Epidemiology Summary: Incidence and Prevalence of IBD in the United Kingdom

Key Takeaways

The epidemiology report on Inflammatory Bowel Disease (IBD) is part of a wider piece of research conducted by the University of Nottingham titled 'Contemporary epidemiology of coeliac disease, dermatitis herpetiformis, Crohn's disease and ulcerative colitis in the UK'. Jointly funded by Coeliac UK and Crohn's & Colitis UK, this report summarises the incidence of IBD diagnosis across the United Kingdom between 2000 and 2020, and the prevalence of IBD diagnosis in the year 2020. From the examination of anonymised health records from over 38.3 million people registered with general practices, this summary provides an overview of who is diagnosed with IBD in the UK. Due to the large sample size, this research accurately explores more granularly how the incidence and prevalence of Crohn's Disease, Ulcerative Colitis, and Unclassified IBD varies by age, gender, ethnicity, location and socioeconomic deprivation.

Methodology

The study population included all individuals who were actively registered with general practices at any time between January 2000 and July 2020, and who contributed anonymised data to the Clinical Practice Research Datalink (CPRD). Prevalence was calculated on July 1st, 2020. In total, anonymised health records from more than 38.3 million people were analysed. 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. 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. The CPRD population sample showed good representativeness of the whole UK population from Office of National Statistics (ONS) information and with the further inclusion of Hospital Episode Statistics (HES) records for England, the study was able to report on incidence and prevalence by a range of demographic factors including age, gender, ethnicity, location and socioeconomic deprivation.

Incidence: diagnosis of IBD between 2000 and 2020

The measure of incidence provides information on the number of people who have been newly diagnosed with IBD between 2000 and 2020. Incident cases of IBD were defined by the earliest date on which an individual had a clinical diagnosis or had been prescribed a medicine used to treat inflammation of the gut (aminosalicylates) after 12 months of active registration time.

Between 2000 and 2020, over 103,000 people received a new diagnosis of IBD during more than 286 million person-years of active general practice registration in the population. This represented a population incidence rate of 36 new cases per 100,000 person-years (i.e., one new case of IBD identified among every 2,767 people if they were each followed for one year). Crohn's & Colitis UK have used this data to calculate that this equates to approximately 25,000 people having been diagnosed with IBD in the UK during 2020, this translates to 66 people being diagnosed with IBD

every day in the UK. While incidence rates have remained stable for the last 15 years, due to population growth it is likely the number of people diagnosed with IBD in the UK per day will increase further.

The study also highlights the different incidence rates by devolved nations. After adjusting for differences in population sociodemographics, incidence was higher in Scotland and Northern Ireland compared with England and Wales. Within England, adjusted incidence in the North East and the East of England was higher than all other regions. Age and gender was also studied to provide insight into the rate of diagnosis by age and how diagnosis differs between men and women.

Additionally, information on patients with HES-linked records (who accounted for 85% of the study population living in England) provided further insight into the proportion of people with different sociodemographics being diagnosed with IBD and the different forms of the condition. For example, incidence was higher in people with recorded White ethnicity compared with all other ethnic groups.

Prevalence: living with a diagnosis of IBD in 2020

The measure of prevalence provides information on the number of people who are living with an IBD diagnosis at a certain point in time. Prevalent cases were defined by having a clinical diagnosis on or before July 1st, 2020.

From a 2020 baseline population of 16.1 million individuals, over 131,000 people were identified with IBD which represented a prevalence of 0.8%. This equates to one in every 123 people having a diagnosis of IBD. Crohn's & Colitis UK have calculated that this equates to over 500,000 people in the UK currently living with this condition. Ulcerative colitis continues to have a higher prevalence (0.4%) compared with Crohn's disease (0.3%) and unclassified IBD (0.07%) in the UK population.

When looking at the overall prevalence of IBD broken down by devolved nation and accounting for the differences in age structure across nations, prevalence was highest in Scotland and Northern Ireland, and lower in England and Wales. Regional variation in England showed the lowest prevalence in London after accounting for differences in age structure across regions.

Looking more granularly, the study reveals that:

- prevalence only marginally differed between genders and rose to over 1% among those over 70 years of age
- prevalence was higher in people with recorded White ethnicity compared with all other ethnicity groups for people living in England
- prevalence was higher in rural compared with urban areas of England
- prevalence decreased with increasing socioeconomic deprivation within all devolved nations except for Wales

Faecal calprotectin testing (FCT): Prior to IBD diagnosis

This study examined the records of people with an IBD diagnosis to assess the use of faecal calprotectin testing (FCT) prior to diagnosis. Among people with incident IBD diagnosed between 2009 and 2019, under 3% had recorded FCT in their general practice (GP) record within the year before diagnosis. There was a notable increase in FCT prior to diagnosis from 2014 onwards, although the figure remained low, with only 4% of people in the UK having FCT recorded in GP

records prior to diagnosis in 2019. Scotland had the highest prevalence of FCT tests in GP records within the year prior to diagnosis (9% in 2019) compared to all other nations in the UK.

Diagnosis of irritable bowel syndrome prior to IBD

Among people with incident IBD, 13% had diagnostic codes for irritable bowel syndrome, 24% had been prescribed antispasmodic drugs and 29% 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.