Original research

Incidence and prevalence of inflammatory bowel disease in Devon, UK

Ben Hamilton ^{1,2} Harry Green ^{1,3} Neel Heerasing ¹
 Peter Hendy,¹ Lucy Moore,¹ Neil Chanchlani ^{1,2} Gareth Walker ^{1,2}
 Claire Bewshea ¹ Nicholas A Kennedy ^{1,2} Tariq Ahmad ^{1,2}
 James Goodhand ^{1,2}

► Additional material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/flgastro-2019-101369>).

¹Exeter IBD Pharmacogenetics Research Group, University of Exeter, Exeter, UK

²Department of Gastroenterology, Royal Devon and Exeter Hospital NHS Foundation Trust, Exeter, UK

³Genetics of Complex Traits, University of Exeter, Exeter, UK

Correspondence to

Dr Ben Hamilton, Exeter IBD Research Group, Royal Devon and Exeter NHS Foundation Trust, Exeter EX2 5DW, UK; benjamin.hamilton@nhs.net

BH and HG are joint first authors.

Received 20 November 2019

Revised 28 April 2020

Accepted 14 May 2020

Published Online First

24 June 2020

© Author(s) (or their employer(s)) 2021. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Hamilton B, Green H, Heerasing N, et al. *Frontline Gastroenterology* 2021;**12**:461–470.

ABSTRACT

Background and aims We sought to define temporal changes in prevalence of inflammatory bowel disease (IBD) in East Devon, UK, in order to facilitate service planning over the next 5 years.

Methods Multiple primary and secondary care databases were used to identify and verify cases. Point prevalence and incidence of IBD were reported in April 2017 and from 2008 to 2016, respectively. Future prevalence and healthcare activity requirements were estimated by linear regression.

Results Prevalence of ulcerative colitis (UC), Crohn's disease (CD) and inflammatory bowel disease unclassified (IBDU) were 479.72, 265.94 and 35.34 per 100 000 persons, respectively. In 2016, the incidence rates of UC, CD and IBDU were 15.4, 10.7 and 1.4 per 100 000 persons per year, respectively. There were no significant changes in the incidence of CD ($p=0.49$, $R=0.26$) or UC ($p=0.80$, $R=0.10$). IBD prevalence has increased by 39.9% (95% CI 28.2 to 53.7) in the last 10 years without differences in the rate of change between UC and CD. Overall, 27% of patients were managed in primary care, a quarter of whom were eligible but not receiving endoscopic surveillance. Outpatient clinics, MRI and biologic use, but not helpline calls, admissions, or surgeries increased over and above the change in IBD prevalence.

Conclusions We report one of the highest prevalence and incidence rates of IBD from Northern Europe. Overall, IBD incidence is static, but prevalence is increasing. We estimate that 1% of our population will live with IBD between 2025 and 2030.

BACKGROUND

Globally, the incidence rates of the inflammatory bowel disease (IBD), ulcerative colitis (UC) and Crohn's disease (CD) are

Key messages

What is already known on this topic

- Globally, the incidence rates of the inflammatory bowel disease (IBD), ulcerative colitis (UC) and Crohn's disease (CD) are increasing. In Europe, however, incidence rates seem to be plateauing in the more industrialised north and west, but are still rising in the south and east. Even in regions where incidence is now reportedly static, the prevalence of IBD is increasing due to the compounding effect of low disease-related mortality and increasing life expectancy.
- Data from the UK are insufficient, however, due to methodological limitations.

What this study adds

- We report one of the highest prevalence and incidence rates of IBD from Northern Europe, with a prevalence of UC, CD and IBD unclassified of 479.72, 265.94 and 35.34 per 100 000 persons, respectively.
- We have confirmed that over the past 8 years, the incidence of IBD has remained static, but the overall prevalence is increasing.¹
- Relevant to colorectal cancer surveillance services, 27.4% of patients with IBD were managed exclusively in primary care, 23.3% of whom were eligible for surveillance (comprising 6.8% of all patients with IBD in East Devon).

increasing.^{1–3} The situation in Europe is more nuanced: incidence rates seem to be plateauing in the more industrialised North and West but are still rising in the South and East.^{4,5} Even in regions where incidence is now reportedly static, the prevalence of IBD is increasing due to the compounding

Key messages

How might it impact on clinical practice in the foreseeable future

- ▶ We estimate that our IBD population will grow by 15.7% over the next 5 years and will reach 1% by 2030.
- ▶ Our healthcare activity model projects an increased demand for outpatient clinic visits, MRI scanning and biologic use over and above IBD prevalence, but a relatively proportional usage of helpline calls, admissions or IBD-related surgery.
- ▶ It is imperative that IBD service planning across the UK accounts for these observed trends.

effect of low disease-related mortality and increasing life expectancy.^{6–8} Unlike adults, however, the incidence continues to rise in children throughout Europe.

Datasets from the UK are relatively limited. Between 1990 and 2013, the incidence of UC and CD was reportedly static (8.3–13.9 and 5.6–10.6 new cases per 100 000 persons per year, respectively).^{1 9–11} Studies reporting IBD prevalence between 1990 and 2002 estimated that 166–388 and 91–243 per 100 000 persons lived with UC and CD, respectively.^{9 10 12–16} In 2018, the point prevalence for IBD in Lothian, Scotland, was 432 and 284 cases per 100 000 persons, respectively, with an all-age point prevalence of 1 in 125.⁷ Despite this, numerous historic studies were variably limited by case ascertainment bias because of a reliance on diagnostic coding and incomplete primary care population coverage.^{9 10 12–16}

Despite consensus guidelines recommending all patients have access to secondary care services, approximately a third of patients with IBD are reportedly managed in primary care. Precise data, however, are sparse and limited by inclusion criteria, discrepancies between primary and secondary care record-keeping, and varying systems for documenting specialist follow-up.^{16–19}

Costs associated with IBD care are high, with an estimated cost per patient per year of £3084 for UC and £6156 for CD.²⁰ These are further increased by disease relapses, emergency admissions, biological drug use and surgeries.²¹ Current healthcare use should inform future healthcare planning, where possible.^{19 22}

We designed a novel integrated service evaluation across primary and secondary care to (1) define the point prevalence and recent temporal changes in the incidence of IBD, (2) characterise the phenotype of patients with IBD cared for in primary and secondary care, and (3) report current healthcare use to predict future demands for IBD-related services over 5 years.

METHODS**Study design and clinical setting**

Our data were drawn from the Royal Devon and Exeter Hospital, serving a catchment area population of 410 233 from Mid and East Devon in the southwest of the UK.²³

The Royal Devon and Exeter Foundation NHS Trust serves the Eastern locality of the Northern, Eastern and Western Devon Clinical Commissioning group.²⁴ Our catchment population was defined according to data published by NHS Digital, and all 49 referring GP practices in our catchment were invited to take part (online supplementary appendix 1).²³

We performed an epidemiological study to report the prevalence and incidence of IBD in East Devon, UK. A working group comprising representation from primary and secondary care helped to devise this evaluation. Point prevalence was reported on 30 April 2017 and incidence was reported from 1 January 2008 onwards. Primary care data were collected between April 2016 and April 2017.

Patients diagnosed with IBD were first identified through searches within secondary care databases and primary care records, and then all cases were verified by note review.

Case identification

We searched our hospital database (Dendrite Clinical Systems LTD, Henley-on-Thames, UK) to identify patients diagnosed with IBD at our Trust. Checks were then made of our endoscopy (Unisoft Medical Systems, Enfield, UK) and histology (Swift Integrated Healthcare Solutions DXC Technology Company, Virginia, USA) databases to identify missing patients. Electronic reports of all lower gastrointestinal endoscopy procedures undertaken from 2008 onwards were searched for IBD-related terms (online supplementary appendix 2). Free-text searches of the same IBD-related terms were undertaken in all gastrointestinal histology reports over the same time period. In addition, all records of patients with IBD managed exclusively in private practice were reviewed.

Practice managers searched general practice (GP) databases (EMIS Health, Leeds, UK and/or SystmONE, Leeds, UK) for 10th Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) diagnostic codes corresponding to IBD to generate primary care lists of patients with possible IBD (online supplementary appendix 3). Our research team visited each practice between April 2016 and April 2017 and cross-checked this list with three-point validation of name, date of birth and NHS number, removing patients already known to our secondary care service to prevent double counting of cases. We reviewed electronic and Lloyd-George primary care records of all possible cases and extracted clinically relevant data (online supplementary appendix 4) for confirmed cases using a purpose designed electronic database using REDCAP (Vanderbilt University Medical Centre, Tennessee, USA). Primary care patients were categorised as unknown to our service, previously known to our service and discharged to primary care, or lost to follow-up if not seen in secondary care during the previous 3 years.

Case verification

Case inclusion required a diagnosis of UC, CD or inflammatory bowel disease unclassified (IBDU) by a consultant gastroenterologist. Individuals diagnosed with IBD living within our catchment area but followed up at neighbouring hospitals were included. Where patients were unknown to the RDE, we stipulated confirmatory evidence to support the diagnosis in the form of correspondence from a secondary care specialist, histology, endoscopic or operative findings. Patients diagnosed elsewhere who moved into our catchment area were included in our prevalence, but not incidence analyses.

Patients who were known to the RDE but who lived outside of our catchment area were excluded. Unverified cases of IBD without corroborating correspondence from a specialist, or diagnoses based on radiological or clinical grounds alone, were excluded.

IBD and healthcare outcomes

Demographic data including smoking, approximate socioeconomic status according to English Indices of Deprivation (derived from patient's postcode),²⁵ disease duration, age at diagnosis, IBD phenotype according to the Montreal Classification,²⁶ immunosuppressant, anti-tumour necrosis factor medication exposure and surgical history were collated from clinic letters, our IBD database and GP records, where available (online supplementary appendix 4). We gathered healthcare activity outcome data for all years between 2010 and 2017, including gastroenterology outpatient appointments, endoscopic procedures (for all indications including surveillance), diagnostic imaging tests, emergency admissions, surgical procedures and pharmacy issues for biologic drugs. Data prior to 2010 were excluded on the grounds of inconsistent quality, changes in entry systems and missingness. Mortality data were obtained from our hospital mortuary records and the Devon County Council registry office. Patients' migration into or out of our catchment was determined by changes in postcode.

Statistical methods

Incidence was defined as the number of new cases of IBD diagnosed at the RDE and was expressed per 100 000 persons per year. Point prevalence was defined as the number of living patients with IBD in our catchment area on 30 April 2017 and expressed per 100 000 persons. Mortality and incidence were indirectly age-standardised to the UK background population.²⁷ Linear regression supported by exploratory non-parametric regression analyses were used to characterise temporal changes in the incidence of IBD and to compare rates of change between UC and CD.

Differences in demographic, phenotypical, medical and surgical management between patients diagnosed with UC and CD, as well as between patients managed in primary versus secondary care, were sought using χ^2

tests for categorical data and Kruskal-Wallis tests for continuous non-parametric data. Where missing data were significant (>20%), p values were not calculated. Based on principles of other epidemiological works, we used a one-dimensional recurrence relation to model recent past and 5-year future prevalence of IBD, summarised by the following equation²⁸:

$$P(t+1) = P(t) + (I(t) - D(t)) + (M_i(t) - M_o(t))$$

$P(t)$ is the total prevalence at year t (observed in 2017), $I(t)$ is the incidence at year t estimated from our model of incidence per 100 000 and Office of National Statistics population projections for our catchment area²⁷; $D(t)$ is an estimate of the number of people who will die with IBD, calculated from the death rate multiplied by $P(t)$; and $M_i(t)$ and $M_o(t)$ are the number of people with IBD who will migrate in and out of our area per year, respectively. This equation was iterated backwards to estimate past prevalence per year.

We sought temporal changes in IBD healthcare activity data, adjusted by our estimates of IBD prevalence using linear regression analyses. The dependent variable was IBD healthcare activity outcome per 1000 prevalent IBD cases and the independent variable time in years. We used Pearson's correlation coefficient of $R > 0.5$ to define a change in practice independent of changes in prevalence and report p-trend.

All analyses were undertaken in R V.3.4.3 (2017, The R Foundation for Statistical Computing) and were two tailed, and p values of < 0.05 were considered significant. Corrections were made for multiple testing using the Bonferroni method. Individuals with incomplete clinical data were analysed for variables for which data were available, and the adjusted denominator for each variable is specified.²⁹

RESULTS

Study overview

Overall, 48 of 50 invited GP practices took part in our study representing 98.5% of our total 410 233 catchment population. Case identification and verification are shown in [figure 1](#). In our secondary care search, we confirmed 2797 cases from a possible 4907 patients; we excluded 1267 (25.8%) because they lived outside our catchment area, and 618 (12.6%) because they did not have IBD. In our primary care search, we confirmed a further 407 unique cases from 3657 patients with possible IBD, of whom 2301 (63.1%) were already known to secondary care, and we excluded a further 945 (25.9%) because they did not have, or we could not verify, the diagnosis of IBD.

Point prevalence and changes in incidence of IBD

The point prevalence of IBD in April 2017 was 781.01 per 100 000 persons. The prevalence of UC, CD and IBDU were 479.72, 265.94 and 35.34 per 100 000 persons, respectively. Age, sex and disease phenotype distribution pyramids are shown in [figure 2A,B](#). Our

Figure 1 Flow diagram showing the total number of cases at each stage in the search, excluded cases, subsequent primary and secondary care management breakdown. Patients were considered to be managed in secondary care if they had an outpatient appointment with gastroenterology, IBD nurses or surgeons in the last 3 years, without being expressly discharged from clinic, or had ongoing endoscopy in the last 3 years. GP, general practice; IBD, inflammatory bowel disease; IBS, irritable bowel syndrome; OPA, outpatient appointment; RDE, Royal Devon and Exeter Foundation NHS Trust.

paediatric IBD cases represented 1.02% of our cohort, with a prevalence of 8 per 100 000.

The incidence of IBD in 2016 was 27.7 per 100 000 persons per year. The incidence of UC, CD and IBDU were 15.4, 10.7 and 1.4 per 100 000 persons per year, respectively. Between 2008 and 2016, there was no significant change in the incidence of IBD ($p=0.48$, $R=0.29$), UC ($p=0.80$, $R=0.10$) or CD ($p=0.49$, $R=0.26$) (figure 3). The incidence between 2008 and 2016 when indirectly age-standardised to the UK background population was 328.33 per 100 000 per 9 years (95% CI 327.37 to 329.38) or 36.48 per 100 000 per year (online supplementary appendix 5).²⁷

There were no significant differences in sex, ethnicity or socioeconomic status between patients diagnosed with UC or CD (table 1). Patients diagnosed with CD were younger at diagnosis than patients with UC (figure 4) and were more likely to be current smokers. More patients with CD had been treated with an immunomodulator (50.2% vs 24.6%) or biologic (28.3% vs 8.7%) than patients with UC or IBDU. There were

no significant differences in disease duration between patients with CD and UC at the time of the study.

A total of 878 (27.4%) patients with IBD were managed in primary care at the time of the study (table 2). Of these patients, 536 (61%) were unknown to our service; 105 (12%) had been lost to follow-up; and 237 (27%) had been discharged to primary care. Patients managed in primary care were older (59.3 years (47.5–72.0) vs 52.0 years (37.8–66.1), $p<0.001$), had longer disease duration (21.1 years (18.3–29.3) vs 13.2 years (9.5–18.6), $p<0.001$) and were more likely to have UC than CD (UC 613 (69.8%) vs 1355 (58.3%) and CD 226 (25.7%) vs 865 (37.2%)) compared with patients still attending secondary care. Patients with UC managed exclusively in primary care were more likely to have undergone a proctocolectomy (13.2% vs 1.6%, $p<0.001$). There were no significant differences in sex or socioeconomic status between primary and secondary care patients with IBD. We confirmed 205 (23.3%) patients managed in primary care met the National Institute for Health and Care Excellence

Figure 2 (A) Age/sex pyramid of IBD versus Devon and UK background populations. Units given are percentages of the population group. (B) Age/sex pyramid of IBD by phenotype. Units given are percentages of the IBD cohort as a whole. IBD, inflammatory bowel disease.

(NICE) criteria for colorectal cancer surveillance²²; 38 had CD and 167 had UC/IBDU. In secondary care, 719 (30.9%) patients were confirmed to meet the NICE

criteria for surveillance, of whom 222 had CD and 497 had UC/IBDU.

Figure 3 Incidence per 100 000 of background population against time for UC (green) and Crohn's disease (red). Mean incidence of UC was 17.7 (95% CI 15.8 to 19.6) per 100 000 background population per year, and the mean incidence of Crohn's disease was 10.1 (95% CI 7.2 to 12.9) per 100 000 background population per year. Incident cases were defined as patients who lived within our catchment at the date of diagnosis. IBD, inflammatory bowel disease; UC, ulcerative colitis.

Temporal trends and predicted future IBD prevalence

The crude mortality rate of our IBD population from 2015 to 2016 was 13.1 (95% CI 9.7 to 17.6) deaths per 1000 patients per year, compared with Devon's crude mortality rate of 11.5 deaths per 1000 population per year and the UK background rate of 8.4 per 1000 population per year.³⁰ When age-standardised against the UK background population, there were 51.9 predicted deaths for our population structure vs an observed 43, giving an age-standardised mortality ratio of 0.82 and indirect standardised death rate of 7.0 per 1000 (95% CI 4.9 to 9.1) (online supplementary appendix 6).^{27 30}

The mean migration rate of patients diagnosed in our catchment area who subsequently moved out was 4.3 patients per year (95% CI 3.4 to 5.3), while the mean migration rate of patients who moved into our area with an existing diagnosis of IBD was 20.6 patients per year (95% CI 26.8 to 24.5).

Table 1 Patient demographics by disease subtype

		Ulcerative colitis (n=1968)	Crohn's disease (n=1091)	IBDU (n=145)	P value
Age (median)		56.5 (42.4–69.5)	49.9 (35.9–64.7)	55.1 (40.4–69.2)	<0.001
Sex	Male	983 (49.9%)	505 (46.2%)	67 (46.2%)	0.132
	Female	985 (50.1%)	586 (53.8%)	78 (53.8%)	
Ethnicity	British/white	1832 (93.1%)	1020 (93.4%)	137 (94.5%)	0.603
	Mixed	9 (0.4%)	2 (0.2%)	1 (0.7%)	
	Asian	8 (0.4%)	4 (0.3%)	1 (0.7%)	
	Not recorded	119 (6.1%)	65 (6.0%)	6 (4.1%)	
Smoking history	Never	830 (42.1%)	425 (39.0%)	61 (42.1%)	<0.001
	Current	105 (5.3%)	188 (17.2%)	14 (10.1%)	
	Ex	675 (34.3%)	346 (31.7%)	45 (31.0%)	
	Not recorded	358 (18.2%)	132 (12.1%)	25 (17.2%)	
Socioeconomic decile		6.0 (5.0–7.0)	6.0 (4.0–7.0)	6.0 (4.0–7.0)	0.957
Age at diagnosis		37.8 (27.0–52.5)	31.0 (22.0–46.8)	40.8 (29.0–55.1)	<0.001
Disease duration		12.0 (6.0–22.0)	12.0 (5.0–21.2)	9.0 (5.0–16.0)	0.014
Managed by	Primary care	613 (31.0%)	226 (20.7%)	39 (26.9%)	<0.001
	Secondary care	1355 (68.9%)	865 (79.3%)	106 (73.1%)	

IBDU, inflammatory bowel disease unclassified.

Using the aforementioned incidence, mortality and migration data, we estimate that the prevalence of IBD has increased by 39.9% (95% CI 28.2% to 53.7%) in the last 10 years. No significant differences were seen between the rates of change in the prevalence of UC and CD. Our linear model suggests that there will be a 15.7% (95% CI 10.8% to 22.3%) rise in the prevalence of IBD over the next 5 years (figure 5) and that prevalence will reach 1% of the population by 2030 (95% CI 2025 to 2040).

Healthcare use 2010–2017 and future projection

After adjusting our year-on-year healthcare activity data for the estimated increase in IBD prevalence, significant increases were observed in rates of outpatient clinic appointments (431 per 1000 to 637 per 1000, $p<0.05$), but not IBD helpline calls, or the number of or length of stay of emergency gastroenterology admissions (table 3). There was a threefold increase in the proportion of patients treated with biological therapies (45.8 per 1000 to 141.0 per 1000, $p<0.05$). Rates of computed tomography, ultrasound

and endoscopy tracked the increase in prevalence, whereas the use of barium studies has declined (39.7 per 1000 to 5.1 per 1000, $p<0.05$) and the use of magnetic resonance increased (24.3 per 1000 to 54.8 per 1000 $p<0.05$).

DISCUSSION

Key results

We report one of the highest prevalence and incidence rates of IBD from Northern Europe.^{1 3 7 31} We have confirmed that over the past 8 years, the incidence of IBD has remained static, but the overall prevalence is increasing.^{3 7 8} Patients managed in primary care were older, had longer disease durations and were more likely to have UC than CD compared with those managed in secondary care. Relevant to colorectal cancer surveillance services, 27.4% of patients with IBD were managed exclusively in primary care, 23.3% of whom were eligible for surveillance (comprising 6.8% of all patients with IBD in East Devon). Outpatient clinic visits, MRI scanning and biologic use have increased when adjusted for growth in IBD prevalence,

Figure 4 Age at diagnosis of IBD by disease and sex represented as density plot. Mean age at diagnosis for Crohn's disease was 31 years (95% CI 22.0 to 46.8) and for ulcerative colitis was 37.8 years (95% CI 27.0 to 52.5). IBD, inflammatory bowel disease.

Table 2 Patient demographics and management by care provider

		Primary care (n=878)	Secondary care (n=2326)	P value
Age at point prevalence	(mean)	59.3 (47.5–72.0)	52.0 (37.8–66.1)	<0.001
Sex	Male	425 (48.4%)	1130 (48.6%)	0.935
Ethnicity	British/white	696 (79.3%)	2293 (98.6%)	NA (missing data)
	Mixed	3 (0.3%)	6 (0.3%)	
	Asian	3 (0.3%)	8 (0.4%)	
	Not recorded	176 (20.1%)	19 (0.8%)	
Smoking history	Never	371 (42.3%)	945 (40.6.0%)	NA (missing data)
	Current	59 (6.7%)	248 (10.6%)	
	Ex	231 (26.3%)	835 (35.9%)	
	Not recorded	217 (24.7%)	298 (12.8%)	
Income decile	(median)	6.0 (5.0–7.0)	6.0 (4.0–7.0)	0.422
Disease	UC	613 (69.8%)	1355 (58.3%)	<0.001
	CD	226 (25.7%)	865 (37.2%)	
	IBDU	39 (4.4%)	106 (4.5%)	
Age at diagnosis	(years)	38.0 (35.4–48.2)	38.8 (35.6–51.8)	0.752
Disease duration	(years)	21.1 (18.3–29.3)	13.2 (9.5–18.6)	<0.001
Montreal: age	A1	63 (7.2%)	154 (6.6%)	0.126
	A2	443 (50.4%)	1159 (49.8%)	
	A3	336 (38.2%)	951 (40.9%)	
	Not recorded	36 (4.1%)	62 (2.7%)	
Montreal: location (CD only)	L1	60 (26.5%)	383 (44.3%)	NA (missing data)
	L2	58 (24.8%)	240 (27.7%)	
	L3	18 (7.9%)	232 (26.9%)	
	L4	2 (0.9%)	4 (0.5%)	
	Not recorded	88 (38.9%)	6 (0.6%)	
Montreal: behaviour (CD only)	B1	47 (20.7%)	533 (61.6%)	NA (missing data)
	B2	9 (3.9%)	219 (25.2%)	
	B3	4 (1.7%)	87 (10.0%)	
	Not recorded	166 (73.4%)	26 (3.0%)	
Montreal: extent (UC only)	E1	160 (26.1%)	371 (27.4%)	NA (missing data)
	E2	107 (17.4%)	540 (39.9%)	
	E3	167 (27.2%)	438 (32.3%)	
	Not recorded	218 (35.5%)	6 (0.4%)	
CD treatment	Immunomodulator (ever)	13 (5.7%)	535 (61.9%)	<0.001
	Biological (ever)	2 (0.8%)	307 (35.5%)	
	Bowel resection (any)	82 (36.3%)	299 (34.6%)	
UC/IBDU treatment	Immunomodulator (ever)	45 (7.3%)	475 (35.1%)	<0.001
	Biological (ever)	8 (1.2%)	176 (12.9%)	
	Subtotal colectomy	55 (8.4%)	103 (7.0%)	
	Proctocolectomy	86 (13.2%)	23 (1.6%)	
Eligible for surveillance (meet NICE criteria)	CD	38 (16.8% of CD)	222 (25.7% of CD)	<0.001
	UC/IBDU	167 (25.6% of UC/IBDU)	497 (34.1% of UC/IBDU)	
	Total eligible	205 (23.3% of primary care IBD)	719 (30.9% of secondary care IBD)	

Patients were considered as managed in secondary care if they had attended a consultant or nurse specialist IBD clinic or surgical outpatient appointment in the last 3 years, with ongoing follow-up planned and not expressly discharged by their clinician. Eligibility for surveillance based on NICE criteria is (1) disease duration greater than 10 years and (2) disease involving more than 50% or two segments of the colon. Patients with unknown Montreal L or E phenotype, or had undergone a total colectomy were not included.
 _CD, Crohn's disease; IBDU, inflammatory bowel disease unclassified; N/A, not applicable; NICE, National Institute for Health and Care Excellence; UC, ulcerative colitis.

but helpline calls, admissions or IBD-related surgeries have not. We estimate that our IBD population will grow by 15.7% over the next 5 years, and will reach 1% by 2030.

Interpretation

The increasing prevalence observed in this study reflects the compounding effect of increasing population longevity, low disease-related mortality and

population growth from net-inward migration in the face of a high local incidence. These factors have yet to reach a steady state. Our predictive model was developed to take advantage of our availability of more granular detail than simple ORs. The higher reported incidence rates in our study compared with earlier UK reports may be influenced by the introduction of stool calprotectin testing and open-access colonoscopy,

Figure 5 Prevalence of IBD 2008–2025, using linear regression model of historic and predicted future prevalence of all IBD, ulcerative colitis and Crohn's disease. Shaded ribbon intervals represent 95% CIs taking into account incident rate, migration into area, migration out of area and death rate, respectively. IBD, inflammatory bowel disease.

as well as our systematic capture of IBD cases across primary and secondary care.^{32 33}

Our model excluded incident data prior to 2010, required confirmatory evidence for a diagnosis of IBD and excluded patients with missing data or ambiguous

home address within our catchment area; as a consequence, our model may have underestimated the future prevalence of IBD.

Similar to recent studies, we report an ageing IBD population.⁷ Thirty per cent of our IBD population was over 65 years of age, and 15% was over 75 years. Management of elderly patients with IBD is often challenging and costly due to the increased risks and complications associated with the disease and its medical and surgical treatment.³⁴

Our study highlighted a group of 205 patients managed exclusively in primary care who had not been offered surveillance despite being eligible. We estimate that if each of these patients requires a colonoscopy on average every 3 years (high risk yearly, low risk 5 yearly), the service would need to deliver an additional 17 surveillance lists per annum (68 colonoscopies) at the lowest estimate. The true figure may be significantly higher, given the number of patients in primary care whose disease location/extent was not recorded.

Table 3 IBD-associated healthcare activity per 1000 patients from 2010 to 2017 and predicted to 2022

	2010	2011	2012	2013	2014	2015	2016	2017	P value and R value
Prevalence	2500	2606	2698	2792	2892	3013	3124	3204	
Outpatient clinic appointments	396	413.7	500.7	491.1	537.34	592.43	636.01	624.18	p=5.2e-5 R=0.97
Inflammatory bowel disease helpline calls*					1206.1	1400.9	1445.4	1462.7	p=0.07 R=0.85
Emergency hospital admissions under gastroenterological care	29.2	31.08	34.84	31.88	39.42	37.84	39.41	31.87	p=0.18 R=0.53
Mean length of stay (days)	7	-	-	-	9	-	-	6	N/A
Patients on biological therapy	45.8	56.6	93.5	114	102.9	122.7	141	148.3	p=1.3e-4 R=0.96
Infliximab	33.2	36.9	61.3	71.8	59.5	72.0	68.7	-	
Adalimumab	12.6	19.8	32.1	42.2	43.5	31.4	34.4	-	
Vedolizumab	-	-	-	-	-	12.7	25.7	-	
Golimumab	-	-	-	-	-	4.0	8.7	-	
Ustekinumab	-	-	-	-	-	-	2.9	-	
Endoscopies (all lower gastrointestinal)	196.5	253.3	284.9	265.8	267.7	303.9	273.7	236.1	p=0.34 R=0.39
Capsule endoscopies	-	-	-	-	16.3	19.0	18.6	17.1	N/A
Surgical resections	19.9	26.4	19.4	23.8	18.1	20.0	19.0	16.8	p=0.13 R=-0.58
Radiological imaging									
CT	84.3	76.8	90.8	100.6	100.8	91.7	90.3	81.6	p=0.68 R=0.18
MR	24.3	50.8	36.6	46.9	53.9	61.7	54.3	54.8	p=0.03 R=0.76
US	67.3	76	78.1	78.6	71.3	87.1	66.5	62.6	p=0.6 R=-0.22
Barium	39.7	23.3	22.1	11.9	7.0	5.3	5.1	0.9	p=9.0e-4 R=0.86

Clinics, admissions, endoscopies and imaging are reported as annual number of episodes per 1000 patients with IBD. Biologics are reported as annual number of patients issued biological therapy per 1000 patients with IBD. P refers to the p value of the gradient in a linear regression model.

*Helpline calls are shown as total calls received within the year.

CT, computed tomography; MRI, magnetic resonance; US, ultrasound.

The growth in outpatient clinic activity and MRI scanning adjusted for prevalence probably reflects the drive for closer monitoring of disease activity and the increasing number and complexity of treatment options now available for patients with IBD. Rates of biologic use have also increased adjusted for prevalence.

Strengths, limitations and generalisability

Our study has several strengths: first, and unlike previous studies from the UK with low levels of population coverage, we had participation from the majority of primary care practices, representing 98.5% coverage of our catchment population. Second, all cases were rigorously verified with 26.6% and 88.9% of potential cases excluded from our secondary and primary care searches, respectively. Third, unlike other studies in primary care that relied on questionnaires or self-reported measures to identify primary care cases of IBD,^{9 12 13 16} we used a dedicated research team who visited each GP practice to ensure consistent data collection. Additionally, our phenotype and demographic data were far more detailed than other large-scale population studies based on using national registries.^{4 11 35}

We acknowledge, however, some important limitations. First, by insisting on confirmatory evidence to verify a case of IBD, we may have underestimated the true prevalence of IBD. Second, we found that in primary care, phenotype data were poorly recorded, so we have a high proportion of missing data, in particular, relating to the Montreal classification of disease phenotype in patients not known to the RDE. Consequently, we are likely to have also underestimated the proportion of patients eligible for colorectal cancer surveillance. Third, because of variable data quality, changes in entry systems, legacy coding practices and organisational changes, our outcomes are reported over a relatively short time period. Finally, our prediction model assumes that the IBD service will develop according to recent trends, and we accept that our model's assumptions may be invalidated by changes in major healthcare policies or the introduction of new therapies. This is unavoidable, as a dynamic model of this detail would be unfeasibly complex to construct.³⁶

Although the Royal Devon and Exeter is a referral centre for IBD and intestinal failure, in this study, we excluded 1267 patients who live outside our catchment area, so the secondary care patients we report herein are likely to be representative of those attending non-tertiary centres in the UK. It is likely therefore, that a similar pattern of static incidence, compounding prevalence and increasing healthcare requirements reported herein is occurring across the UK; however, we accept that rates of inward migration, particularly at retirement, may be higher in East Devon. Whether other UK regions have a similar proportion of patients managed exclusively in primary care has not been studied.

CONCLUSIONS

We report one of the highest prevalence and incidence rates of IBD from Northern Europe. Overall, IBD incidence is static, but prevalence is increasing. We estimate that 1% of our population will live with IBD between 2025 and 2030. Compounding IBD prevalence needs to be accounted for when future-proofing IBD services.

Correction notice This article has been corrected since it published Online First. The order of author has been corrected, affiliations for all authors updated and ORCID ID's added.

Twitter Nicholas A Kennedy @DrNickKennedy

Acknowledgements We thank all primary care practices which helped us to collect the clinical information necessary for this study, as well as the South West Academic Health Sciences Network. Thanks to Hanlie Olivier, Marian Parkinson and Helen Gardner-Thorpe for their ongoing administrative support.

Contributors NH, PH, GW and TA participated in the conception, design and coordination of the study. NH, PH, LM and GW collected primary care data, and BH, NH and NAK collected secondary care data. NH and PH performed the case verification. Data analysis was performed by BH and HG. The manuscript was written by BH, HG, NH, NC, CB, TA and JG. All authors assisted in the review and approval of the final manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval This study was classified as a service evaluation, in accordance with the guidelines of the UK Health Research Authority; formal ethical approval and individual patient consent were not mandated.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data contain patient identifiable information and under GDPR must be stored deidentified where possible on secure NHS servers, and is not publicly available. Limited datasets may be shared to other NHS users when clinical justification is warranted.

ORCID iDs

Ben Hamilton <http://orcid.org/0000-0002-0349-278X>
 Harry Green <http://orcid.org/0000-0002-5105-184X>
 Neil Heerasing <http://orcid.org/0000-0003-0579-2062>
 Neil Chanchlani <http://orcid.org/0000-0003-0207-6706>
 Gareth Walker <http://orcid.org/0000-0002-3883-8816>
 Claire Bewshea <http://orcid.org/0000-0002-0965-9587>
 Nicholas A Kennedy <http://orcid.org/0000-0003-4368-1961>
 Tariq Ahmad <http://orcid.org/0000-0002-6058-5528>
 James Goodhand <http://orcid.org/0000-0003-3112-376X>

REFERENCES

- 1 Molodecky NA, Soon IS, Rabi DM, *et al.* Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology* 2012;142:46–54.
- 2 Kaplan GG. The global burden of IBD: from 2015 to 2025. *Nat Rev Gastroenterol Hepatol* 2015;12:720–7.
- 3 Ng SC, Shi HY, Hamidi N, *et al.* Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. *Lancet* 2018;390:2769–78.
- 4 Burisch J, Pedersen N, Čuković-Čavka S, *et al.* East-West gradient in the incidence of inflammatory bowel disease

- in Europe: the ECCO-EpiCom inception cohort. *Gut* 2014;63:588–97.
- 5 Roberts SE, Thorne K, Thapar N, *et al.* A systematic review and meta analysis of paediatric inflammatory bowel disease incidence and prevalence across Europe. *J Crohns Colitis* 2020. doi:10.1093/ecco-jcc/jjaa037
 - 6 Nocerino A, Feathers A, Ivanina E, *et al.* Mortality risk of inflammatory bowel disease: a Case–Control study of new York state death records. *Dig Dis Sci* 2019;1–8.
 - 7 Jones G-R, Lyons M, Plevris N, *et al.* Ibd prevalence in Lothian, Scotland, derived by capture-recapture methodology. *Gut* 2019;68:gutjnl-2019-318936.
 - 8 Genin M, Fumery M, Occelli F, *et al.* Fine-Scale geographical distribution and ecological risk factors for Crohn's disease in France (2007-2014). *Aliment Pharmacol Ther* 2020;51:139–48.
 - 9 García Rodríguez LA, González-Pérez A, Johansson S, *et al.* Risk factors for inflammatory bowel disease in the general population. *Aliment Pharmacol Ther* 2005;22:309–15.
 - 10 Gunesh S, Thomas GAO, Williams GT, *et al.* The incidence of Crohn's disease in Cardiff over the last 75 years: an update for 1996-2005. *Aliment Pharmacol Ther* 2008;27:211–9.
 - 11 Vegh Z, Burisch J, Pedersen N, *et al.* Incidence and initial disease course of inflammatory bowel diseases in 2011 in Europe and Australia: results of the 2011 ECCO-EpiCom inception cohort. *J Crohns Colitis* 2014;8:1506–15.
 - 12 Yapp TR, Stenson R, Thomas GA, *et al.* Crohn's disease incidence in Cardiff from 1930: an update for 1991-1995. *Eur J Gastroenterol Hepatol* 2000;12:907–11.
 - 13 Stone MA, Mayberry JF, Baker R. Prevalence and management of inflammatory bowel disease: a cross-sectional study from central England. *Eur J Gastroenterol Hepatol* 2003;15:1275–80.
 - 14 Probert CS, Jayanthi V, Hughes AO, *et al.* Prevalence and family risk of ulcerative colitis and Crohn's disease: an epidemiological study among Europeans and South Asians in Leicestershire. *Gut* 1993;34:1547–51.
 - 15 Lewis JD, Brensinger C, Bilker WB, *et al.* Validity and completeness of the general practice research database for studies of inflammatory bowel disease. *Pharmacoepidemiol Drug Saf* 2002;11:211–8.
 - 16 Rubin GP, Hungin AP, Kelly PJ, *et al.* Inflammatory bowel disease: epidemiology and management in an English general practice population. *Aliment Pharmacol Ther* 2000;14:1553–9.
 - 17 Bennett AL, Munkholm P, Andrews JM. Tools for primary care management of inflammatory bowel disease: do they exist? *World J Gastroenterol* 2015;21:4457–65.
 - 18 Tan M, Holloway RH, Lange K, *et al.* General practitioners' knowledge of and attitudes to inflammatory bowel disease. *Intern Med J* 2012;42:801–7.
 - 19 Lamb CA, Kennedy NA, Raine T, *et al.* British Society of gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. *Gut* 2019;68:s1–106.
 - 20 Ghosh N, Premchand P. A UK cost of care model for inflammatory bowel disease. *Frontline Gastroenterol* 2015;6:169–74.
 - 21 Pillai N, Dusheiko M, Maillard MH, *et al.* The evolution of health care utilisation and costs for inflammatory bowel disease over ten years. *J Crohns Colitis* 2019;13:744–54.
 - 22 National Institute for Health and Care Excellence. *NICE Quality Standard 81 - Inflammatory bowel disease*, 2015.
 - 23 NHS Digital. Numbers of Patients Registered at a GP Practice - July 2016 - NHS Digital, 2016. Available: <http://digital.nhs.uk/catalogue/PUB21150> [Accessed 19th Feb 2018].
 - 24 Eastern Devon – Northern, Eastern and Western Devon Clinical Commissioning Group. Available: <https://www.newdevonccg.nhs.uk/your-ccg/eastern-devon-100113> [Accessed 18th Dec 2018].
 - 25 Office for National Statistics. English indices of deprivation 2015 - GOV.UK. Available: <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015> [Accessed 9th Jan 2019].
 - 26 Silverberg MS, Satsangi J, Ahmad T, *et al.* Toward an integrated clinical, molecular and serological classification of inflammatory bowel disease: report of a working Party of the 2005 Montreal world Congress of gastroenterology. *Can J Gastroenterol* 2005;19:5A–36.
 - 27 Office for National Statistics. Population projections for local authorities: Table 2 - Office for National Statistics, 2016. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/localauthoritiesinenglandtable2> [Accessed 29th Jan 2019].
 - 28 Brinks R. Illness-Death model in chronic disease epidemiology: characteristics of a related, differential equation and an inverse problem. *Comput Math Methods Med* 2018;2018:1–6.
 - 29 NHS Health Research Authority. *Service evaluation CLINICAL/ NON-FINANCIAL audit usual practice (in public health including health protection)*, 2017.
 - 30 Office for National Statistics. Deaths registered in England and Wales 2017. Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2017> [Accessed 18th Dec 2018].
 - 31 Burisch J, Munkholm P. The epidemiology of inflammatory bowel disease. *Scand J Gastroenterol* 2015;50:942–51.
 - 32 An Y-K, Prince D, Gardiner F, *et al.* Faecal calprotectin testing for identifying patients with organic gastrointestinal disease: systematic review and meta-analysis. *Med J Aust* 2019;211:461–7.
 - 33 Cantoro L, Di Sabatino A, Papi C, *et al.* The time course of diagnostic delay in inflammatory bowel disease over the last sixty years: an Italian multicentre study. *J Crohns Colitis* 2017;11:975–80.
 - 34 Taleban S, Colombel J-F, Mohler MJ, *et al.* Inflammatory bowel disease and the elderly: a review. *J Crohn's Colitis* 2015;9:507–15.
 - 35 Genin M. *Fine - scale geographical distribution and ecological risk factors for Crohn ' S disease in France (2007 - 2014, 2019: 1–10.*
 - 36 Kruijshaar ME, Barendregt JJ, Hoeymans N. The use of models in the estimation of disease epidemiology. *Bull World Health Organ* 2002;80:622–8.