminate colitis	96976	J4z6.00

Inflammatory bowel disease CPRD Aurum	**Description**	**CPRD medcode**	**SNOMED CODE**
ulcerative colitis	Arthropathy in ulcerative colitis	309743013	201727001
	Chronic ulcerative proctitis	3346671000006113	52231000
	Chronic ulcerative proctosigmoiditis	3351321000006113	52506002
	Chronic ulcerative rectosigmoiditis	3351311000006117	52506002
	Colitis gravis	3553381000006110	64766004
	Exacerbation of ulcerative colitis	2532953017	414156000
	H/O: ulcerative colitis	411543016	275549008
	History of ulcerative colitis	5574431000006111	275549008
	Juvenile arthritis in ulcerative colitis	309836013	201807008
	UC - Ulcerative colitis	3553391000006113	64766004
	UC - Ulcerative colitis confined to rectum	3346681000006111	52231000

	Ulcerative colitis	107644019	64766004
	Ulcerative colitis and/or proctitis	85931000006112	295046003
	Ulcerative colitis confined to rectum	3346691000006114	52231000
	Ulcerative colitis confined to rectum and sigmoid colon	3351341000006118	52506002
	Ulcerative pancolitis	2872721013	444548001
	Ulcerative proctitis	496249010	52231000
	Ulcerative proctocolitis	435370011	295046003
	Ulcerative proctocolitis NOS	302956014	295046003
	Ulcerative proctosigmoiditis	3351351000006116	52506002
	Ulcerative rectosigmoiditis	496332018	52506002
	[RFC] Ulcerative colitis	906191000006113	9.06191E+14
	[X]Other ulcerative colitis	303762015	64766004
Crohn's disease	Arthropathy in Crohn disease	4808981000006112	201728006
	Arthropathy in Crohn's disease	309744019	201728006
	CD - Crohn's disease	3047391000006119	34000006
	CDAI - Crohn's disease activity index	5548931000006111	273364009
	Crohn disease	3047411000006119	34000006
	Crohn disease of colon	3316801000006112	50440006
	Crohn disease of duodenum	3414711000006118	56287005
	Crohn disease of ileum	3113551000006113	38106008
	Crohn disease of large bowel	2621151000006116	7620006
	Crohn disease of rectum	2559821000006114	3815005
	Crohn disease of small intestine	3420881000006117	56689002
	Crohn disease of terminal ileum	4785581000006112	196977009
	Crohn's colitis	601031000006119	50440006
	Crohn's disease	56765016	34000006
	Crohn's disease NOS	1222351011	34000006
	Crohn's disease activity index	5548921000006113	273364009
	Crohn's disease of colon	3316751000006117	50440006
	Crohn's disease of duodenum	3414681000006119	56287005
	Crohn's disease of oral soft tissues	4784091000006115	196578009
	Crohn's disease of rectum	2559781000006115	3815005
	Crohn's disease of the ileum NOS	302940016	38106008
	Crohn's disease of the ileum unspecified	302939018	38106008
	Crohn's disease of the large bowel NOS	396357012	7620006

	Crohn’s disease of the small bowel NOS	302941017	56689002
	Crohn’s disease of the terminal ileum	601091000006115	196977009
	Crohn’s duodenitis	3414701000006116	56287005
	Crohn’s ileitis	3113541000006111	38106008
	Crohn’s proctitis	2559801000006116	3815005
	Crohns disease	3047421000006110	34000006
	Crohns disease, colon	3316811000006110	50440006
	Crohns disease, large intestine	2621161000006119	7620006
	Crohns disease, small intestine	3420891000006119	56689002
	Exacerbation of Crohn disease of large intestine	6853111000006114	414153008
	Exacerbation of Crohn disease of small intestine	6853131000006115	414154002
	Exacerbation of Crohn’s disease of large intestine	2532950019	414153008
	Exacerbation of Crohn’s disease of small intestine	2532958014	414154002
	GC - Granulomatous colitis	3316791000006111	50440006
	Granulomatous colitis	3316771000006110	50440006
	Granulomatous enteritis	3047381000006117	34000006
	Granulomatous enteritis	56770011	34000006
	Harvey and Bradshaw index	5551391000006118	273508005
	Juvenile arthritis in Crohn disease	4809351000006111	201805000
	Juvenile arthritis in Crohn’s disease	309833017	201805000
	Oral Crohn’s disease	4784111000006112	196578009
	Orofacial Crohn’s disease	302322010	196578009
	RE - regional enteritis	3047431000006113	34000006
	Regional colitis	3316761000006115	50440006
	Regional enteritis	3047371000006115	34000006
	Regional enteritis - Crohn	886291000006112	34000006
	Regional enteritis - Crohn’s disease	179501000006113	34000006
	Regional enteritis NOS	302947018	34000006
	Regional enteritis of rectum	2559791000006117	3815005
	Regional enteritis of small intestine	3420851000006113	56689002
	Regional enteritis of the colon	179521000006115	50440006
	Regional enteritis of the duodenum	497569010	56287005
	Regional enteritis of the jejunum	302937016	196976000
	Regional enteritis of the large bowel	1495442018	7620006
	Regional enteritis of the rectum	488238014	3815005
	Regional enteritis of the small bowel	179571000006119	56689002

	Regional ileitis of small intestine Regional ileocolitis [RFC] Crohns disease [X]Other Crohn's disease	3420861000006110 302946010 906051000006118 303761010	56689002 196983007 9.06051E+14 34000006
IBD generic diagnosis	Dietary education for inflammatory bowel disease IBD - Inflammatory bowel disease Inflammatory bowel disease Management of IBD (inflammatory bowel disease) Management of inflammatory bowel disease	2338581000000110 2891431000006118 41137017 2269901000000115 2269891000000116	9.09671E+14 24526004 24526004 700104004 700104004
IBD indeterminate diagnosis	Indeterminate colitis	353407019	235746007

Inflammatory bowel disease Hospital Episode Statistics (HES)	**Description**	**ICD-10 code**
ulcerative colitis	Ulcerative colitis Ulcerative (chronic) pancolitis Ulcerative (chronic) proctitis Ulcerative (chronic) rectosigmoiditis Left sided colitis Other ulcerative colitis Ulcerative colitis, unspecified	K51 K51.0 K51.2 K51.3 K51.5 K51.8 K51.9
Crohn's disease	Crohn disease [regional enteritis] Crohn disease of small intestine Crohn disease of large intestine Other Crohn disease Crohn disease, unspecified	K50 K50.0 K50.1 K50.8 K50.9
IBD indeterminate diagnosis	Indeterminate colitis	K52.3

Appendix B Numbers of people in case and baseline populations

Table 9-1 Baseline population and people with new diagnoses of inflammatory bowel disease in the United Kingdom (Incidence analyses)

	Whole population				Females				Males			
Characteristic	**Incident IBD**		**Baseline population**		**Incident IBD**		**Baseline population**		**Incident IBD**		**Baseline population**	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Age (years)												
<15	3,481	3.4	5,552,551	14.5	1,415	2.7	2,708,450	13.9	2,066	4.1	2,844,101	15.1
15-19	5,100	4.9	1,864,518	4.9	2,174	4.1	942,554	4.8	2,926	5.7	921,964	4.9
20-24	7,765	7.5	3,291,709	8.6	3,942	7.5	1,820,178	9.3	3,823	7.5	1,471,531	7.8
25-29	8,455	8.2	3,713,140	9.7	4,515	8.6	2,030,954	10.4	3,940	7.7	1,682,186	8.9
30-34	8,832	8.5	3,488,756	9.1	4,721	9.0	1,778,142	9.1	4,111	8.1	1,710,614	9.1
35-39	9,048	8.7	2,950,522	7.7	4,711	8.9	1,426,354	7.3	4,337	8.5	1,524,168	8.1
40-44	8,711	8.4	2,465,877	6.4	4,520	8.6	1,154,504	5.9	4,191	8.2	1,311,373	7.0
45-49	8,252	8.0	2,207,100	5.8	4,116	7.8	1,036,408	5.3	4,136	8.1	1,170,692	6.2
50-54	8,097	7.8	2,110,989	5.5	4,003	7.6	1,010,722	5.2	4,094	8.0	1,100,267	5.8
55-59	7,759	7.5	1,948,469	5.1	3,799	7.2	942,616	4.8	3,960	7.8	1,005,853	5.3
60-64	7,361	7.1	1,705,127	4.4	3,535	6.7	824,235	4.2	3,826	7.5	880,892	4.7
65-69	6,509	6.3	1,484,066	3.9	3,213	6.1	718,303	3.7	3,296	6.5	765,763	4.1
70-74	5,465	5.3	1,402,900	3.7	2,765	5.3	698,838	3.6	2,700	5.3	704,062	3.7
75-79	4,196	4.0	1,209,618	3.2	2,316	4.4	624,261	3.2	1,880	3.7	585,357	3.1
80&over	4,578	4.4	2,928,248	7.6	2,898	5.5	1,790,853	9.2	1,680	3.3	1,137,395	6.0
Gender												
Male	50,966	49.2	18,816,218	49.1								
Female	52,643	50.8	19,507,372	50.9								
Socioeconomic deprivation quintile (general practice-level)												
1-least deprived	17,540	16.9	6,283,878	16.4	8,848	16.8	3,224,439	16.5	8,692	17.1	3,059,439	16.3
2	18,372	17.7	6,764,882	17.7	9,305	17.7	3,461,152	17.7	9,067	17.8	3,303,730	17.6
3	19,748	19.1	7,158,849	18.7	10,059	19.1	3,663,673	18.8	9,689	19.0	3,495,176	18.6
4	23,833	23.0	9,118,082	23.8	12,082	23.0	4,636,402	23.8	11,751	23.1	4,481,680	23.8
5-most deprived	24,116	23.3	8,997,899	23.5	12,349	23.5	4,521,706	23.2	11,767	23.1	4,476,193	23.8
Country												
England	89,680	86.6	33,687,424	87.9	45,541	86.5	17,156,307	87.9	44,139	86.6	16,531,117	87.9
Scotland	7,557	7.3	2,422,620	6.3	3,887	7.4	1,226,261	6.3	3,670	7.2	1,196,359	6.4
Wales	4,297	4.1	1,663,966	4.3	2,193	4.2	844,264	4.3	2,104	4.1	819,702	4.4
Northern Ireland	2,075	2.0	549,580	1.4	1,022	1.9	280,540	1.4	1,053	2.1	269,040	1.4
Total population	103,609	100.0	38,323,590	100.0	52,643	100.0	19,507,372	100.0	50,966	100.0	18,816,218	100.0

Table 9-2 Total midyear* baseline population and people with diagnosed inflammatory bowel disease** in the United Kingdom (Prevalence analyses)

	Whole population				Females				Males			
Characteristic	**inflammatory bowel disease**		**Midyear population**		**inflammatory bowel disease**		**Midyear population**		**inflammatory bowel disease**		**Midyear population**	
	Number	*%*	Number	*%*	Number	*%*	Number	*%*	Number	*%*	Number	*%*
Age at midyear (years)												
0-9	181	*0.1*	1713807	*10.7*	77	*0.1*	835987	*10.4*	104	*0.2*	877820	*10.9*
10-19	2470	*1.9*	1853712	*11.5*	1041	*1.6*	908023	*11.3*	1429	*2.2*	945689	*11.8*
20-29	11331	*8.6*	2208415	*13.7*	5281	*7.9*	1113497	*13.8*	6050	*9.5*	1094918	*13.6*
30-39	19593	*14.9*	2360920	*14.7*	9844	*14.7*	1163884	*14.5*	9749	*15.2*	1197036	*14.9*
40-49	21474	*16.4*	2125316	*13.2*	11169	*16.6*	1029171	*12.8*	10305	*16.1*	1096145	*13.6*
50-59	25567	*19.5*	2169646	*13.5*	13321	*19.8*	1063799	*13.2*	12246	*19.1*	1105847	*13.7*
60-69	21810	*16.6*	1633317	*10.2*	11063	*16.5*	817484	*10.2*	10747	*16.8*	815833	*10.1*
70-79	18877	*14.4*	1258967	*7.8*	9628	*14.3*	660266	*8.2*	9249	*14.5*	598701	*7.4*
80&over	9771	*7.5*	763894	*4.7*	5697	*8.5*	452849	*5.6*	4074	*6.4*	311045	*3.9*
Gender												
Male	63953	*48.8*	8043034	*50.0*								
Female	67121	*51.2*	8044960	*50.0*								
Socioeconomic deprivation quintile (general practice-level)												
1-least deprived	25401	*19.4*	2785112	*17.3*	13102	*19.5*	1409337	*17.5*	12299	*19.2*	1375775	*17.1*
2	25089	*19.1*	2925918	*18.2*	12859	*19.2*	1468387	*18.3*	12230	*19.1*	1457531	*18.1*
3	25818	*19.7*	3010200	*18.7*	13338	*19.9*	1514386	*18.8*	12480	*19.5*	1495814	*18.6*
4	28499	*21.7*	3717660	*23.1*	14456	*21.5*	1846660	*23.0*	14043	*22.0*	1871000	*23.3*
5-most deprived	26267	*20.0*	3649104	*22.7*	13366	*19.9*	1806190	*22.5*	12901	*20.2*	1842914	*22.9*
Country												
England	108385	*82.7*	13587624	*84.5*	55463	*82.6*	6786898	*84.4*	52922	*82.8*	6800726	*84.6*
Scotland	12433	*9.5*	1284409	*8.0*	6406	*9.5*	647373	*8.0*	6027	*9.4*	637036	*7.9*
Wales	7226	*5.5*	873122	*5.4*	3732	*5.6*	439572	*5.5*	3494	*5.5*	433550	*5.4*
Northern Ireland	3030	*2.3*	342839	*2.1*	1520	*2.3*	171117	*2.1*	1510	*2.4*	171722	*2.1*
Total population	131074	*100.0*	16087994	*100.0*	67121	*100.0*	8044960	*100.0*	63953	*100.0*	8043034	*100.0*

*midyear=In cohort on July 1 2020 **diagnosis in general practice record before or on July 1 2020

Appendix C Population pyramids of age and gender distribution

The following population pyramids compare the CPRD baseline population (2020 mid-year population of 16,087,994) with the Office of National Statistics 2019 mid-year population counts for the UK (66,796,807), England (13,587,624), Scotland (1,284,409), Wales (873,122), and Northern Ireland (342,839). *Note that scales on graphs are different; x-axis label is persons rather than millions.*

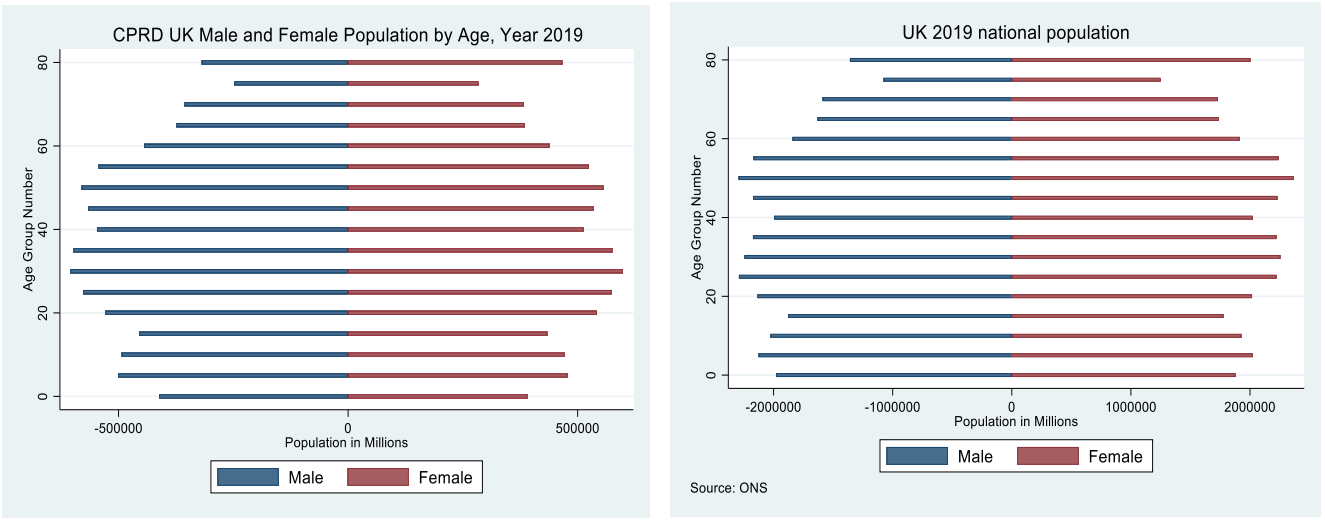

Figure 9-1 Population pyramids: United Kingdom CPRD population (left) and ONS population (right)

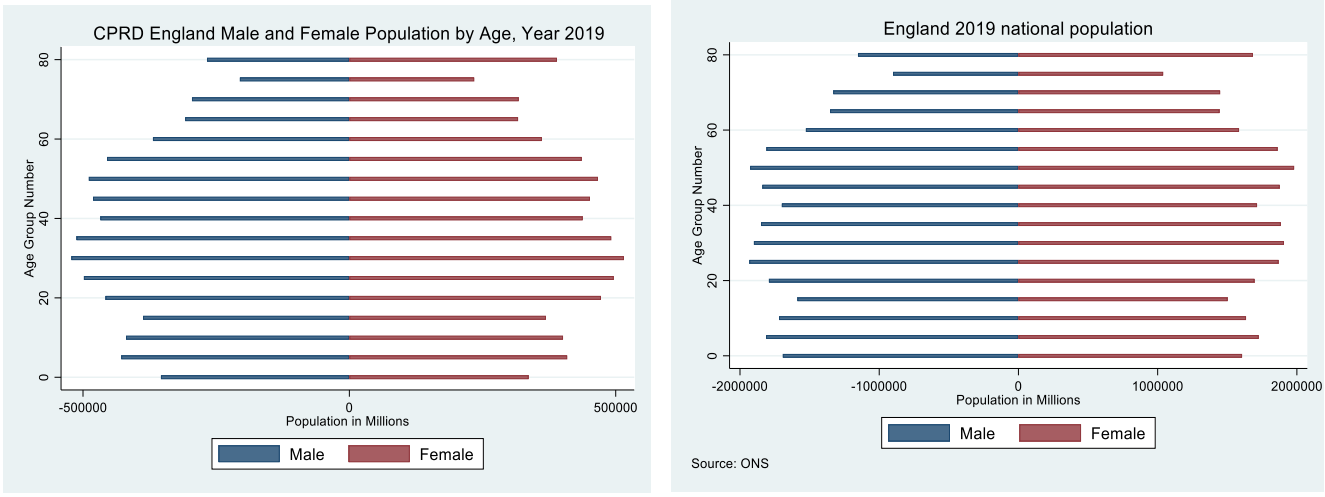

Figure 9-2 Population pyramids: England CPRD population (left) and ONS population (right)

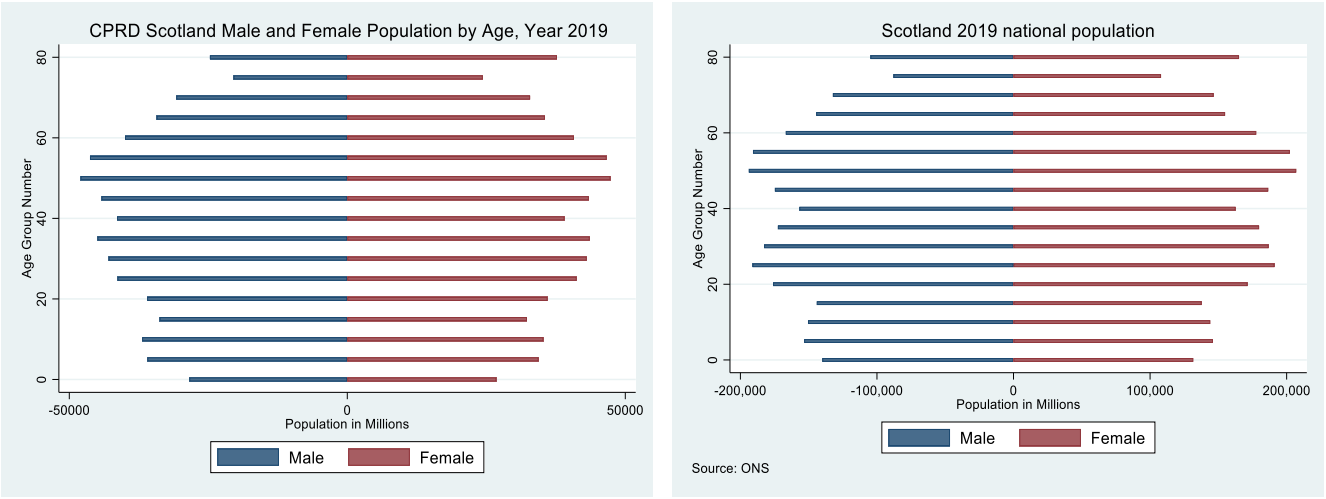

Figure 9-3 Population pyramids: Scotland CPRD population (left) and ONS population (right)

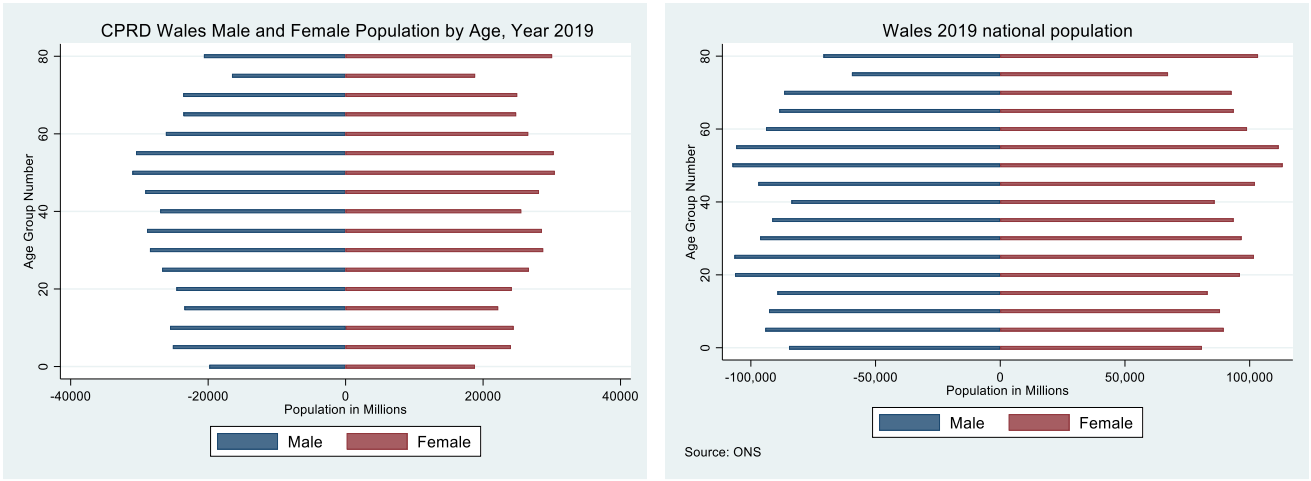

Figure 9-4 Population pyramids: Wales CPRD population (left) and ONS population (right)

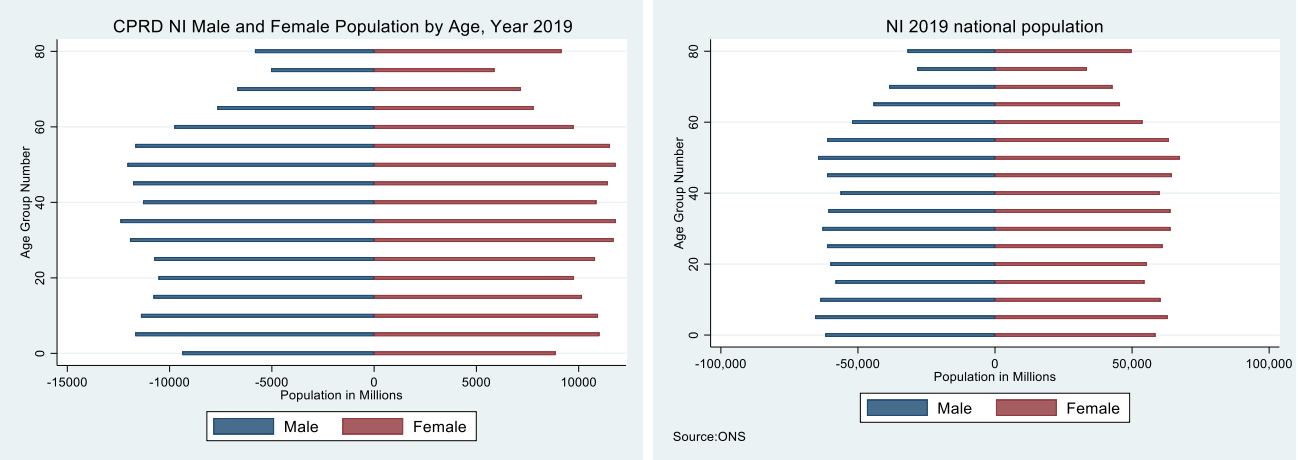

Figure 9-5 Population pyramids: Northern Ireland CPRD population (left) and ONS population (right)