

DEMOS

**THE ECONOMIC
COST OF
INFLAMMATORY
BOWEL DISEASE
IN THE UK**

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NOVEMBER 2021

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An estimated 500,000 people in the UK are affected by Inflammatory Bowel Disease (IBD) and face unwarranted variation in the care they receive. *500,000 Reasons Why* is a campaign initiated and funded by Takeda to champion the needs of these half a million individuals, calling for a single ask to improve standards of care.

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EXECUTIVE SUMMARY

CAREER

Results from an unweighted sample of 500 people living with inflammatory bowel disease (IBD) in the UK show that having the condition is associated with individuals making career-limiting choices:

- 57% stated that they have, at some point, either reduced their hours or gone part-time because of their IBD
- 46% said that they had left a job because of their IBD
- 51% said they had applied for lower-paid work because of their IBD

There is also some evidence of discriminatory behaviour against people with IBD in the workplace: 49% of our sample agreed with the statement "I believe I was made redundant because of my IBD".

Overall, around two thirds (68%) thought that having IBD had negatively affected their career.

PRODUCTIVITY

We asked the 466 people in our sample who were in work about the effect of the condition on their productivity and time away due to ill health over the six months preceding the survey.

- 72% of our sample felt that their IBD had prevented them from working either "a fair amount" or "a great deal" over the previous six months.
- 94% had missed some time from work as a result of their IBD; the average was nine days missed over the previous six months.

EDUCATION

We asked the entire group about the effect of IBD on their education, regardless of how old they had been when they were diagnosed.

- 63% of respondents felt that the effect on their education was "somewhat" or "significantly" negative, with individuals typically missing 9-10 days per year of school, college or university.

- Although the effect was greater among people who had been diagnosed in childhood, a majority (61%) of those who were diagnosed in adulthood also felt that there had been a negative effect on their education, suggesting that there is a significant amount of underdiagnosis in younger people.

INCOME

Using a matched-pair methodology, we could find no statistically significant difference between the incomes of people with IBD and people without. However, people who reported that living with IBD had negatively affected their career had higher average incomes than people who said it had not, suggesting that there may be a greater effect in more senior roles.

ECONOMY-WIDE EFFECTS

Using the data from our sample we found the average cost to employers of a team member having time away from work due to IBD is in the region of £2,000 per person per year. Extrapolating this figure to the whole of the UK gives a ballpark estimate, subject to a number of assumptions, of annual costs to employers due to IBD of around £600m.

Separately, IBD exerts a real cost to the taxpayer in terms of higher benefit payments. A quarter of people in our IBD sample were in receipt of means-tested benefits, nearly three times as many as in our matched control group. Similarly, the proportion of people in receipt of disability-related state benefits was five times higher in the disease group than in the control group.

RECOMMENDATION

Taken together, we therefore recommend that the government undertakes its own estimates of the annual individual, macroeconomic and fiscal impact of people with disabilities being unable to participate in the labour market to the same extent as their peers.

INTRODUCTION

The aim of this research is to explore the economic effects that arise from the condition of IBD. This is done in a number of different ways: by asking individual people living with IBD about the effect it has had on their working lives; by estimating the financial losses to employers from staff taking time off from work due to IBD; by conducting a matched-pair analysis with a carefully selected control group to explore connections between income and having IBD; and, separately, between take-up of state benefits and having IBD.

Our approach is to use market research to obtain information from a sample of 500 adults living with IBD (the 'disease group') and, where applicable, compare this against information obtained from a carefully selected matched group of adults without IBD (the 'control group').

In this introduction, we set the scene by first describing the characteristics of IBD in general, and then the particular characteristics of our disease group sample.

THE GENERAL CHARACTERISTICS OF INFLAMMATORY BOWEL DISEASE

IBD describes two main conditions: ulcerative colitis and Crohn's disease, although it is also possible to obtain a diagnosis of unspecified IBD. It is a long-term condition characterised by the inflammation of the gut. The main difference between ulcerative colitis and Crohn's disease is the part of the body affected: ulcerative colitis only affects the large

intestine (colon), while Crohn's disease can affect any part of the digestive system, from the mouth to the anus.¹

The main symptoms of both conditions are pain, cramps or swelling in the abdomen, recurring or bloody diarrhoea, mouth ulcers, loss of appetite and/or weight loss which could lead to anaemia, and feeling generally unwell including extreme tiredness and, in some cases, a high temperature.^{2,3}

IBD is also characterised by uncertainty and unpredictability. Symptoms tend to come and go, having relapse phases when they flare up and other phases when the disease is in remission.⁴ However, even when in remission many people report continuing IBD-related fatigue (41%), abdominal pain (62%) and difficulty with continence (up to 75%).⁵

According to the National Institute for Health and Care Excellence (NICE), around half of those with ulcerative colitis will have at least one flare-up per year; about 80% of these are mild to moderate and about 20% are characterised as severe. Over someone's lifetime, around a quarter (25%) of people with ulcerative colitis will have one or more episodes of acute severe colitis.⁶

COMORBIDITIES

Having IBD is linked to other debilitating conditions. There is evidence linking it over time to arthritis, eye inflammation, liver inflammation (primary sclerosing cholangitis), skin problems (erythema nodosum or pyoderma gangrenosum), strictures, fistulas and colorectal cancer.^{7,8,9}

1 NHS. Inflammatory bowel disease. 2020. Available at www.nhs.uk/conditions/inflammatory-bowel-disease [accessed 05/07/2021]

2 NHS. Inflammatory bowel disease. 2020. Available at www.nhs.uk/conditions/inflammatory-bowel-disease [accessed 05/07/2021]

3 Crohn's & Colitis UK. What are the symptoms? 2017. Available at www.crohnsandcolitis.org.uk/about-crohns-and-colitis/what-are-the-symptoms [accessed 05/07/2021]

4 Qualter, P. and others. Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition. *Quality of Life Research*. Vol. 30, pp. 497–506, 2021. Available at doi.org/10.1007/s11136-020-02653-9 [accessed 05/07/2021]

5 National Institute for Health Research. Funding and awards. (no date). Available at <https://fundingawards.nihr.ac.uk/award/RP-PG-0216-20001> [accessed 05/07/2021]

6 National Institute for Health and Care Excellence. Quality standards and indicators briefing paper: inflammatory bowel disease. 2014. Available at www.nice.org.uk/guidance/qs81/documents/inflammatory-bowel-disease-briefing-paper2 [accessed 05/07/2021]

7 Crohn's & Colitis UK. Ulcerative colitis: your guide. September 2019. Available at <http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Publications/ulcerative-colitis.pdf> [accessed 05/07/2021]

8 Crohn's & Colitis UK. What are the symptoms? 2017.

9 UK IBD Genetics Consortium. What is Inflammatory Bowel Disease (IBD)? (no date). Available at www.ibdresearch.co.uk/what-is-inflammatory-bowel-disease-ibd/what-is-ibd [accessed 05/07/2021]

Indeed, according to NICE, five years after onset, 15% to 20% of people with Crohn's disease are disabled by their disease to some degree. Children with IBD can experience delayed puberty and a growth impairment that can result in a reduced final adult height.¹⁰

There are also psychological effects: patients report how the symptoms of the disease can be embarrassing and socially limiting, which makes telling others about their condition difficult. The course of the disease is unpredictable, and the treatment and management regimes can be frustrating.¹¹ The pain itself has a significant impact on mental health both directly, and indirectly; for example parents report that pain, incontinence and fatigue impact their capacity to spend quality time with their children, undertake the school run or attend school events.¹² Overall, people with Crohn's or colitis are two to three times more likely to use an antidepressant medicine than people without the conditions.¹³

The underlying causes of the disease are unclear but the NHS references genetics, other problems relating to the immune system and, in the case of Crohn's disease, smoking.¹⁴ Neither is there a cure: treatment aims to relieve symptoms but it is unclear if they alter the natural course of the disease, with effective management seen as the key to resuming a 'normal' life.¹⁵

TREATMENTS

Changing diet and lifestyle can help manage IBD.¹⁶ Cases may be treated with aminosalicylates and immunosuppressants (including steroids), with some evidence that aggressive therapy at an early

stage can have significantly positive effects for prognosis.^{17, 18} For the one in three (30%) of patients who fail to respond or are intolerant to these drugs, biological therapies may be considered.¹⁹

For those whose symptoms do not improve with medication, or to prevent future relapses, surgery is a common option.²⁰ The NHS estimates that around three in ten (29%) of people with ulcerative colitis require a colectomy to remove all or part of the colon and rectum.^{21, 22} The NHS also estimates that 60-75% of people with Crohn's disease will need surgery to remove or repair damage to their digestive system; this typically requires either a temporary or permanent stoma.^{23, 24}

PREVALENCE

There are a number of different estimates of the prevalence of IBD in the general population which we summarise in Appendix 1. There is also evidence that incidence is increasing.²⁵ The most recent (2021) estimate used by the patient group Crohn's & Colitis UK is over 500,000 people in the UK with IBD, based on three recent regional studies in Scotland, Wales and Devon.²⁶

People can develop IBD at any age, but it tends to be diagnosed between the ages of 15 and 40 and is most likely to present in people during their teens and twenties.^{27, 28} Up to a third of patients with Crohn's disease are diagnosed before the age of 21 and the peak incidence of ulcerative colitis diagnosis is between the ages of 15 and 25 years.²⁹

Globally, incidence is rising with cases more common in urban than rural areas, and in northern, developed countries in Northern Europe and North America,

10 National Institute for Health and Care Excellence. Quality standards and indicators briefing paper: inflammatory bowel disease. 2014.

11 Qualter and others. Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK. 2021.

12 Mukherjee, S., and Sloper, P. Understanding the impact of inflammatory bowel disease on parents and their children. Social Policy Research Unit, University of York, March 2001. Available at www.york.ac.uk/inst/spru/pubs/pdf/boweldisease.pdf [accessed 05/07/2021]

13 Crohn's & Colitis UK. Depression and IBD. 2018. Available at <https://www.crohnsandcolitis.org.uk/research/research-projects/projects/depression-and-ibd> [accessed 05/07/2021]

14 NHS. Inflammatory bowel disease. 2020.

15 UK IBD Genetics Consortium. What is Inflammatory Bowel Disease (IBD)?

16 Crohn's & Colitis UK, Food and IBD, Webpage, 2021. Available at <https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/food>

17 NHS. Inflammatory bowel disease. 2020.

18 Trueland, J. Supplement: 'The UK is out of sync' on bowel disease care. HSJ, 9 June 2015. Available at www.hsj.co.uk/supplement-archive/supplement-the-uk-is-out-of-sync-on-bowel-disease-care/5086587_article [accessed 05/07/2021]

19 UK IBD Genetics Consortium. What is Inflammatory Bowel Disease (IBD)?

20 NHS. Inflammatory bowel disease. 2020.

21 National Institute for Health and Care Excellence. Quality standards and indicators briefing paper: inflammatory bowel disease. 2014.

22 UK IBD Genetics Consortium. What is Inflammatory Bowel Disease (IBD)?

23 NHS. Inflammatory bowel disease. 2020.

24 NHS. Colostomy. 2020. Available at www.nhs.uk/conditions/colostomy [accessed 05/07/2021]

25 Molodecky, A. and others. Increasing Incidence and Prevalence of the Inflammatory Bowel Diseases With Time, Based on Systematic Review. *Gastroenterology*, Volume 142, Issue 1, pp. 46-54.E42, January 2012. Available at <https://doi.org/10.1053/j.gastro.2011.10.001> [accessed 05/07/2021]

26 IBD UK. Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change. 2021. Available at http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Health_Services/CROJ8096-IBD-National-Report-WEB-210427.pdf [accessed 05/07/2021]

27 NHS. Inflammatory bowel disease. 2020.

28 UK IBD Genetics Consortium. What is Inflammatory Bowel Disease (IBD)?

29 National Institute for Health and Care Excellence. Quality standards and indicators briefing paper: inflammatory bowel disease. 2014.

although the numbers are beginning to increase in developing countries.³⁰ Within the UK, a cohort study of all the patients registered with GPs (2000-2018) found some regional variation: incidence of Crohn's disease was highest in Northern Ireland, Scotland and the North West, while that of ulcerative colitis was highest in the North East, the East of England and the East Midlands.³¹

Mortality rates from ulcerative colitis have improved steadily over the past 30 years, but acute severe disease still has a mortality rate of up to 2% of people diagnosed. The most recent UK audit demonstrated an overall UK national mortality of 0.8%. There is also evidence of psychological morbidity linked to Crohn's disease.³²

Against this background, the next section describes the characteristics of the sample of people with IBD that we obtained during the course of our research.

CHARACTERISTICS OF OUR SAMPLE OF PEOPLE LIVING WITH IBD

We used a market research company to obtain a sample of 500 adults in the UK that self-identified in a screener question that they had the health condition of inflammatory bowel disease (the 'disease group').³³ We did not specify any other constraints for the selection of this disease group: it is therefore not necessarily representative, either of the UK population as a whole or of the profile of people living with IBD in particular. Instead demographic data was collected for the purpose of creating a matched control group in order, where applicable, to be able to control for other factors that affect economic outcomes.

The following paragraphs introduce our disease group by describing its main demographic, health and economic characteristics.

Demographic characteristics

Our disease sample is disproportionately male (59%), with an average age of 38 and around half (49%) the group in the 35-44 age bracket (Chart 1).

The average age at which people were diagnosed with IBD in our sample was 26, although the spread is wide, with some people who were diagnosed in early childhood and others in late middle age (Chart 2).

CHART 1: AGE DISTRIBUTION

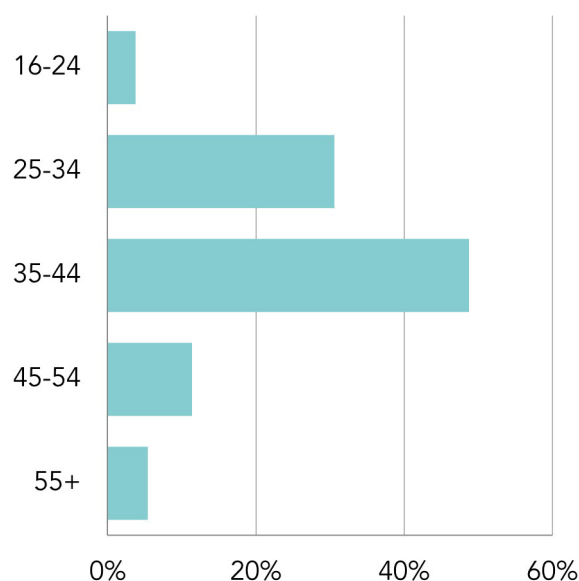
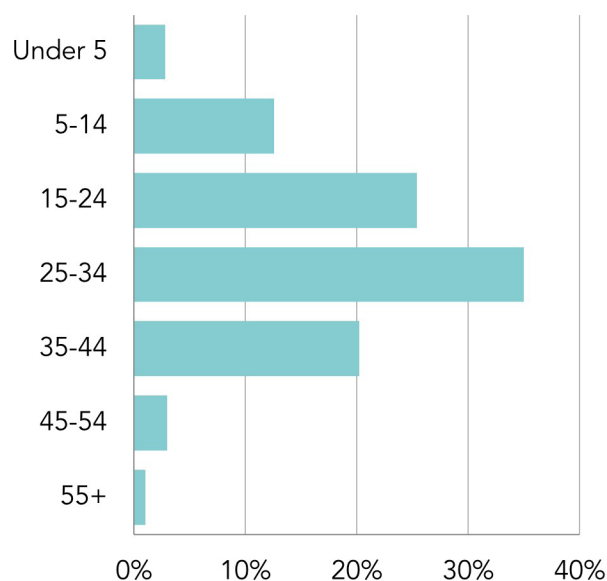


CHART 2: AGE WHEN DIAGNOSED



30 Molodecky, A. and others. Increasing Incidence and Prevalence of the Inflammatory Bowel Diseases With Time, Based on Systematic Review. *Gastroenterology*, Volume 142, Issue 1, pp. 46-54.E42, January 2012. Available at <https://doi.org/10.1053/j.gastro.2011.10.001> [accessed 05/07/2021]

31 Pasvol, T.J. and others. Incidence and prevalence of inflammatory bowel disease in UK primary care: a population-based cohort study. *BMJ Open* 2020;10:e036584. Available at <http://dx.doi.org/10.1136/bmjopen-2019-036584> [accessed 05/07/2021]

32 National Institute for Health and Care Excellence. Quality standards and indicators briefing paper: inflammatory bowel disease. 2014.

33 500 people with IBD in the UK were surveyed between 24 March 2021 and 6 April 2021. Results were unweighted.

This means that there is a large variation in the number of years that people in our disease group had been living with the disease: nearly four in ten (39%) of people in our disease group had been living with IBD for less than 5 years, but one in ten (10%) had lived with it for over 25 years. The average (mean) years since diagnosis in our sample is 11 years, with a median of 8 years (Chart 3).

We had respondents from all parts of the UK although the proportion in London was larger (25%) than might be expected given the distribution of the population as a whole or, as described above, the known geographic incidence of the disease in the UK (Chart 4).

The ethnicity mix of our sample was not dissimilar to the general population, with 84% describing their ethnicity as white (UK: 87%) and 15% as either Asian, Black or Mixed (UK: 13%).

Around three-quarters of respondents in our disease group lived in a household with children under the age of 12 so might be expected to have some caring responsibilities; of these the average number of children under 12 was two (Chart 5).

CHART 3: YEARS SINCE DIAGNOSIS

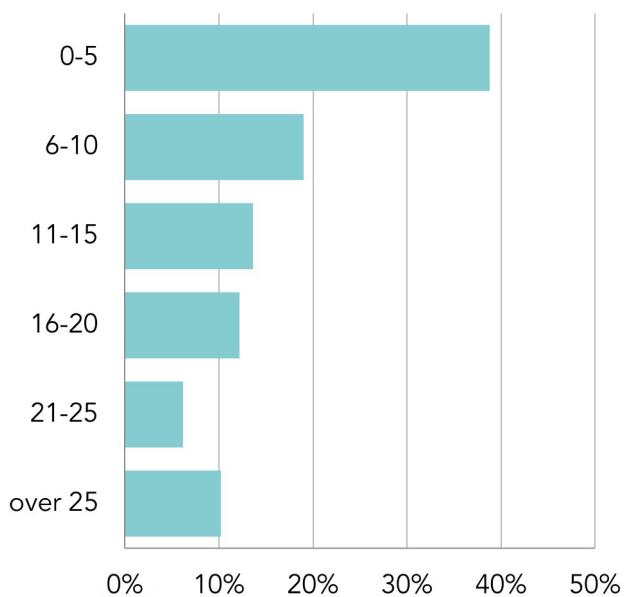
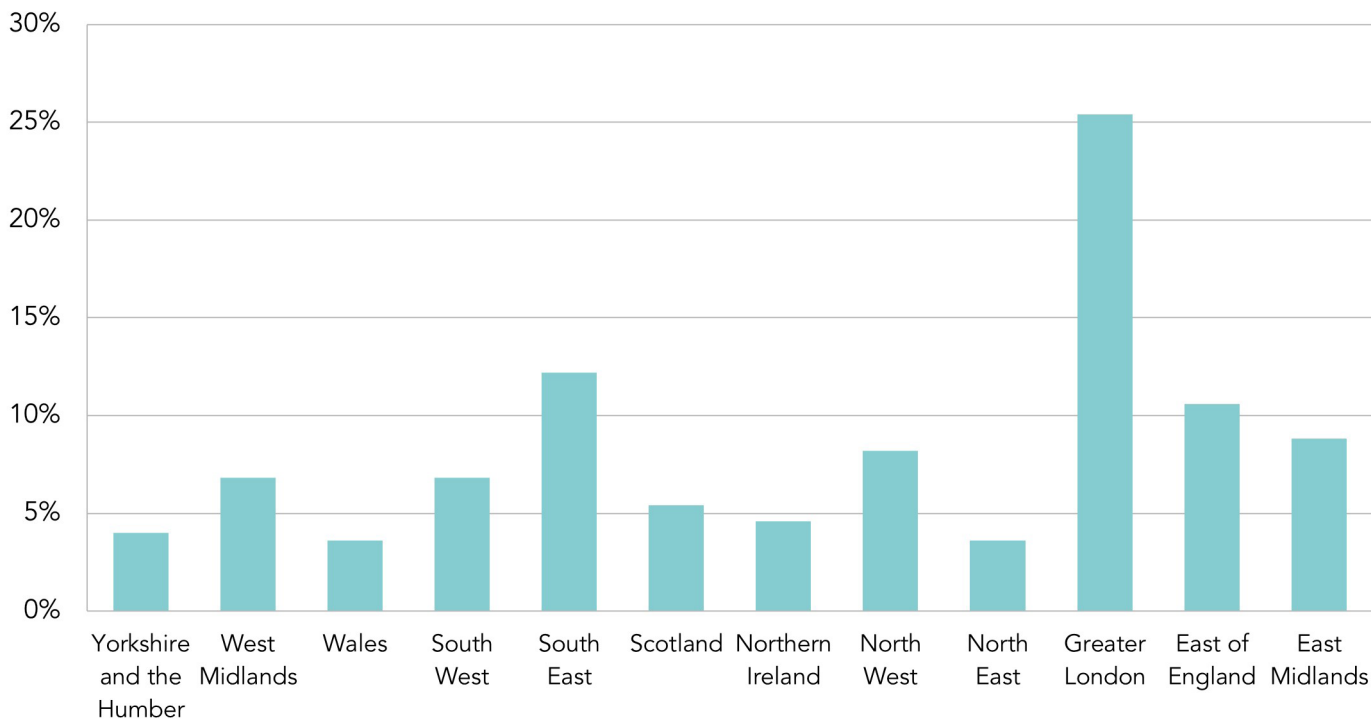


CHART 4: DISEASE GROUP BY REGION



Health characteristics

Most of our sample (89%) were currently taking one or more types of medication for IBD, and a minority (28%) had also had surgery.³⁴ Three quarters (75%) described the severity of their IBD symptoms as either “very” or “somewhat” severe (Chart 6). Practically everyone (94%) said that their IBD reduced their ability to carry out day-to-day activities; around four in ten (43%) said that it prevented them carrying out day-to-day activities “a lot” (Chart 7).

When we asked the disease group sample whether respondents had a physical or mental health condition that was not linked to IBD, we found that 44% of our sample had a non-IBD health condition that was sufficiently severe to count as a disability under the Equality Act 2010.³⁵ It is therefore possible that, in our sample at least, there may be significant comorbidity of IBD with other seemingly unconnected conditions.

Economic characteristics

Despite these impediments, most people (85%) in our sample stated that they worked full-time and when we explored whether there was a connection between working part-time hours and severity of disease, we did not find a connection: those with more severe symptoms were no less likely to be working full time (Chart 8).

Despite predominantly being in work, just over half the group (51%) was also in receipt of state benefits, the most common being a means-tested benefit (26% of the total sample) or a disability benefit (22%). A significant minority (15%) are also in receipt of Carer’s Allowance, which is a benefit given to people on low incomes who care for someone else for over 35 hours a week (Chart 9). The implications of this finding on the way we approached our research is discussed in Section 1.

Our sample is skewed to people from higher socioeconomic family backgrounds. When asked about the main occupation of the chief income earner of the house that they grew up in, around four in five (81%) selected an answer that corresponded to social grade ABC1 (Chart 10). For context, around half the UK population as a whole is in group ABC1.³⁶

CHART 5: NUMBER OF CHILDREN UNDER AGE OF 12

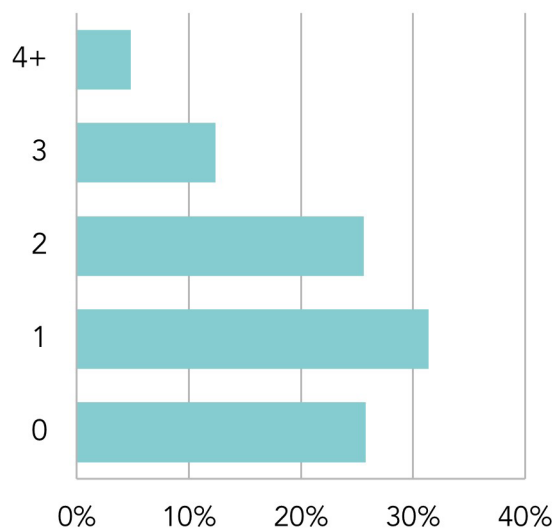
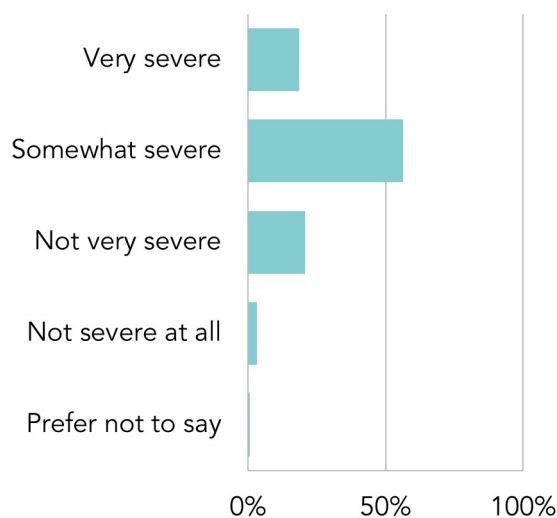


CHART 6: HOW WOULD YOU GENERALLY DESCRIBE THE SEVERITY OF YOUR CROHN'S OR COLITIS OR OTHER FORM OF IBD OVER THE LAST 3 MONTHS?



³⁴ In our sample, of the 143 people who had had surgery for IBD, 123 were still taking medication.

³⁵ That is, it had lasted (or is expected to last) over 12 months and it affected the individual's day-to-day activities. See: Office for National Statistics. Measuring disability: comparing approaches. 6 August 2019. Available at www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/measuringdisabilitycomparingapproaches/2019-08-06#the-equality-act-disability-definition-eadd [accessed 05/07/2021]

³⁶ National Readership Survey. Social Grade. (no date). Available at www.nrs.co.uk/nrs-print/lifestyle-and-classification-data/social-grade [accessed 05/07/2021]

CHART 7: DOES YOUR IBD REDUCE YOUR ABILITY TO CARRY OUT DAY TO DAY ACTIVITIES?

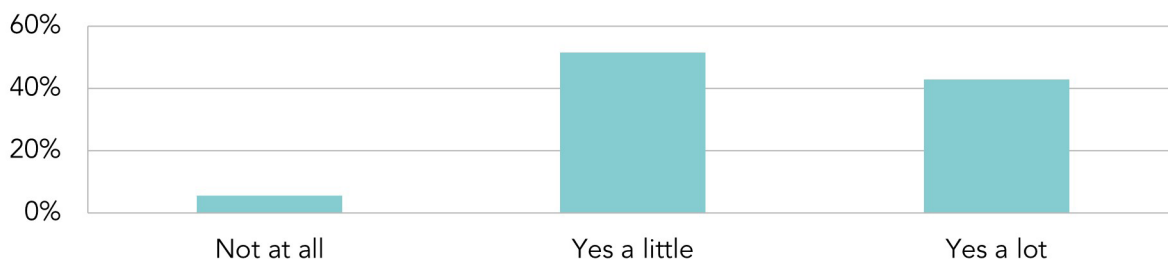


CHART 8: WORKING STATUS

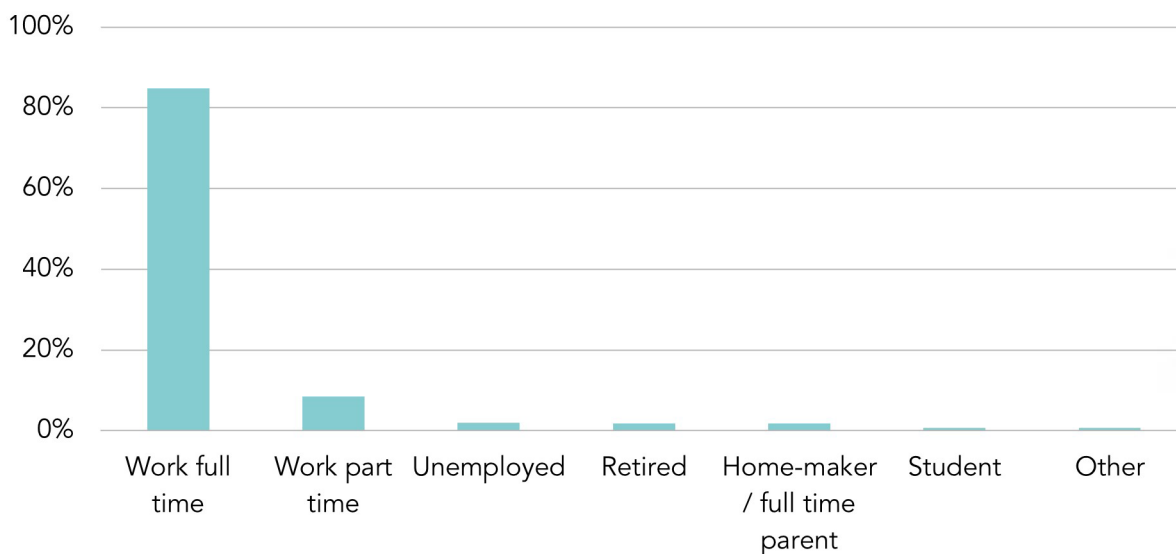
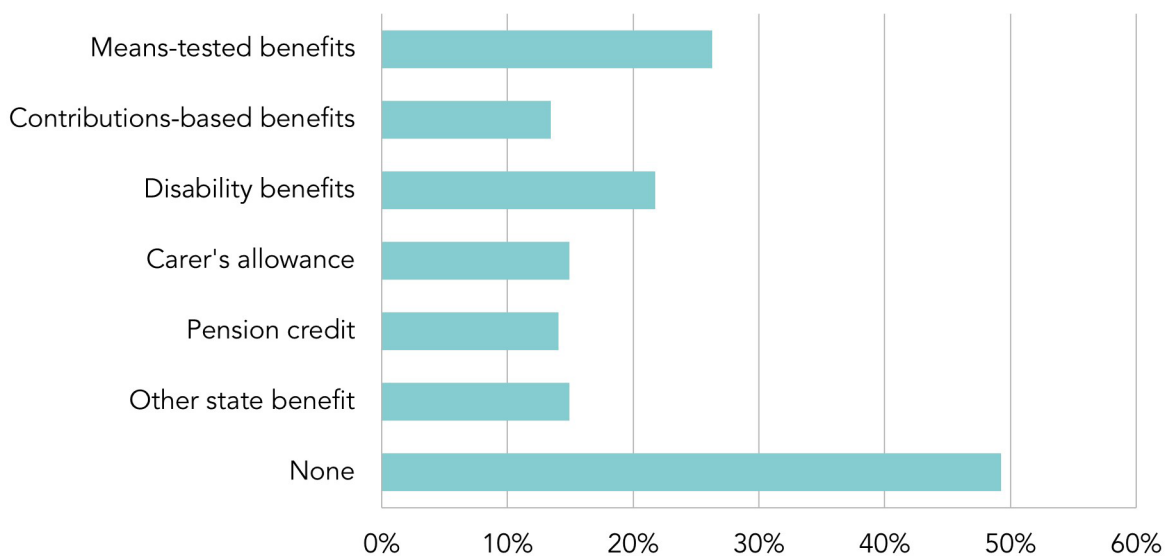


CHART 9: WHETHER IN RECEIPT OF BENEFITS



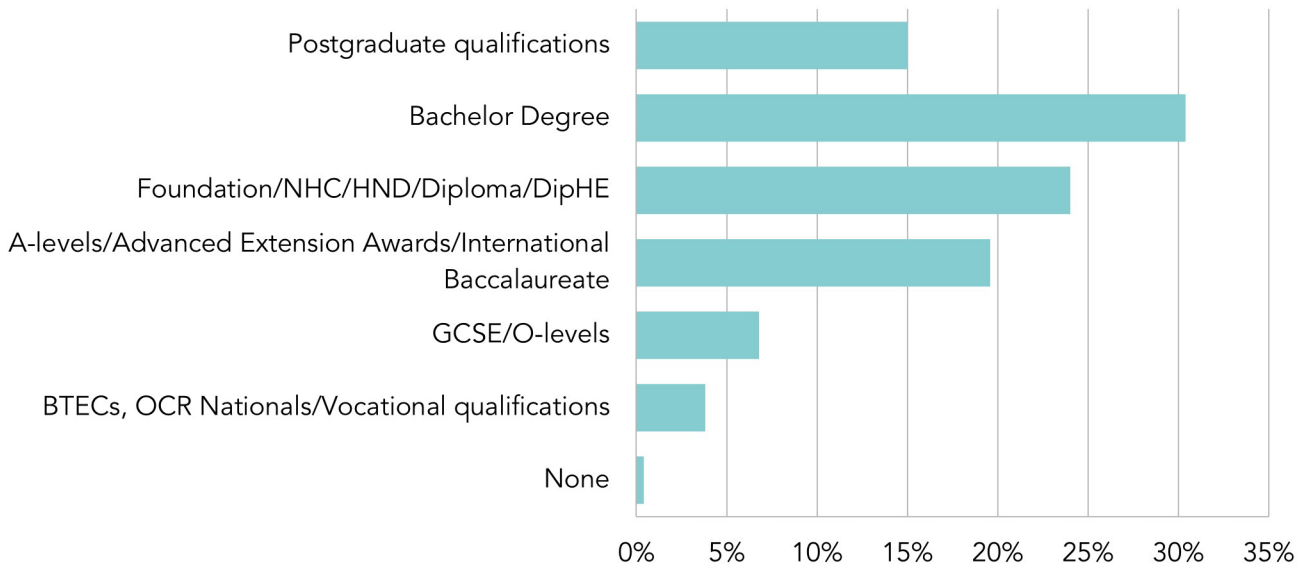
Notes: Means tested benefits consist of: Universal credit/income-based ESA/ income-based JSA/income support/ child tax credit/working tax credit/housing benefit. Contributions-based benefits consist of contributions-based JSA or ESA. Disability benefits consist of: Incapacity Benefit/DLA/PIP/Industrial Injuries Benefit/Severe Disablement Allowance. Percentages do not add to 100% because some people are on more than one benefit.

CHART 10: SOCIAL GRADE



Our disease sample is also relatively highly educated: 45% are either graduates or postgraduates, compared to 42% for the UK population as a whole (Chart 11).³⁷ Although we control for both levels of education and socioeconomic background when undertaking comparative analysis, these results nevertheless mean that the sample sizes for people in the lower socioeconomic groups are particularly small.

CHART 11: HIGHEST EDUCATION QUALIFICATION



37 Office for National Statistics. Graduates in the UK labour market: 2017. 24 November 2017. Available at www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/articles/graduatesintheuklabourmarket/2017 [accessed 05/07/2021]

For those people in work, we asked them to tell us their personal income from work (excluding benefit income) and obtained income information from 445 people.³⁸ The distribution of this income data, as can be seen from Chart 12 is roughly symmetrical, around a median income of £35,000. The average (mean) is higher, at £43,000, because a small number of individuals had much higher incomes.

In the next section we explore what our data says about how IBD affects the economic lives of the individuals in our disease group; Section 2 then considers whether it is possible to extrapolate an aggregate effect on the UK as a whole.

CHART 12: INCOME DISTRIBUTION



38 The full question was: "What is your personal income from work before tax per year? If you are furloughed or on sick pay, please include your current income, not the income you received before. This question is only about your income from work. Do not include income from state benefits, rent, interest or dividends. If you are retired, please include any income from a work-related or contributory state pension, but not from pension credit." Respondents were invited to submit a freeform numerical answer. If they skipped this question, a further question was asked at the end of the survey as follows: "What is your personal income from work before tax per annum?" with respondents invited to select a single response within a 10K income band. For these respondents, we then estimated their income as the central point within the band.

SECTION 1: EFFECTS ON INDIVIDUAL WORKING LIVES

Most people with IBD lead active lives, but this does not mean their education, work, social and family life is not affected, particularly for those that experience severe symptoms.³⁹ The unpredictability of the disease can be very disruptive to everyday living; flare-ups can lead to frequent and urgent need for the toilet (up to 20 times per day is common).⁴⁰ More invisible problems - that can even occur in periods of remission - such as loss of sleep, pain and fatigue can have profound effects on energy levels, mental health and quality of life.⁴¹

Living with IBD can therefore affect an individual's ability to achieve their full potential at work. A survey of IBD patients by the charity Crohn's & Colitis UK found that half of respondents felt their IBD had prevented them reaching their full potential and a similar proportion felt it had impacted their career progression.⁴² A systematic review of the economic impact of IBD in people's lives published by the Journal of Crohn's and Colitis in 2014 concluded there was "a high burden of work-related outcomes among inflammatory bowel disease patients

regardless of the methodology used".⁴³ A case-control study undertaken in the US in 2002 that controlled for age and gender found that IBD had a "significant impact" on labour force participation, particularly for younger and more highly educated patients.⁴⁴

The impact of the conditions on education can also be profound. Most children are able to attend school, but there are times when they may miss lessons due to ill health, and their education may also be affected by feeling 'different' from their peers.⁴⁵

In this section we report the results of the specific survey questions around working lives that we asked our sample of 500 people in the UK living with IBD. As described in the introduction, this is an unweighted sample so is not necessarily representative of the IBD population as a whole; in particular the socioeconomic family background of our sample appears higher than the UK average.

39 Ghosh, S. and Mitchell, R. Impact of inflammatory bowel disease on quality of life: Results of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) patient survey. Journal of Crohn's and Colitis, Volume 1, Issue 1, September 2007, pp. 10–20. Available at <https://doi.org/10.1016/j.crohns.2007.06.005> [accessed 05/07/2021]

40 UK IBD Genetics Consortium. What is Inflammatory Bowel Disease (IBD)? (no date). Available at www.ibdresearch.co.uk/what-is-inflammatory-bowel-disease-ibd/what-is-ibd [accessed 05/07/2021]

41 UK IBD Genetics Consortium. What is Inflammatory Bowel Disease (IBD)? (no date). Available at www.ibdresearch.co.uk/what-is-inflammatory-bowel-disease-ibd/what-is-ibd [accessed 05/07/2021]

42 Gay, M. and others. Crohn's, Colitis and Employment - from Career Aspirations to Reality. Crohn's & Colitis UK, 2011. Available at www.lmfno.org.uk/Admin/Public/Download.aspx?file=Files%2FFiles%2FBrosjyrer%2FCrohns_Colitis_Employment.pdf [accessed 05/07/2021]

43 Büsch, K. and others. Sick leave and disability pension in inflammatory bowel disease: A systematic review. Journal of Crohn's and Colitis, Volume 8, Issue 11, 1 November 2014, pp.1362–1377. Available at <https://doi.org/10.1016/j.crohns.2014.06.006> [accessed 05/07/2021]

44 Boonen, A. and others. The impact of inflammatory bowel disease on labor force participation: results of a population sampled case-control study. Inflammatory Bowel Diseases, Volume 8, Issue 6, 1 November 2002, pp. 382-389. Available at <https://doi.org/10.1097/00054725-200211000-00002> [accessed 05/07/2021]

45 Crohn's & Colitis UK. Crohn's disease: your guide.. 2019. Available at <http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Publications/crohn-disease.pdf> [accessed 05/07/2021]

THE MAJORITY OF PEOPLE WITH IBD WORK FULL-TIME

As we have seen, the vast majority of people in our sample are working full-time, with little apparent connection between severity of condition and the number of hours worked. However, in response to questions around how their condition had affected the trajectory of their working lives we found around two thirds (68%) of our sample thought that having IBD had had a negative effect on their career, with 23% saying it was “significantly negative” and a further 45% saying it was “somewhat negative” (Chart 13).

Unsurprisingly, the negative impact was more pronounced for people who stated that they had a severe form of the condition: three quarters (76%) of people who said their IBD was “severe” stated that the impact on their career had been “significantly” or “somewhat” negative, whereas for those who said that their IBD was “not severe” just under half (48%) stated that the impact on their career had been “significantly” or “somewhat” negative.

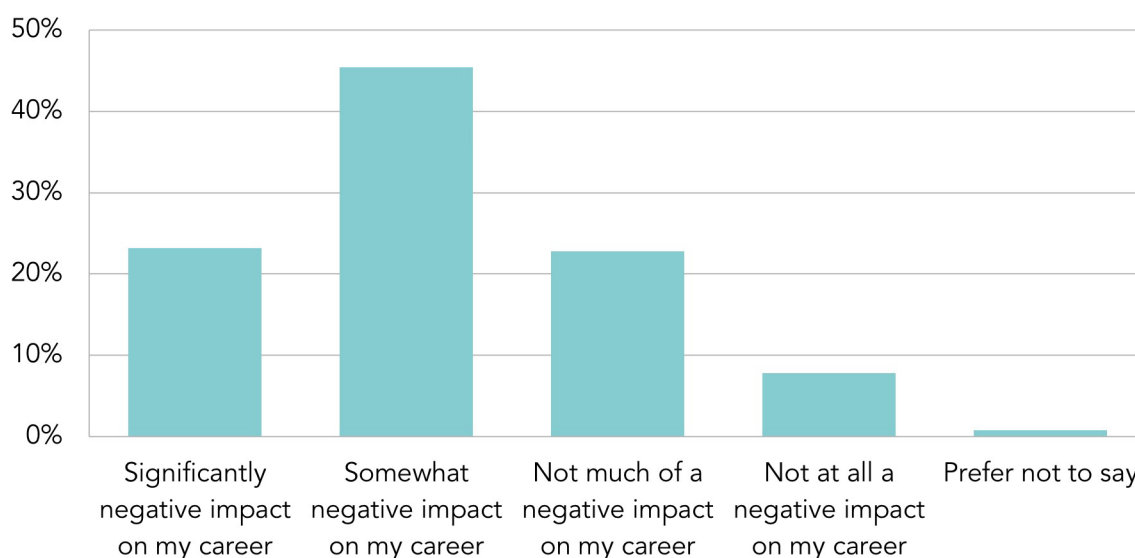
We then asked a series of questions around how having IBD had affected the decisions that people had made over the course of their working lives.

As shown in Chart 14, here we found a stronger connection between hours worked and having IBD than is suggested by looking at people’s current employment status: 57% stating that they have, at some point, either reduced their hours or gone part-time because of IBD, a similar proportion to a previous study undertaken by Crohn’s & Colitis UK.⁴⁶

There is a clear opportunity for employers to ensure flexible work environments exists for people with IBD and other invisible and fluctuating conditions. While the majority of people with IBD are in full-time work, many of them have had to adapt their careers because of a lack of flexibility. We found strong connections between having IBD and making work choices that could be career-limiting such as leaving a job (46% agree) and applying for lower-paid work (51% agree). Particularly worrying is the finding that around half (49%) of our sample agreed with the statement I believe I was made redundant because of my IBD”, demonstrating that greater awareness of this condition and flexibility among employers should be a priority.

Again, the extent to which people agreed with our statements was affected by the severity with which they experienced their condition: those who considered their condition to be less severe were, in each case, less likely to agree with the statement we posed.

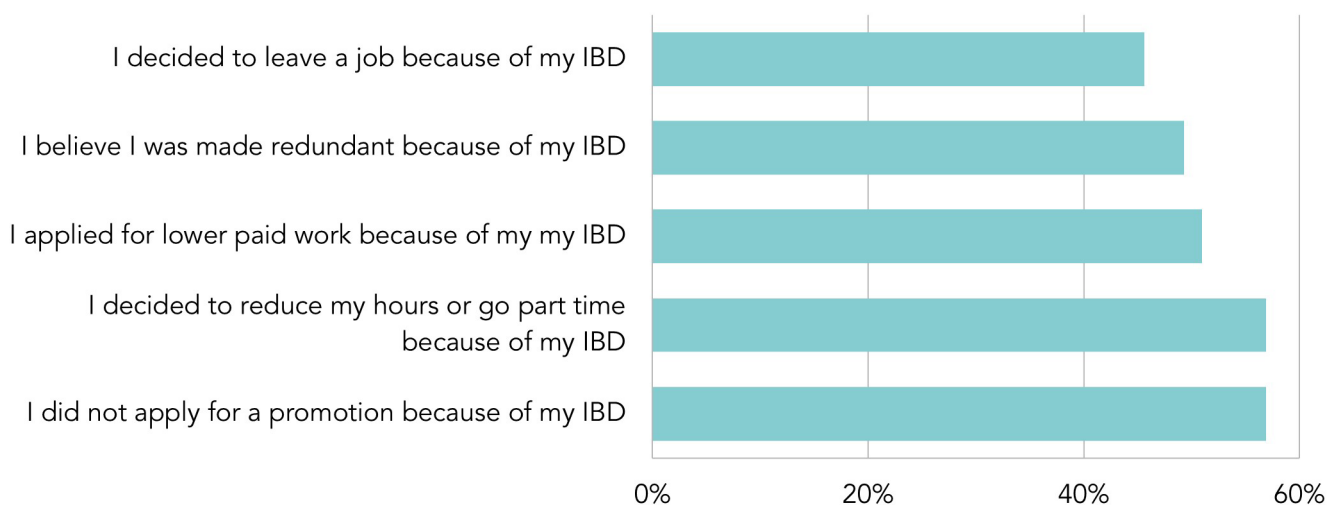
CHART 13: HOW MUCH OF A NEGATIVE IMPACT HAS LIVING WITH IBD HAD ON YOUR CAREER?*



* Full question: Thinking generally about your working life, how much of a negative impact has living with IBD had on your career, or has it had no negative impact at all? Examples might be if living with IBD had stopped you from getting a promotion, prevented you from pursuing your desired career path, or led to early retirement.

46 Gay, M. and others. Crohn’s, Colitis and Employment - from Career Aspirations to Reality. Crohn’s & Colitis UK, 2011. Available at www.lmfno.org.uk/Admin/Public/Download.aspx?file=Files%2FFiles%2FBrosjyrer%2FCrohns_Colitis_Employment.pdf [accessed 05/07/2021]

CHART 14: THINKING GENERALLY ABOUT ANY EXPERIENCE YOU MAY HAVE HAD IN THE WORKPLACE, TO WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENTS? (% AGREE EITHER 'SOMEWHAT' OR 'STRONGLY')



PRODUCTIVITY AT WORK

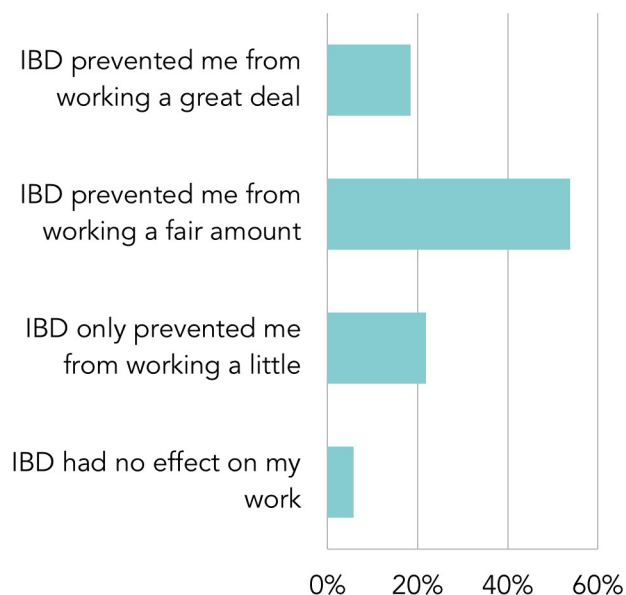
The negative impact of IBD is not only felt by those who live with the condition; there are implications for employers as well, through needing to manage the effect on productivity and absence due to sickness. We asked the 466 people in our sample who were in work about the effect of the condition on their productivity and time away due to ill health over the six months preceding the survey.

As Chart 15 shows, almost three quarters (72%) of our sample felt that their IBD had had a significant impact on their productivity, preventing them from working either “a fair amount” or “a great deal” over the previous six months, with a much smaller proportion (28%) stating that their IBD only prevented them from working “a little” or “had no effect” on their work.

For those in work, the vast majority (94%) had missed some time from work in the previous six months as a result of their IBD; the average was around nine days missed during the previous six months (Chart 16).⁴⁷ By way of context, the average for the UK population as a whole is four work days missed due to sickness over a full year.⁴⁸

These results are consistent with a similar study published in 2011 by Crohn’s & Colitis UK which found three quarters (72%) of respondents with IBD who were in work stated that their IBD had had some

CHART 15: DISEASE GROUP IN WORK - DURING THE PAST SIX MONTHS, HOW MUCH DID YOUR IBD AFFECT YOUR PRODUCTIVITY WHILE YOU WERE WORKING?*



*Full question: During the past six months, how much did your IBD affect your productivity while you were working? Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual.

47 This is an estimate obtained by taking the midpoint of the banded response for each individual.

48 Office for National Statistics. Sickness absence in the UK labour market. 3 March 2021. Available at www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/datasets/sicknessabsenceinthelabourmarket [accessed 05/07/2021]

effect on their work in the past seven days, with one in twenty (6%) saying it had completely prevented them from working.⁴⁹

EFFECT ON EDUCATION

We asked our entire cohort of 500 people, regardless of their age when they received their diagnosis, to what extent they thought having IBD had affected their education. Overall, only three in twenty (15%) of our sample said that having IBD had “not at all a negative impact” on their education. We found that just under two thirds (63%) of respondents felt that the effect on their education was “somewhat” or “significantly” negative (Chart 17) with individuals typically missing 9-10 days per year of school, college or university (Chart 18).

In fact, even for those who were diagnosed in adulthood, a majority (61%) felt that there had been a negative effect on their education, suggesting that there is a significant amount of underdiagnosis among younger people. This is consistent with a survey by the Royal College of Physicians in 2012 that showed only a quarter (24%) of GPs feel “very confident” in recognising IBD, with two thirds (67%) only being “somewhat confident”.⁵⁰ Separately, an academic study published in 2021 showed that 1 in 10 people (9.6% Crohn’s disease, 10.4% ulcerative colitis) report symptoms in their gut to their GP 5 years before diagnosis, concluding that there is a need for faster pathways within the NHS system.⁵¹

INCOME

The evidence in the introduction to this report is suggestive that having IBD is linked to lower incomes. We saw, for example, that around half of our sample (51%) agreed with the statement “I applied for lower paid work because of my IBD.” A previous study by Crohn’s & Colitis UK demonstrated around a third of respondents perceived they had earned less as a result of their IBD.⁵²

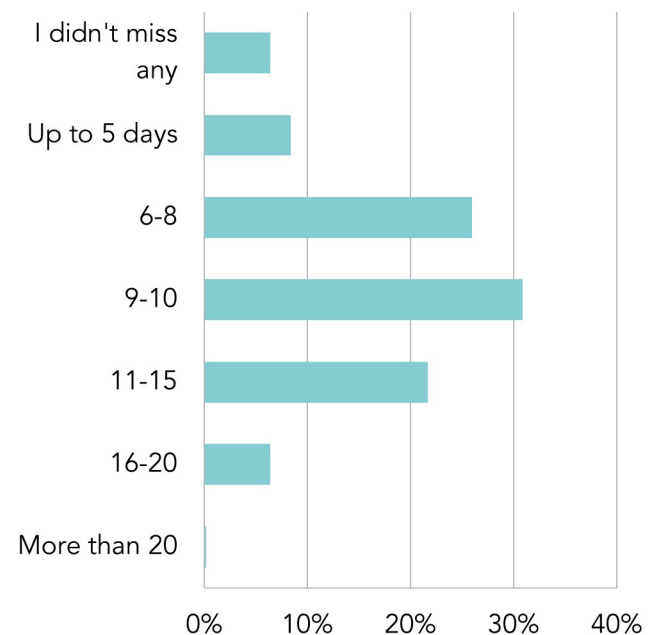
49 Gay, M. and others. Crohn’s, Colitis and Employment - from Career Aspirations to Reality. Crohn’s & Colitis UK, 2011. Available at www.lmfno.org.uk/Admin/Public/Download.aspx?file=Files%2FFiles%2FBrosjyrer%2FCrohns_Colitis_Employment.pdf [accessed 05/07/2021]

50 National Institute for Health and Care Excellence. Quality standards and indicators briefing paper: inflammatory bowel disease. 2014.

51 Blackwell, J. and others. Prevalence and Duration of Gastrointestinal Symptoms Before Diagnosis of Inflammatory Bowel Disease and Predictors of Timely Specialist Review: A Population-Based Study. *Journal of Crohn’s and Colitis*, Volume 15, Issue 2, February 2021, pp. 203–211. Available at <https://doi.org/10.1093/ecco-jcc/jjaa146> [accessed 05/07/2021]

52 Gay, M. and others. Crohn’s, Colitis and Employment - from Career Aspirations to Reality. Crohn’s & Colitis UK, 2011. Available at www.lmfno.org.uk/Admin/Public/Download.aspx?file=Files%2FFiles%2FBrosjyrer%2FCrohns_Colitis_Employment.pdf [accessed 05/07/2021]

CHART 16: DISEASE GROUP IN WORK - DURING THE LAST SIX MONTHS, HOW MANY DAYS DID YOU MISS FROM WORK BECAUSE OF IBD?*



*Full question: During the last six months, how many days did you miss from work because of IBD? Include sick days and parts of days you started late or stopped early because of your health problems, including for medical appointments. If you have been shielding due to the Covid-19 pandemic because of your IBD, only include these days if shielding meant you were unable to work.

CHART 17: THINKING GENERALLY ABOUT YOUR TIME IN SCHOOL AND UNIVERSITY OR COLLEGE (IF APPLICABLE), HOW MUCH OF A NEGATIVE IMPACT DO YOU THINK THAT HAVING IBD HAS HAD ON YOUR EDUCATIONAL ACHIEVEMENTS OR DID IT HAVE NO NEGATIVE IMPACT AT ALL

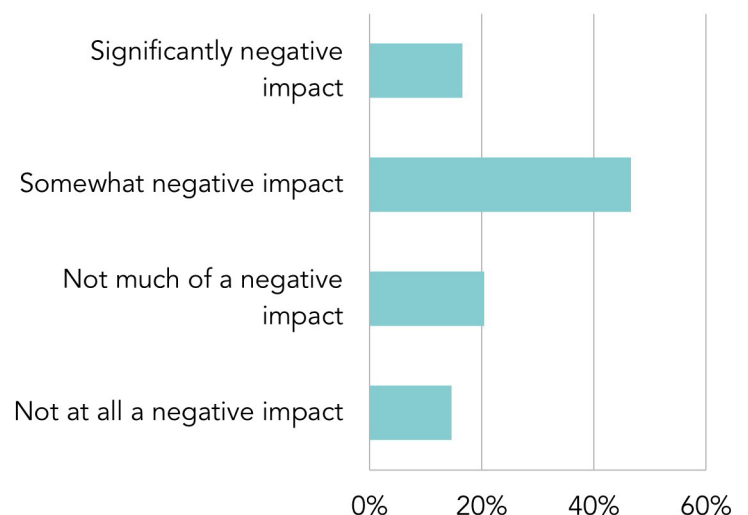
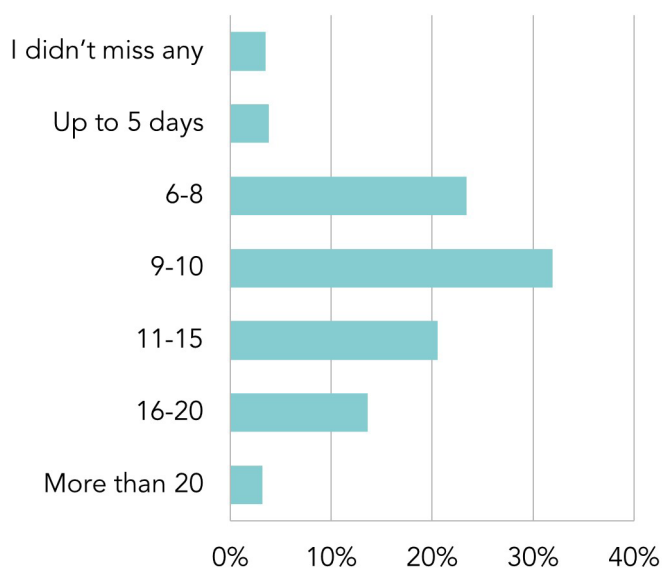


CHART 18: "HOW MANY DAYS ON AVERAGE DID YOU MISS EACH YEAR OF SCHOOL, COLLEGE OR UNIVERSITY DUE TO IBD?" (BASE: 316 PEOPLE IN DISEASE GROUP WHO SAID IBD HAD HAD A 'SOMEWHAT' OR 'SIGNIFICANTLY' NEGATIVE EFFECT ON THEIR EDUCATION)



An older study (2004) on the cost of IBD in the UK estimated a median loss of earnings over six months was £239 for colitis patients and £299 for Crohn's disease patients.⁵³

In order to test this assertion we used a matched cohort methodology commonly used in medical testing. Having collected demographic data from our disease group sample we then worked with a polling provider to create a one-for-one matched control group with the same characteristics as the disease group - apart from not having IBD - and then asked the same income question of this control group. We then used standard statistical techniques to explore whether there was a difference in income that could be attributed to IBD.

A key consideration was which variables to control for. We obtained information from the disease group on a wide range of demographic variables that might reasonably be thought to affect income and then explored the data to narrow the control variables down to a manageable shortlist.

This process led to us controlling for the following variables:

- Gender
- Age (banded)
- UK region
- Ethnicity (white/not white)
- Having children under the age of 12 in the household
- Socioeconomic class of the main income earner in the household the respondent grew up in
- Highest level of education
- Whether in receipt of Carer's Allowance

We did not control for hours worked or other forms of working status, because part of the hypothesis under investigation is whether IBD affects engagement with the labour market including hours worked. We considered controlling for the income of other adults in the household on the grounds that a partner's earnings may affect the work choices of an individual, but an initial exploration of the disease group dataset suggested that respondent and partner income were positively correlated, suggesting the connections between the two are more complex and did not need to be controlled for. We also considered controlling for whether the respondent had a disability that was separate from IBD, but on reflection decided against this given the very high incidence of a separate disability in the disease group combined with evidence from the literature review, as described above, that having IBD is strongly linked to having other debilitating conditions.

However, we did control for whether the individual was in receipt of Carer's Allowance since the threshold for that benefit is relatively high - caring for another individual for over 35 hours a week - such that we felt that, as with having dependent children, it was reasonable to hypothesise it could affect decisions around how to engage with the labour market.

Once the data had been cleaned to remove individuals who either chose not to disclose information about income, or who reported an income level that looked unreliable, we were left with 220 pairs with good data for both the control and disease record; that is, 440 records in total.⁵⁴ This was a sufficiently large sample size for statistical analysis. The full results are in Appendix 2.

53 Bassi, A. and others. Cost of illness of inflammatory bowel disease in the UK: a single centre retrospective study. *Gut*, Volume 53, September 2004, pp. 1471-1478. Available at <https://doi.org/10.1136/gut.2004.041616> [accessed 05/07/2021]

54 In addition we had a further 90 pairs (180 records) where at least one of the pair had an estimated income taken as the mid-point of a £10K band. There were also a further 92 pairs where at least one of the pair did not work so had zero income and 65 pairs where at least one of the pair had unreliable data or refused to answer the income question.

In summary, we found no statistically significant difference between the average incomes of the IBD group and the matched control group ($p>0.1$). We were surprised however to find that those people who said that living with IBD had negatively affected their career had higher incomes on average than people who said it had not. This might suggest that the negative economic impact of living with IBD is greater in more senior roles.

Specifically, of those who had IBD, the average income of people who said that living with IBD had had a negative impact on their career is £42,404 which is higher than the average income of £34,224 reported by people who said that living with IBD had not had a negative impact on their career ($p<0.05$)

Similarly, of those who had IBD, the average income of people who said that they had left a job because of their IBD is higher at £43,003 than the average income of people who did not leave a job because of their IBD at £35,151 ($p<0.05$).

Additionally, of those who had IBD, the average income of people who said that living with IBD

had had a negative impact on their educational achievements was higher than the average income of those who said that living with IBD had not had an impact on their educational achievements, at £42,408 compared to £35,387 ($p<0.05$).

Difference-in-difference analyses suggest that education and family socioeconomic background are affecting incomes in the control group in a different way to incomes in the disease group ($p<0.05$).

Taken together, this could be interpreted as evidence suggesting that having IBD holds back people with the highest earning potential from full participation in the labour market, but that there is less of an effect for those with lower earning potential.⁵⁵

We also found that women in the IBD group had higher average earnings (£33,011) than women in the matched control group (£25,848) and that this effect was statistically significant at the 0.05 level ($p=0.028$). In line with the main result, we found no statistically significant difference between incomes in the IBD group and the control group for men.

⁵⁵ As we saw in the introductory section, our sample is skewed towards people from higher socioeconomic family backgrounds which meant that the sample size for those on lower incomes was particularly small, increasing its potential unreliability despite controlling for these variables. This is relevant because our results were particularly affected by the bottom of the income distribution having higher earnings in the disease group compared to the control group. An alternative explanation is that there may have been a difficulty with the phrasing of the income question in the survey: respondents were explicitly asked to exclude income from state benefits but may not have done so in practice. This would have affected the results because people with IBD in our sample are more likely to be in receipt of state benefits (Chart 10 and Chart 11).

SECTION 2: ECONOMY-WIDE EFFECTS

So far, we have found strong evidence that having IBD does have a negative effect on people’s working lives and, for many, in the way that they view their education and career achievements. However this does not appear to cause a systemic effect that can be measured in terms of income, at least for the IBD population as a whole, and so the macroeconomic effect, if any, is uncertain.

TAXPAYER COSTS

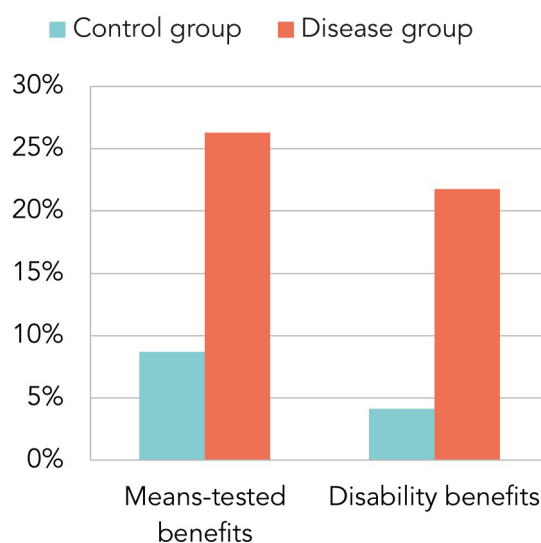
If, as described above, having IBD potentially has a greater negative effect on the careers of people in more senior roles, then the progressive nature of the income tax system suggests there may be an overall taxpayer loss from IBD since higher earners pay a greater proportion of their income in taxation. Further exploration would be required to establish this.

However, we also collected information on the benefit status of people in both our disease and control groups and found that people in our IBD group were in general more likely to be in receipt of state benefits than people in the control group.⁵⁶ In particular, a quarter of people in our IBD sample (26%) were in receipt of means-tested benefits, nearly three times as many as in our control group (9%). Similarly, over one in five people in our IBD sample (22%) were in receipt of a disability-related state benefit compared to under one in twenty (4%) in the control group (Chart 19). It seems therefore that there is a cost to the taxpayer and the economy from IBD through the mechanism of increased benefit payments.

This finding is consistent with previous research conducted outside the UK: a study of people with IBD in Brazil, for example, found that the overall cost to Brazil’s welfare state from IBD, although small, was quantifiable and amounted to approximately 1% of all social security benefits.⁵⁷

For this analysis we have not undertaken primary research on the cost to the NHS of managing and treating patients with IBD. For context, however,

CHART 19: PROPORTION OF DISEASE AND CONTROL GROUPS CLAIMING MEANS-TESTED AND DISABILITY BENEFITS



⁵⁶ 51% of people in our IBD group were in receipt of a state benefit excluding child benefit and winter fuel allowance compared to 29% in the control group. This includes Carer’s Allowance which, as described in Section 1, was controlled for.

⁵⁷ de S. B. Fróes, R. and others. The socio-economic impact of work disability due to inflammatory bowel disease in Brazil. The European Journal of Health Economics, Volume 19, April 2018, pp. 463-470. Available at <https://doi.org/10.1007/s10198-017-0896-4> [accessed 05/07/2021]

research reported by the Royal College of Physicians suggests that the costs to the NHS of managing patients with IBD is around £900 million, based on an average cost of £3,000 per patient per year.⁵⁸ This is consistent with an earlier academic study that found average six month costs per patient were £1,256 for colitis and £1,652 for Crohn's disease.⁵⁹

THE EFFECT OF IBD ON EMPLOYERS

As we saw in Section 1, on average around nine working days are missed due to IBD among employees over a six month period (Chart 18). We obtained a sense of the aggregate financial impact on employers on an annual basis as follows:

Step 1: For each individual we estimated the actual number of work days missed in a six-month period due to IBD by taking the mid-point of the respondent's banded answer in the survey question. So, for example, if they selected "9-10 days" we estimated the actual number of days missed as 9.5.

Step 2: This was then doubled for each individual to give the number of days missed per year.

Step 3: For each individual we obtained an implied daily rate of pay by dividing their annual income figure by the number of working days in the year (262 in 2021).⁶⁰

Step 4: For each individual the implied daily rate of pay was then multiplied by the number of days lost each year due to IBD to give an annual cost of missed days.

Step 5: The average figure for the sample as a whole was then calculated.

On this basis, we estimate that the average employer cost of staff sickness from IBD is in the region of £2,000 per individual per year.⁶¹

In order to be able to estimate an effect across the economy, we used an estimate of 500,000 people with IBD across the UK as a whole (Appendix 1). Our data did not suggest that people with IBD were any

less likely to be working. Given this, and that IBD is typically diagnosed in late teens and early twenties, it seems reasonable to assume for the purpose of our analysis that the proportion of people living with IBD who are working is the same as the proportion of the population aged 16+ that are in work; this data is available from the Office of National Statistics and as of January-March 2021 stood at 60%.⁶²

Combining this information gives a ballpark estimate, subject to the caveats below, of the annual cost to UK employers from time lost from work due to IBD as being in the region of £600m per year (£2,000 x 500,000 x 0.6).⁶³

There are a number of assumptions implicit in this raw estimate, not least that the income distribution of the sample is representative of the IBD population as a whole, which as previously discussed may not be the case.

It also assumes that workers with IBD continue to be paid for time they take off sick which may not be the case for everyone depending on their contractual arrangements. This would overstate the employer cost. However neither does it include other employment costs paid by employers the value of which are linked to income, such as National Insurance Contributions, the omission of which understates the cost.

The estimate also does not attempt to quantify the effect on employers of reduced productivity due to staff ill health while they are clocked on as working, despite a large proportion of our sample stating that they do often feel that their productivity has been negatively affected (Chart 15). On top of that, we did not collect information as to whether the individuals in our sample who said that they worked were actually self-employed, in which case time off may not represent an employer cost but instead a missed opportunity for the individual to increase their income further. Neither have we adjusted for the fact that our disease sample is skewed to higher socioeconomic groups.

58 Royal College of Physicians. National audit of inflammatory bowel disease (IBD) service provision: UK IBD audit national report. September 2014. Available at <https://docplayer.net/21803868-National-audit-of-inflammatory-bowel-disease-ibd-service-provision.html> [accessed 05/07/2021]

59 Bassi, A. and others. Cost of illness of inflammatory bowel disease in the UK: a single centre retrospective study. *Gut*, Volume 53, September 2004, pp. 1471-1478. Available at <https://doi.org/10.1136/gut.2004.041616> [accessed 05/07/2021]

60 For individuals who only reported a banded income, we took the mid-point of the band. Unreliable and outlier records were removed, leaving 413 records.

61 Median £2,176; mean £2,427. Given the broad brush nature of the estimates, results are reported to one significant figure.

62 Office for National Statistics. Labour Force Survey Table A01: Summary of labour market statistics. 15 June 2021. Available at www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/datasets/summaryoflabourmarketstatistics [accessed 05/07/2021]

63 This represents lost output, or increased costs, rather than lost GDP; the effect on 'value added', or company profitability, cannot be inferred from this approach but is likely to be significantly less.

CONCLUSION

We find strong qualitative evidence among people with IBD that the condition has had a negative effect on their career and earnings prospects, with a suggestion that this is particularly the case for people in more senior positions.

IBD exerts a real cost to the taxpayer, aside from the direct NHS costs, in terms of higher benefit payments.

IBD also exerts a real cost to employers. Using the data from our sample we found the average cost to employers of a team member having time away from work due to IBD is in the region of £2,000 per person per year. Extrapolating this figure to the whole of the UK gives a ballpark estimate, subject to a number of assumptions, of annual costs to employers due to IBD of around £600m.

Taken together, we therefore recommend that the government undertakes its own estimates of the annual individual, macroeconomic and fiscal impact of people with disabilities being unable to participate in the labour market to the same extent as their peers.

APPENDIX 1: IBD PREVALENCE IN THE UK

Our literature review found conflicting opinions on the question of the number of people in the UK that currently have IBD (Table 1). The most recent estimate (2021) based on three recent regional studies in Scotland, Wales and Devon, used by the patient group Crohn's & Colitis UK is 500,000 people in the UK with IBD.⁶⁴

Given that there is some evidence that prevalence is increasing and that lower UK estimates are based on older data, we use the same estimate of 500,000 people with IBD for the purposes of our analysis.

TABLE 1: ESTIMATES OF THE PREVALENCE OF IBD IN THE UK

Organisation	Date	UK estimate: number	UK estimate: rate
Academic systematic review (Europe-wide data, not UK) ⁶⁵	2012	554,000 people with IBD*	322 per 100,000 people have Crohn's disease 505 per 100,000 people have ulcerative colitis
NICE ⁶⁶	2014	261,000 people (115,000 Crohn's disease; 146,000 ulcerative colitis)	157 per 100,000 people have Crohn's disease 240 per 100,000 have ulcerative colitis
Royal College of Physicians ⁶⁷	2018	201,000 people with IBD*	300 per 100,000 people and increasing
Crohn's & Colitis UK - main patient group ⁶⁸	2021	500,000 people with IBD	1 in 133 people

* Demos calculation using a UK population estimate of 67m people.

64 IBD UK. Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change. 2021. Available at http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Health_Services/CROJ8096-IBD-National-Report-WEB-210427.pdf [accessed 05/07/2021]

65 Molodecky, A. and others. Increasing Incidence and Prevalence of the Inflammatory Bowel Diseases With Time, Based on Systematic Review. *Gastroenterology*, Volume 142, Issue 1, pp. 46-54.E42, January 2012. Available at <https://doi.org/10.1053/j.gastro.2011.10.001> [accessed 05/07/2021]

66 National Institute for Health and Care Excellence. Quality standards and indicators briefing paper: inflammatory bowel disease. 2014.

67 Royal College of Physicians. IBD Audit Programme: Review of events, impact and critical reflections. January 2018. Available at <https://ibdregistry.org.uk/wp-content/uploads/2018/02/IBD-audit-programme-2005%E2%80%932017.pdf> [accessed 05/07/2021]

68 IBD UK. Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change. 2021. Available at http://s3-eu-west-1.amazonaws.com/files.crohnsandcolitis.org.uk/Health_Services/CROJ8096-IBD-National-Report-WEB-210427.pdf [accessed 05/07/2021]

APPENDIX 2: RESULTS OF STATISTICAL TESTS ON INCOME DIFFERENCES

SUMMARY

There is no statistically significant difference in the average income between the disease group and the control group ($p > 0.1$). The statistically non-significant difference between the two groups is £2,417 with the IBD group earning slightly more than the control group.

KEY RESULTS

Chart 20 presents the distribution of income between the two matched groups, i.e. the groups with the best data allowing for perfect matches. The average income is £37,348 (s.d. = 22,093) in the control group and £39,764 (s.d. = 21,164) in the IBD group.

CHART 20: INCOME DISTRIBUTION IN THE CONTROL AND DISEASE GROUPS

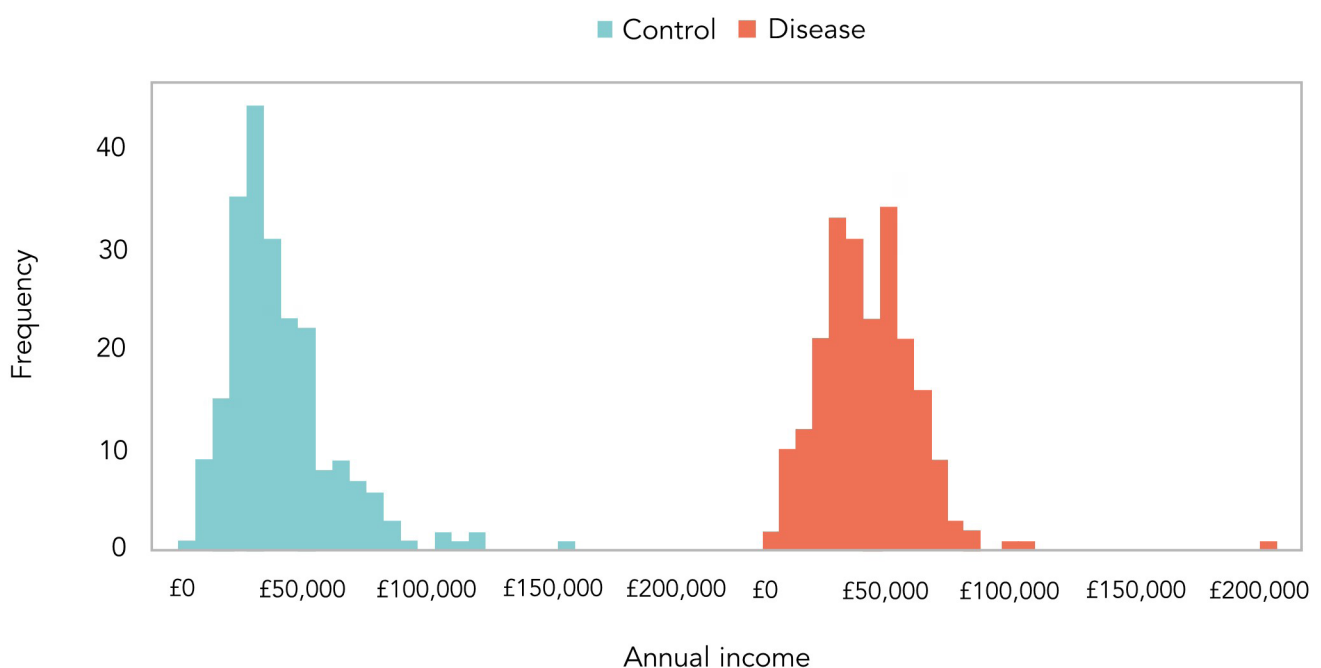


Table 2 provides a statistical test for the income difference between the control group and the disease group. Model 1 in Table 2 provides a test for the average difference in income between the two groups. The regression coefficient is 2,417, showing that people in the IBD group earn, on average, £2,417 more than the control group. Importantly, this difference is not statistically significant as the standard error is 2,063. Model 2 includes fixed effects at the matched pair level. Specifically, the model controls for the matched ID of the respondents and thereby only models the within pair variation in income. As the groups are similar on the covariates of interest (gender, age, education, ethnicity, region, children in the household and socio-economic background), such a model provides results substantially similar to Model 1, i.e., there is no statistically significant income difference between the two groups.

In brief, there is no systematic evidence that the IBD group has a lower income compared to the control group. Chart 21 provides a visual presentation of the results in Table 2, i.e. the regression coefficients with 95% confidence intervals.

Next, we also consider the results when estimating the income difference with the observations where there are at least one zero or at least one estimation. Chart 22 provides the key results here. For the data with the perfect matches, we see the estimate of £2,417 from Model 1 in Table 2. Again, we see that none of the income differences are statistically significant, and the 95% confidence intervals overlap with 0 in all three cases. It is noteworthy that we get the most precise estimate when relying on the perfect matches.

TABLE 2: IMPACT OF IBD ON INCOME DIFFERENCE, OLS REGRESSION

	Model 1 £	Model 2 £
Disease (IBD)	2,417 (2,063)	2,560 (1,929)
Matched pair fixed effects	No	Yes
Observations	440	440

Note: Unstandardised regression coefficients with standard errors in parenthesis.

CHART 21: IMPACT OF IBD ON INCOME DIFFERENCE, VISUAL PRESENTATION

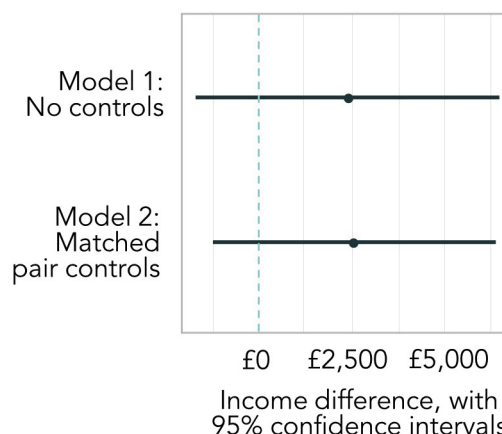


CHART 22: IMPACT OF IBD ON INCOME DIFFERENCE, OLS REGRESSION ESTIMATES

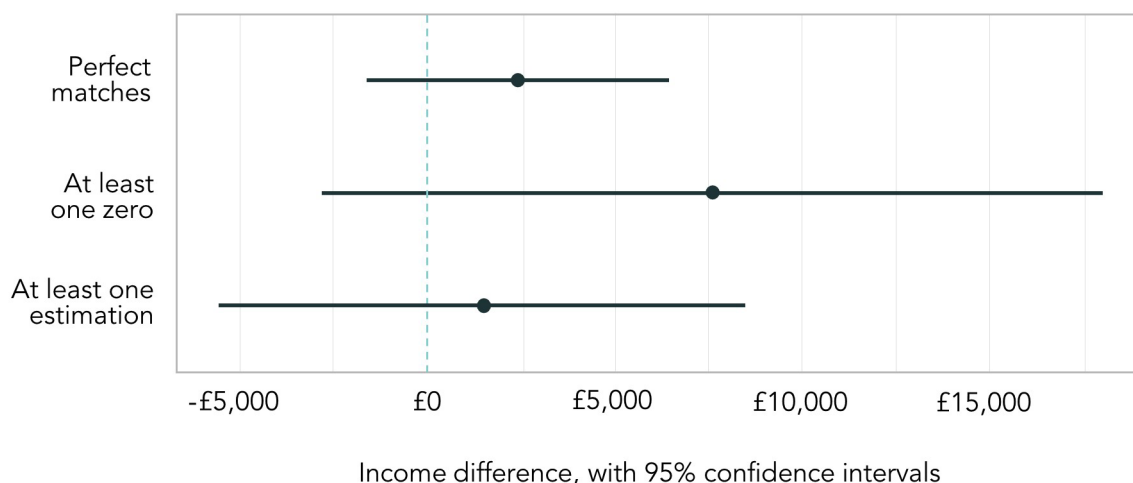


TABLE 3: AVERAGE INCOME DIFFERENCES FOR SUBCATEGORIES WITHIN THE IBD GROUP

	A	B	Sig
How much of a negative impact has living with IBD had on your career? A: Not at all a negative impact on my career; Not much of a negative impact on my career B: Significantly negative impact on my career; Somewhat negative impact on my career	£34,224	£42,404	**
I decided to leave a job because of my IBD. A: Strongly disagree; Somewhat disagree B: Strongly agree; Somewhat agree	£35,151	£43,003	**
Region A: Not living in Greater London B: Living in Greater London	£37,544	£46,425	**
Highest level of education A: No postgraduate qualifications B: Postgraduate qualifications	£38,690	£45,076	*
Socioeconomic class of parents A: Not higher managerial, administrative or professional B: Higher managerial, administrative or professional	£38,481	£44,620	*
How much of a negative impact do you think living with IBD has had on your educational achievements? A: Not at all a negative impact; Not much of a negative impact B: Somewhat negative impact; Significantly negative impact	£35,387	£42,408	**
Other disability aside from IBD A: No B: Yes	£39,883	£39,855	

Significance tests: * $p < 0.1$, ** $p < 0.05$

VARIATION IN INCOME WITHIN AND BETWEEN GROUPS

People in the IBD group differ in their experience with the disease, such as the severity of the disease and its overall impact on career choices. Table 3 summarises the average income for the IBD group segmented by responses to a selection of other variables. Surprisingly, on average, people who say their IBD has had a negative impact on their career report higher income levels.

Table 4 shows the average income for the different groups and a significance test for whether income differs across the groups, using a statistical test for difference-in-differences.

Specifically, this significance test is an interaction test between the category and IBD. It provides a test for whether the category (e.g., education) has a different impact on income for the control group and the IBD group (and thus whether the difference within one group is significantly different from the difference in the other group).

The average income differences between the groups are conditional upon the composition of the groups. That is, what we categorise as the low and high groups for the education and socioeconomic class of parents. For the highest level of education, if we add respondents with a bachelor degree to the 'High' group, the difference is no longer statistically significant. For socioeconomic class, we need to add "Intermediate managerial, administrative or professional", "Supervisory or clerical, junior managerial, administrative or professional", and "Skilled manual workers" before the difference is no longer statistically significant. Table 5 shows the values for these different group compositions.

People with IBD who were brought up in households in higher socioeconomic classes (supervisory roles and above) earned on average £41,868 whereas their matched pairs in the control group earned on average £44,046. Conversely, people with IBD who were brought up in households in lower socioeconomic classes (skilled manual and below) earned £36,997, whereas their matched pairs in the control group earned on average £28,534. This difference between the two groups is statistically significant (difference-in-difference test, $p < 0.05$).

TABLE 4: AVERAGE INCOME DIFFERENCES BETWEEN GROUPS

	Control		IBD		Sig
	A	B	A	B	
Region A: Not living in Greater London B: Living in Greater London	£37,293	£37,512	£37,544	£46,425	
Highest level of education A: No postgraduate qualifications B: Postgraduate qualifications	£34,322	£52,315	£38,690	£45,076	**
Socioeconomic class of parents A: Not higher managerial, administrative or professional B: Higher managerial, administrative or professional	£32,483	£55,750	£38,481	£44,620	**

Significance tests: *p<0.1, **p<0.05

TABLE 5: AVERAGE INCOME DIFFERENCES BETWEEN GROUPS, ROBUSTNESS TESTS

	Control		IBD		Sig
	A	B	A	B	
Highest level of education A: No bachelor degree or postgraduate qualifications B: Bachelor degree or Postgraduate qualifications	£34,624	£40,122	£37,903	£41,660	
Socioeconomic class of parents A: Higher managerial, administrative or professional; Intermediate managerial, administrative or professional; Supervisory or clerical, junior managerial. administrative or professional B: Other	£28,534	£44,046	£36,997	£41,868	**
Socioeconomic class of parents A: Higher managerial, administrative or professional; Intermediate managerial, administrative or professional; Supervisory or clerical, junior managerial. administrative or professional; Skilled manual workers B: Other	£30,053	£40,752	£37,013	£41,048	

Significance tests: *p<0.1, **p<0.05

DISCUSSION

There are specific challenges and limitations to consider.

- Gender differences in income. Women in the disease group earn £33,011 whereas women in the control group earn £25,848. This effect is statistically significant at the .05 level ($p=0.028$). There is no difference between the disease group and the control group for men. It is unclear what accounts for this discrepancy.
- Potential sampling bias. There might be potential biases in how respondents are sampled. Specifically, despite the selection of respondents on a set of specific characteristics, the respondents might not be comparable. One possibility is that the IBD group is not representative of people with IBD in general.
- Variations within the disease group. The variation in income within the IBD group is noteworthy (see for example Table 2). One could expect that people saying that IBD has had a significant negative impact on their career would report a lower income, but the opposite is the case. This could indicate that there are issues with the data beyond the comparison with the control group, or alternatively that IBD has a different effect for people who are otherwise on different career trajectories.

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