Crohn's, Colitis and Employment - from Career Aspirations to Reality

crohn's and colitis UK

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This report was supported by an educational grant from Abbott.

Acknowledgements

The *Crohn's, Colitis and Employment - from Career Aspirations to Reality* report was commissioned by Crohn's and Colitis UK, a leading UK charity offering comprehensive information and support to people affected by Crohn's disease (Crohn's) and Ulcerative Colitis (UC), together known as inflammatory bowel disease (IBD). The research and report text was guided by a research steering group (RSG) with a breadth and depth of knowledge and experience (please refer to the end of the report for RSG biographies). The activity was supported by an educational grant from Abbott.

Crohn's and Colitis UK would like to thank all RSG members for their time in establishing the employment survey and analysing the results and for their valuable contributions to the final report text.

Crohn's and Colitis UK would also like to give their appreciation to Tiffany Budd, Crohn's and Colitis UK member and artist, who kindly produced and shared her artwork for the design of this report.

Most importantly, Crohn's and Colitis UK would like to thank all of the men and women with Crohn's and UC who participated in this research and gave up their time to answer a host of questions related to the impact of their condition on their working life, and without whom this report would not have been possible.

About Crohn's and Colitis UK

Crohn's and Colitis UK (working name for The National Association for Colitis and Crohn's Disease) provides a valuable support network and information resource for people and families affected by Crohn's and UC as well as raising significant funds for research. Since 1984, members have raised over £6 million and more than 100 research awards have been made to hospitals and universities throughout the United Kingdom. The 70 local Crohn's and Colitis UK Groups across the UK enable its 31,000 members to meet other people who have these illnesses and share information and experiences.

Crohn's and Colitis UK also campaigns for better healthcare services and seeks to raise awareness of these illnesses and their impact on people's lives. Crohn's and Colitis UK is a partner in the UK IBD Audit Project and has been leading the IBD Standards Group developing national standards for NHS IBD Services.

The Crohn's and Colitis UK Information Line (daytime) 0845 130 2233 is available to members and non-members alike who have queries about all aspects of their disease. Crohn's and Colitis Support (afternoons and evenings) offers people a chance to speak by phone to a trained volunteer who has Crohn's or UC. There is a special Parent-to-Parent Helpline and support available for people claiming Disability Benefit.

Membership is open to anyone who wishes to support the charity and costs £12 per year (free for 16-18 year olds).

Acronyms

IBD – Inflammatory Bowel Disease
LTCs – Long-Term Conditions
RSG – Research Steering Group
UC – Ulcerative Colitis
WP – The Work Programme
WPAI - Work Productivity and Activity Impairment Questionnaire

For citation purposes

Gay, M.et al. *Crohn's, Colitis and Employment - from Career Aspirations to Reality. Hertfordshire:* Crohn's and Colitis UK, 2011.

Artwork credits

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Executive Summary

IBD - the main forms being Crohn's and UC – is a chronic disease in which the intestines become swollen, inflamed, and ulcerated. Symptoms include acute abdominal pain, weight loss, tenesmus (constant urge to have a bowel movement), diarrhoea (sometimes with blood or mucus) and severe fatigue. Some patients also experience associated inflammation of the joints, skin, liver or eyes. Symptoms vary in severity from person to person and, as a result of the fluctuating nature of the condition, can present suddenly and unpredictably.

Crohn's and UC are long-term conditions (LTCs) which most commonly first present in the teens and early twenties (25% present in adolescence; median age at diagnosis is 29.5 years).[1] The onset of the condition can be particularly difficult for many young people as it comes at a time when individuals are completing their education, seeking work for the first time, and embarking on a career in their chosen area. This study has found that IBD often has a negative impact upon their educational attainment and working life. For those with IBD who report wanting to work, this impact can be devastating to both the patient themselves and to the economy.

However, the effects of the disease on work can be minimised. Although no cure for IBD has yet been found, treatment aims to control or reduce the inflammation, with the ultimate goal of reaching and maintaining remission.[1] Simple and inexpensive adjustments can be made within the school, university or workplace to make life easier for people with IBD, such as allowing them to sit nearer to a bathroom, or providing flexible working hours so that they may visit their doctor or clinician for treatment or to allow them the extra time in the morning to cope with 'morning urgency' (a feature of the disease) and to deal with their symptoms whilst still arriving to work 'on time'.

With appropriate support from healthcare professionals, teachers and employers, people with IBD can be successful in education and work. However, during conversations with members it became apparent to Crohn's and Colitis UK that this support is not always available, with many members reporting a perceived lack of understanding about IBD amongst employers and other stakeholders. This often results in the reasonable adjustments that can be made to assist those with the condition being overlooked. This is particularly concerning in light of the Coalition Government's recently introduced Work Programme, the objective of which is to ensure that 'working always pays', and as part of which support is expected to be provided by employers to help employees remain in work.[2]

Due to the imminent work policy and welfare reforms juxtaposed with the apparent lack of knowledge around IBD, Crohn's and Colitis UK commissioned research to evaluate the long-term impact of Crohn's and UC on people's career aspirations, opportunities and choices; encompassing those in the employed, no-longer employed, or pre-employed groups. A further objective of the research was to utilise the results in establishing a set of recommendations to inform key stakeholders of the help and support they can provide to individuals with IBD and other LTCs to help them to reach their full working potential.

In 2010 - 2011, Crohn's and Colitis UK therefore commissioned a survey among adults of working age in the UK who have Crohn's or UC, with the survey, analysis and recommendations led by the RSG. This resulted in the following key findings and conclusions:

- IBD has a significant impact on the working lives and wider wellbeing of individuals with the condition;
- IBD affects people from career start to end, impacting aspirations and career choice through to premature retirement;
- The majority of people with Crohn's and UC go to work despite their condition;
- By working together, employers, healthcare professionals and policy makers can help people with IBD reach their full potential in the workplace;
- IBD need not hinder a person's work potential. By making reasonable adjustments, employers can help people with IBD achieve their potential and be productive at work;
- Changes to the welfare system need to ensure that people with fluctuating symptoms, such as in Crohn's and UC, are adequately supported financially during intermittent and unpredictable periods of incapacity for work.

Executive Summary Continued

In conclusion, the findings of this study highlight the overlapping links between the nature of IBD, the individual with IBD and the support offered to them by their employer and wider stakeholders in regards to their working life. Crohn's and Colitis UK are therefore calling for:

- A public-health based programme of information aimed at employers to help them understand the needs of people with Crohn's, UC and other LTCs;
- Increased prioritisation and quality service standards for Crohn's and UC patient treatment and care within the NHS, taking account of patient-preferences and priorities;
- The Work Programme, and other employment initiatives, to take into account the fluctuating symptoms that certain LTCs such as Crohn's and UC produce, to help people with IBD secure and stay in work which is appropriate for their skills and wanted by them;
- Improved working conditions for people with Crohn's or UC in all workplaces.

Reaching their potential in the workplace is a desirable aspiration for many people with IBD; achieving this goal will depend on a multidisciplinary approach to ensure that their working needs are met.

Chapter one:

Introduction and background information

1.1 About IBD

The two main types of IBD are Crohn's and UC. Both are chronic autoimmune conditions in which the body's immune system attacks itself. The conditions affect men and women equally, with diagnosis occurring most commonly in children and adults between the ages of 10 and 40; key educational and working years. The overall prevalence of IBD in the UK is estimated to be 240,000, approximately 400 patients per 100,000 population.[1] Crohn's affects approximately 60,000 people in the UK (approximately 1 patient per 1000 population), and UC affects up to 120,000 people in the UK (approximately 1 patient per 500 population).

Although grouped together as IBD, there are distinct differences between the two conditions. Crohn's can affect anywhere from the mouth to the anus but most commonly affects the small intestine and/or colon (large intestine). It causes inflammation, deep ulcers and scarring to the wall of the intestine and often occurs in patches. The main symptoms are pain in the abdomen, urgent diarrhoea, general tiredness and loss of weight.

UC affects the rectum and the colon. Inflammation and many tiny ulcers develop on the inside lining of the colon resulting in urgent and bloody diarrhoea, pain and continual tiredness. The condition varies according to the proportion of the colon affected.

Both Crohn's and UC are sometimes associated with other inflammatory conditions affecting the joints, skin and eyes. The majority of IBD presents as a fluctuating disease, with the severity of the symptoms varying unpredictably over time, generally following a pattern of remitting and relapsing, with patients likely to experience flare-ups in between intervals of reduced symptoms.

There is currently no known cure for Crohn's or UC. Drugs to suppress the immune system and to induce and maintain remission are the mainstay of medical management; however 30 per cent of IBD patients fail to respond to first-line drugs and will then be considered for anti-TNF-α biological therapy[1] (using biologic drugs that block a specific protein known to increase IBD)[3] or surgery to remove the colon.

Education and working life can be dramatically disrupted by the fluctuating nature of the disease; the recurrent need for the toilet, sleep deprivation and symptoms including fatigue and pain can affect an individual's ability to concentrate. Time taken to attend necessary appointments with a clinician can also disturb working patterns. In addition, the urgency with which people with IBD may need to use the toilet, or the associated fear/affect on the individual of not being able to reach a toilet in time to avoid an episode of incontinence, can greatly impact their ability or confidence to engage in certain work tasks or to embark on certain careers where access to a toilet may be limited.

As a leading provider of information and support services to people with IBD, Crohn's and Colitis UK recognise the significance of the relationship between IBD and employment, and as a result, commissioned this research. We believe that people with Crohn's and UC can be better supported to reach their career aspirations or full working potential. As with other LTCs, strategies can be put in place to help maximise the potential for people with IBD to engage in satisfying and productive employment.

1.2 Policy Context

Strategies surrounding the management of LTCs are a current focus in health policy. Supporting those with LTCs (which also affect younger people) to stay in work, thus maximising their economic productivity, has obvious benefits for society as a whole. However, the proportion of people with a limiting LTC in work remains a third lower than those who do not.[4] This is regrettable, particularly when so many people with LTCs including IBD **want** to work, and suggests that the support currently offered to those with LTCs is sub-optimal.

The 2010 White Paper *Equity and Excellence: Liberating the NHS* calls for an NHS with a relentless focus on delivering the outcomes that matter most to people.[5] The NHS Outcomes Framework[6] builds on this by including a specific framework section which focuses on enhancing quality of life for people with LTCs. 'Functional ability' is noted as a desired improvement area, with employment of people with LTCs provided as an indicator for this outcome.[6] However, it is important to note that achieving "good work"[7] for people with IBD should be prioritised, and that those working towards fulfilment of the policies should consider and factor in the fluctuating nature of symptoms present with conditions such as Crohn's and UC. Equally, we must recognise that healthcare professionals cannot work in silo with their patients to improve the working lives of people with IBD. There are many more stakeholders involved, including educators, career's advisors, and of course employers themselves.

In 2011, the Government published its personalised care planning strategy, which aims to improve the support for people with LTCs and to help them to have better social and working lives.[8] The strategy recognises that in addition to medical needs, other issues affect the health and wellbeing of a person with a LTC. It therefore urges patients and healthcare professionals to work together to consider the impact of the LTC on their quality of life, not just restricted to health but considering broader issues including education and work, and to help the patient to achieve the outcome that they want for themselves.

Welfare to Work reforms focus on capacity rather than incapacity, and introduce measures designed to support people in finding sustainable work and to ensure that disabled people have the same opportunities as non-disabled people to succeed in life and fully participate in society.[2,9] To deliver these outcomes, both the Welfare Reform Bill 2011 and The Work Programme (WP) prospectus highlight the need to treat people as individuals and to understand their capabilities and tailor support to their individual needs. This is important when considering those with IBD; WP delivery partners, advisers and employers need to be educated on the nature of fluctuating symptoms that certain LTCs produce and to facilitate action or working plans which account for and accommodate variable stages of disease. Reasonable workplace adjustments should vary according to individual needs and preferences at different disease stages, as the needs of people with IBD will not be linear.

Dame Carol Black's 2008 Review *Working for a Healthier Tomorrow*,[10] and the Government's response *Health, Work and Wellbeing*,[11] made a series of useful recommendations for policy makers, employers and the NHS to improve the lives of the working age population. As Dame Carol Black, National Director for Health and Work, and David Frost, Director General of the British Chambers of Commerce, undertake the independent review of the sickness absence system,[12] we very much hope that this report will be a useful resource to ensure that those with progressive LTCs with fluctuating symptoms are appropriately supported.

More work is needed to ensure that people with IBD are able to reach their full working potential. A key part of this is the education of employers, teachers and other stakeholders about IBD in order that they can strengthen the support offered to people with the condition. The findings presented in this report assess how IBD affects people's working lives, in order to inform Crohn's and Colitis UK's strategy and activity to guide members in conversations with employers and the NHS to organise support/provide information in facilitating support.

This research is the first of its kind. Although there is a wealth of information on LTCs, only a small percentage concentrates on the impact on employment status, and very few pieces focus on IBD and working life. This research is therefore much needed; we hope that by publishing evidence highlighting employment issues from the perspectives of people with IBD, stakeholders may take-notice and prioritise their needs.

What is Good Work?

According to The Work Foundation, 'good work' refers to an employment relationship that "seeks to balance the interests of individuals, employers and society in order to deliver performance, engagement and fairness. Good work is work that is rewarding for employees, employers and society. For employees, good work provides secure and interesting jobs; choice, flexibility and control over working hours; autonomy and control over the pace and timing of work and the working environment; a say in the critical decisions that affect their futures; and an appropriate balance between effort and reward. From a business perspective, good work is productive and efficient; aims to involve and engage employees; and to encourage their contribution to organisational success".[7]
Visit **www.theworkfoundation.com**

Chapter two:

Methodology

2.1 Research design

The aim of this research was to evaluate the long-term impact of Crohn's and UC on career aspirations, opportunities and choices, and to evaluate the effect of IBD on those who are employed, no longer employed and in the pre-employed group. This chapter describes the research design, the survey population, survey limitations and recommendations for future research.

The research design consisted of a questionnaire of 78 questions, divided into the following sections:

- The first section, for completion by all participants, asked a few standard introductory questions such as the participants' age.

- The second section asked about the participants' condition, for example the number of years since diagnosis and the participants' current disease status and severity of symptoms. Questions included a visual analogue scale, which asked people to rate their health state in the last seven days (on a scale of 1-10 where 0 is the worst possible state). It also asked whether they had any other LTCs.

- Section three was intended for participants who are in employment, and asked about the impact of the disease on the participants' work choices, practices and associated wellbeing factors, for example whether IBD impacts on the participants' job satisfaction. It also asked the participants about the support that is provided to them by their employer, and about their perceived importance of employer support. In addition, the survey included the Work Productivity and Activity Impairment Questionnaire (WPAI) which is a validated tool looking at the impact of health conditions (in this instance IBD) on different aspects of work in the last seven days.

- Section four provided questions for those not in paid employment, to assess whether IBD is a reason for those participants who do not currently work. It also asked about the extent to which IBD played a part in the participants' decision to retire (where applicable) and asked about participants' sources of financial support.

- The fifth section was for those aged 16 – 25 who had not yet entered work. It asked about the participants' pre-employment concerns related to their condition, for example whether they worried about being able to find a job to fit around their IBD. Questions also looked at the impact of IBD on wider attainment and wellbeing issues, such as whether IBD prevented the participants from reaching their full educational potential or whether the condition had impacted on the participants' confidence.

2.1.1 Fieldwork information

The *Crohn's, Colitis and Employment - from Career Aspirations to Reality* research was conducted using online and postal interviews among adults of working age in the UK who have Crohn's or UC. Data were collected between the 4th January 2011 and 28th January 2011. Interviews were conducted online through the Crohn's and Colitis UK website; members or non-members could access the online survey. Data were also completed by post via a mail-out of printed questionnaires to 2000 members of Crohn's and Colitis UK. To avoid sampling bias, the 2000 recipients of the postal surveys were selected according to the natural proportions of those with UC and CD, as well as by national regional statistics. The questionnaire length was 10-20 minutes, dependent on answers given. Most questions were multiple choice, with some open textboxes available for additional comments throughout. For the full top-line research findings, please refer to the appendix at the end of the report.

2.1.2 Study population characteristics

A total of 1906 people participated in the research:

- 1107 respondents had Crohn's, of which:
  - 744 were in paid employment;
  - 306 were not in paid employment;
  - 57 were "pre-employed" – that is, aged 16-25 and had not yet started full-time employment

- 799 respondents had UC, of which:
  - 570 were in paid employment;
  - 195 were not in paid employment;
  - 34 were "pre-employed" – that is, aged 16-25 and had not yet started full-time employment

70 per cent of participants were female, 30 per cent male. The vast majority (82%) of respondents lived in England, with nine per cent from Scotland, three per cent Wales, three per cent Northern Ireland and two per cent 'other'. Only those aged under 16 and above 65 were excluded.

2.2 Research analysis

Data were coded and entered by a full-service market and opinion research firm. Data were analysed using Excel and STATA software. Statistical analyses were performed using Pearson's Chi-squared ($\chi 2$), Fisher's exact test and ANOVA, revealing significance at an α level of 0.05.

2.3 The role of the RSG

The research development was guided by a RSG with a breadth and depth of knowledge and experience across areas such as research development, general and occupational healthcare, and employment issues (for further information please refer to the biographies at the back of this report). The RSG, chaired by Crohn's and Colitis UK, met on a regular basis to determine the aims and objectives of the research. Once agreed, the RSG worked with a research firm to develop the questions. Their combined knowledge and skills were used to analyse the research results and reach the conclusions and recommendations as presented within this report.

2.4 Study limitations

There were some methodological limitations related to the study:

- Respondents were not asked about where they live, other than a country-specific question. Regional breakdowns of data would be useful in future research to help inform regional support service facilitation and the commissioning of healthcare services.

- There was a larger proportion of people with higher education (degree/masters/PhD) in the respondent sample then is representative of the general population. Statistical analyses to test if there were any significant differences in the responses people gave dependent on their education were completed. The analyses revealed that people educated to NVQ/GCSE level stated that IBD had a greater impact on their working life and aspirations than those with a higher level of education. This suggests that the results from the survey could be an underestimate of the impact of IBD on work and general wellbeing.

- There was a larger proportion of females in the respondent sample (70%) then is representative of the UK IBD population, which is an approximately 50 per cent split between males and females. Statistical analyses to test if there were any significant differences in the responses people gave dependent on their gender, revealed that the majority of answers were not significantly different. Where there were differences, it appears that females are more concerned about managing their IBD at work and would compensate more then men to overcome this, whereas men were less likely to discuss their IBD with their employer.

- There was a larger proportion of people working in the public sector in the respondent sample then is representative of the UK general working population. Therefore, the RSG wanted to investigate if the job sector people worked in had an impact on respondents' answers in the survey. The majority of questions showed that there was not a significant difference in responses between the public and private sector, with the exception of questions around working from home. People in the public sector were much less able to work from home and their employers were the least likely to provide this. Furthermore, people in the public sector felt they had less control over their working conditions and worried more about managing a flare-up in their symptoms than the other sectors.

- Statistical analyses to test whether the following variables had an impact on how respondents answered the majority of questions in the survey, showed that age; area where respondents lived (e.g. rural, urban, suburban, village); and whether a person had Crohn's or UC did not have any statistical impact on how respondents answered the questions in the survey. Although these variables did not affect the overall findings, it isn't clear whether the distribution of people across these variables is representative of the UK general population.

2.4.1 Suggestions for future research and reports

The effect of IBD and other LTCs on work and wider wellbeing is extremely complex and multi-factored. Although this survey was detailed and reached its objectives, this report represents only the top-line results from the survey. Future reports may present the results of further in-depth analysis of the data, for example:

- An expansion on section five of this research, considering the effects of IBD on young adults, looking particularly at the effect on their self-stigma. This could be beneficial to provide further recommendations as to how stakeholders could boost their confidence.

- The impact of IBD on working life dependent upon educational attainment and job sector. Initial analyses of these research data caused the RSG to hypothesise that there may be links between the impact of IBD on education, the level of education achieved, the type of job then secured and the ongoing impact of IBD on working life per job sector; however this is a complex area that deserves further consideration.

Additionally, there are many other areas that could be researched to give valuable insights into the impact of IBD on working life, leading to further calls to action and recommendations to stakeholders. As a starting point, the RSG recommends future research is conducted to investigate the links between IBD, psychological wellbeing, and work. Previous research has established a considerable mental health component in LTCs that adversely impacts on patient outcomes.[13] This survey found those who report having mental health conditions e.g. depression, are less likely than those without to be employed (52% vs. 73%, with 69% of total respondents reporting paid employment). They are also less likely to work full-time (53% vs. 64%, with 62% of total employed respondents working full-time). Further research could lead to recommendations for valuable interventions to improve support for people with both IBD and mental health difficulties.

Further research could also add to our understanding of the indirect costs of IBD to businesses and the economy. In the UK, the Confederation of British Industry has estimated that 175 million working days were lost last year to total sickness absence, at a cost to the economy of £13 billion.[14] Previous research suggests that only 75 per cent of people with Crohn's are fully capable of work in the year after diagnosis, with 15 per cent of people unable to work after 5–10 years of disease.[15] For those with UC, after the first year approximately 90 per cent of patients are fully capable of work (defined by less than 1 month off work per year), although UC causes significant employment problems for a minority.[15] Data for levels of costs associated with lost productivity due to Crohn's and UC are variable, but some studies have estimated that `indirect' costs falling on society exceed medical expenditures.[16] Addressing the impact of Crohn's and UC on work can make a real and substantial difference to the health of individuals and the cost to businesses and the economy.[14]

Chapter three:

The impact of living with IBD on the individual's working life

This chapter examines the impact of living with IBD on an individual's working life as perceived by the survey respondents. It considers working lives from the outset, looking at career choices and opportunities and the impact on job satisfaction; it assesses the impact of IBD during employment, considering relationships with colleagues, productivity in the workplace, and workplace worries; and it considers the impact of IBD on retirement. It concludes considering the workplace adjustments that could be made by employers.

All responses detailed below were from respondents in paid employment, unless otherwise stated. The statistics listed refer to the total number of respondents who were asked each question; where the statistics were markedly different (a percentage gap of five or more) between those respondents with either Crohn's or UC the individual figures are provided. For the full top-line research findings, please refer to the appendix at the end of the report.

3.1 Career choices, opportunities and job satisfaction

The survey listed a series of statements designed to assess the impact of living with IBD on work choices and opportunities and asked respondents whether they agreed with the statements or not. Two in five respondents with Crohn's and one third of those with UC agreed completely or somewhat that their IBD had prevented them from pursuing their preferred choice of job (40%, N=744; and 32%, N=570; respectively). When delving deeper into restrictions on job selection, commuting was a significant concern, with nearly half of respondents stating that they agreed completely or somewhat that their IBD restricted them from choosing a job with a long commute (47%, N=1,314). Nearly one quarter of respondents admitted that they would look for a different job if they didn't have IBD (24%, N=1,314. Respondents with Crohn's, 27%, N=744. Respondents with UC, 20%, N=570).

The research findings continued to reveal that IBD impacts on career opportunities as well as choices. Respondents completely or somewhat agreed to the following statements:

- Half stated that their IBD had prevented them from reaching their full potential in the workplace (50%, N=1,314); for those with Crohn's, the percentage was even higher at 53% (N=744. Respondents with UC, 46%, N=570)

- Half of respondents stated that their IBD has had an impact on their career progression (51%, N=1,314). The percentage of respondents with Crohn's stating that their IBD had an impact on career progression rose to 54% (N=744. Respondents with UC, 47%, N=570)

In addition to affecting career opportunities, IBD impacts on earning opportunities; more than one third of respondents perceived earning less as a result of their IBD (35%, N=1,314).

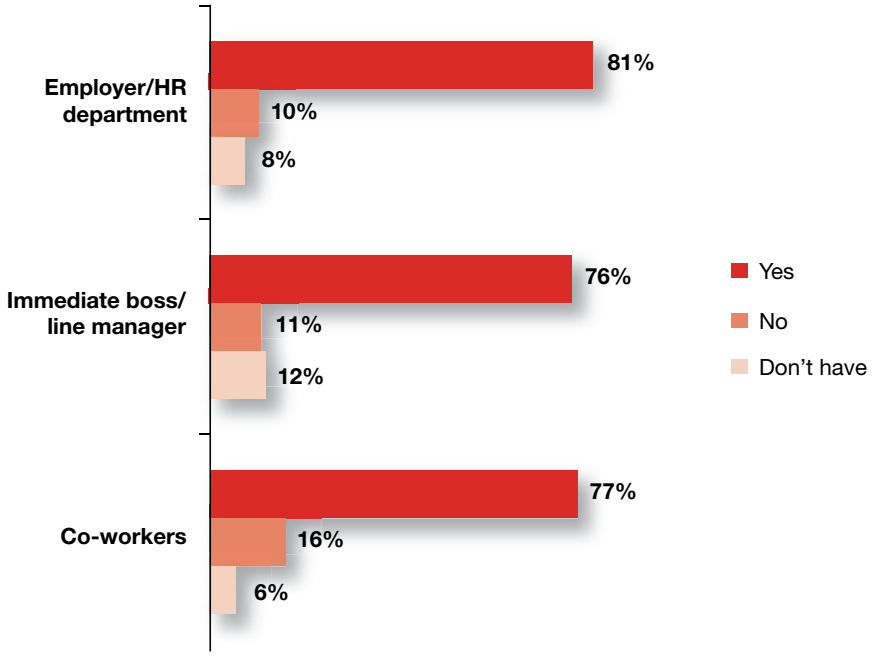
IBD also impacts on job satisfaction; one third of respondents said that their job satisfaction had decreased because of their IBD (33%, N=1,314).

> *"It is particularly saddening that IBD has such an impact on a person's career choices and opportunities. We know from our conversations with members that feeling unable to embark upon their career of preference, or believing that they are unable to progress within a career, is likely to leave a person feeling frustrated and unmotivated. It is therefore unsurprising that this has a knock-on impact on that person's job satisfaction. Since the majority of people spend more than half of their waking hours in the workplace, being unhappy in a career can have a significant impact on a person's overall happiness."*
>
> **Dr Martin Gay, Vice-Chairman, Crohn's and Colitis UK**

3.2 Relationships with colleagues

The research revealed that the majority of people with IBD are very or somewhat comfortable discussing their IBD at work (61%, N=1,314. Respondents with Crohn's, 66%, N=744. Respondents with UC, 56%, N=570). Over three quarters of those with the condition have told their co-workers that they have IBD (77%, N=1,314. Respondents with Crohn's, 80%, N=744. Respondents with UC, 73%, N=570), and four out of five respondents stated that they had told their employer or HR department (81%, N=1,314). Slightly fewer respondents had told their immediate boss or line manager (76%, N=1,314. Respondents with Crohn's, 79%, N=744. Respondents with UC, 73%, N=570).

Figure 1. Responses to the question: "Have you told your employer/ HR department, immediate boss/ line manager and co-workers that you have IBD?"



For those who hadn't told their immediate boss or line manager, reason for non-disclosure included:

- Preferring the boss or line manager not to know (53%, N=143)
- Feeling that there is no-point in disclosure since no-one can help (21%, N=143)
- Feeling at risk of losing their job (20%, N=143. For those with Crohn's, 26%, N=69. For those with UC 15%, N=74)

Despite most employees feeling comfortable about discussing their condition, two in five respondents stated that they worry their colleagues may think that due to IBD symptoms they do not pull their weight at work (40%, N=1,314). In addition, a quarter of respondents stated that they worry about being discriminated against in the workplace as a result of their IBD (26%, N=1,314. Respondents with Crohn's, 29%, N=744. Respondents with UC, 22%, N=570).

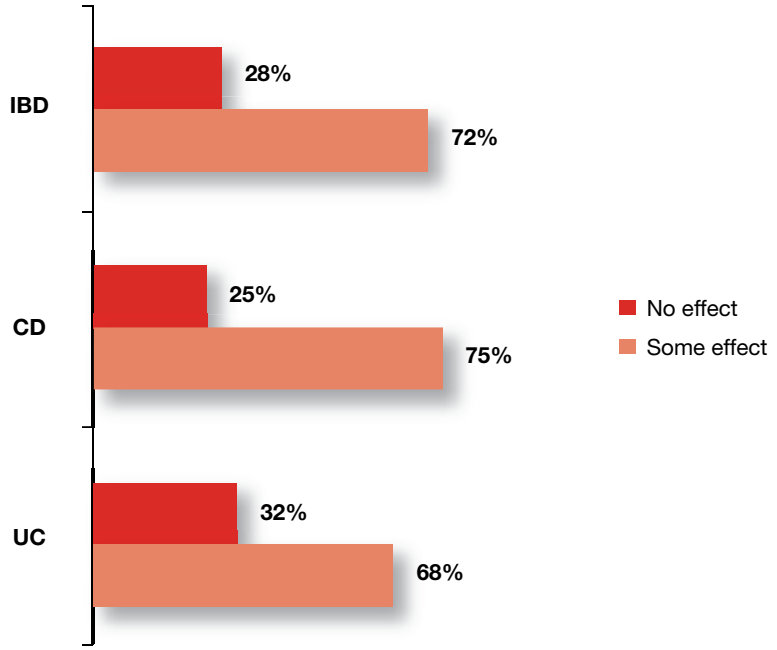
3.3 Productivity in the workplace

The research questionnaire asked respondents to consider how much their IBD symptoms affect their productivity while they are working. As part of the validated WPAI tool, respondents were asked to think about the past seven days, and consider on a scale of one to 10 how much their IBD symptoms affected their work; whether they were limited in the work they could do, whether they accomplished less than they would like, or whether they could not do their work as carefully as usual.

> *"It is reassuring that the majority of people with IBD feel comfortable discussing their condition with their employer if they choose to, since teamwork is vital for working with IBD. Communication between employer and employee is essential to ensuring that reasonable adjustments can be made within the workplace to allow the person with IBD, or for that matter any other LTC, to reach their working potential. Discussing the condition is also valuable in establishing a climate of trust, eradicating any misconceptions about the illness, and removing any unwarranted stigma."*
>
> **Peter Purton, Policy Officer for Disability and LGBT, Trades Union Congress**

- Three quarters of respondents stated that their IBD had had some effect on their work in the past seven days (72%, N=1,314. Respondents with Crohn's, 75%, N=744. Respondents with UC, 68%, N=570), with nearly one third scoring themselves five or higher, suggesting that their symptoms had had a moderate to great effect (29%, N=1,314)

Figure 2. Responses to question: "During the past seven days, how much did IBD symptoms affect your productivity while you were working?"



- One in twenty respondents stated that their IBD symptoms had completely prevented them from working in the last seven days (6%, N=1,314)
- Nearly one third of respondents stated that they would work longer hours if they didn't have IBD (32%, N=1,314)
- More than half of the respondents have had to reduce their working hours as a result of their IBD (57%, N=1,314. Respondents with Crohn's, 59%, N=744. Respondents with UC, 53%, N=570)

3.3.1 Impact of disease severity on the ability to work

Given the results presented in 3.3 and the fluctuating nature of IBD symptoms, the RSG were interested to determine what impact disease severity has on the ability to work. Questionnaire respondents were asked to rate their health state in the last seven days (on a visual analogue scale (VAS) of 1-10 where 0 is the worst possible state). They were also asked to complete a series of questions from the WPAI questionnaire (please see appendix one), which when assessed together revealed the quantitative impact of IBD on work by disease severity.

Based upon their answers, respondents were split into the following quartiles reflecting their current health state:

- Group 1: 0 to 2.5 - this is the group who have the worst health states
- Group 2: > 2.5 to 5 – this group have moderately bad health states
- Group 3: > 5 to 7.5 – this group have moderately good health states
- Group 4: > 7.5 up to and including 10 - this group have the best health states and are broadly comparable to the general population's health

The RSG then considered respondents' work productivity by calculating a percentage of hours missed from work due to IBD and hours affected whilst at work by IBD, by these four groups, as per table one. The results revealed that IBD has a substantial impact on people's 'total work' whilst they are experiencing a bad flare-up (Group one). Conversely, if people are feeling fine in their current health (Group 4: 7.5-10) then they have a total work productivity score better than the general population.[17]

Table one: The impact of IBD on hours missed from work, and hours affected whilst at work, due to IBD stratified by health state

Respondent group Visual Analogue Scale (VAS)	"Productivity loss" (WPAI)	P Value*	Number of respondents
Group 1 (VAS score 0 - 2.5)	**71%**	P<0.0001	N=129
Group 2 (VAS score 2.5 - 5)	**48%**	P<0.0001	N=464
Group 3 (VAS score 5 - 7.5)	**25%**	P<0.0001	N=372
Group 4 (VAS score 7.5 - 10)	**8%**	P<0.0001	N=313

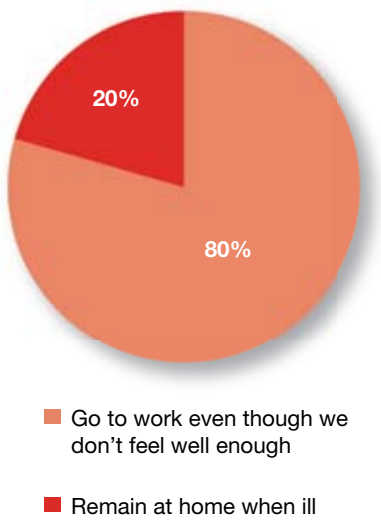
** The significance levels were assessed using the Fisher's exact t-test in a pair-wise comparison i.e. Group 1 vs. Group 2, Group 2 vs. Group 3 etc.*

3.3.2 Conscientiousness of workers

Published evidence suggests that IBD does have an impact on an individual's productivity, and the research findings support this. Yet the survey also revealed that, despite facing such challenges to productivity, employees with IBD tend to be conscientious:

- Four out of five respondents reported sometimes going to work even if they did not feel well enough (80%, N=1,314. Respondents with Crohn's, 83%, N=744. Respondents with UC, 75%, N=570)

Figure 3. Responses to question: "Which of the following best describes you?"

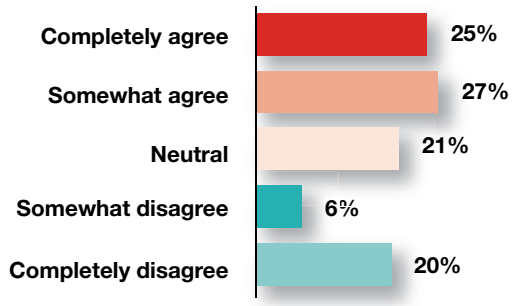


"The correlated VAS and WPAI data are particularly interesting, as they reveal that when people with IBD are fit for work they work brilliantly, but when they are ill they simply cannot. For example, a person may be declared fit for work one week because they fall into group four when assessed, but if they experience a flare-up of their condition two weeks later, they may fall into group one and no longer be able to work. Employers, clinicians and policy makers need to be aware that IBD is a long-term disease with fluctuating symptoms, and that people can shift between these groups from one week to the next. Therefore procedures need to be in place to support people with IBD in the work place."

Karen Bean, Senior Health Economics and Outcomes Research Advisor, Abbott

- More than half of respondents reported giving more effort at work to make up for any shortcomings that resulted from their IBD (52%, N=1,314. Respondents with Crohn's, 57%, N=744. Respondents with UC, 45%, N=570)

Figure 4. Responses to question: "I give more effort at work to make up for any shortcomings that result from my IBD"



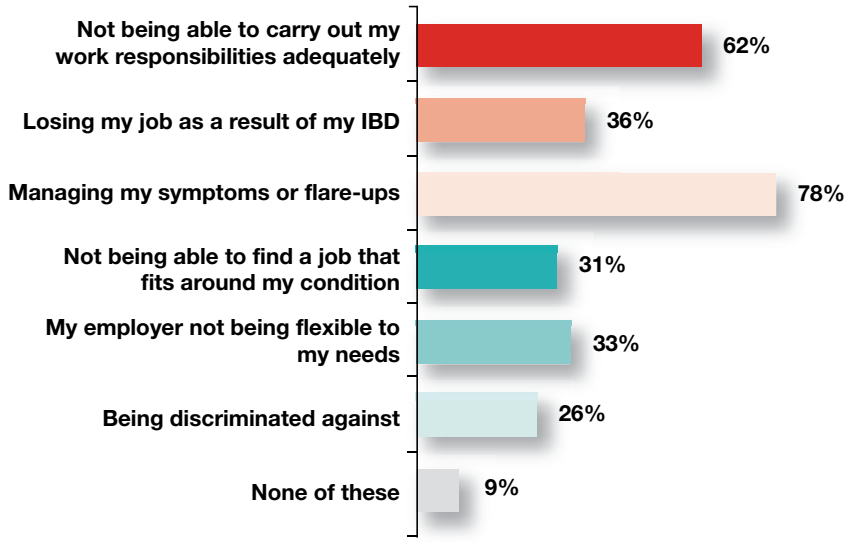
- During the seven days prior to their questionnaire completion, over two thirds of respondents in employment had not missed any hours from work due to problems associated with their IBD (71%, N=1,314) despite two-fifths of all questionnaire respondents experiencing a flare-up within the previous week (40%, N=1,314.

3.4 Workplace worries

The research questionnaire asked respondents to consider what they worry about in the workplace as a result of their IBD. When provided with a list of possible responses:

- The most commonly stated worry was 'managing my symptoms or flare-ups' (78%, N=1,314)
- Nearly two thirds of respondents stated that they worry about not being able to carry out their work responsibilities adequately (62%, N=1,314)
- Approximately one in three respondents worries about not being able to find a job that fits around their condition (31%, N=1,314)
- More than one third of respondents worries about losing their job as a result of their IBD (36%, N=1,314)

Figure 5. Responses to question: "Which of the following do you worry about in the workplace as a result of your IBD?"



3.4.1 Fears about losing work

One third of respondents stated that as a result of their condition, they feel at risk of losing their job (33%, N=1,314) and two in five respondents stated that during a recession, their IBD makes them feel particularly vulnerable to unemployment or job loss (41%, N=1,314). Half of respondents suggested that their IBD makes it difficult to remain employed (50%, N=1,314); reasons provided included:

- The need to take too much time off of work (28%, N=1,314)
- Difficulty getting to and from work (18%, N=1,314. Respondents with Crohn's, 14%, N=744. Respondents with UC, 23%, N=570)
- Receiving too little support and understanding from their employer (11%, N=1,314)

3.5 Early retirement and unemployment

If IBD affects career choice and progression, it seems logical that it may also play a part in a person's decision to leave work. The research revealed that for the majority of retired respondents, their IBD had played some part in their decision to retire (76%, N=167. Respondents with Crohn's, 84%, N=92. Respondents with UC, 65%, N=75). When asked the question 'to what extent did your IBD play a part in your decision to retire when you did?' more than half of these respondents stated 'a great deal' (53%, N=167. Respondents with Crohn's, 66%, N=92. Respondents with UC, 36%, N=75).

Given these significantly high figures, the RSG was interested to determine whether IBD influences *early* retirement in people living with this condition. One of the questions asked at what age people chose to retire the data indicated that there was a notable difference between the retirement ages of people with Crohn's and UC, with a larger proportion of people with CD retiring under 50 years of age (respondents with Crohn's, 35%, N=92. Respondents with UC, 24%, N=75). When looking specifically at the reason for retirement in people with Crohn's aged less than 50, nearly three quarters of these people answered **a great deal** to the question 'to what extent did your IBD play a part in your decision to retire when you did' (72%, N=32).

"It is disappointing to prove that LTCs, such as IBD, play a part in early retirement and for some people, in their ability to work at all. This is an unacceptable loss of working potential. With regular monitoring and appropriate treatment, many of the symptoms of IBD can be managed, and although the disease symptoms fluctuate, it can for many patients be a non-disabling disease for much of the time. Since most of those with the condition want to work, I hope that the findings from this report encourage all stakeholders involved in employment issues to cater for those with IBD so that they may remain fit for work."

Stephen Bevan, Managing Director of the Work Foundation

In addition to impacting on retirement, the survey also revealed that for some people their IBD makes it hard for them to work at all. When looking at responses of those who were not in paid employment, but were also not retired, nor full-time students, volunteers, parents or carers:

- Half stated that their IBD makes it hard for them to work at all (51%, N=224. Respondents with Crohn's, 54%, N=142. Respondents with UC, 46%, N=82)
- Two in five respondents stated that their IBD makes it hard for them to find a suitable job (42%, N=224. Respondents with Crohn's, 37%, N=142. Respondents with UC, 50%, N=82)
- Less than two in ten respondents suggested that their treatment makes it hard for them to get through the process of applying for jobs (14%, N=224. Respondents with Crohn's, 9%, N=142. Respondents with UC, 22%, N=82)

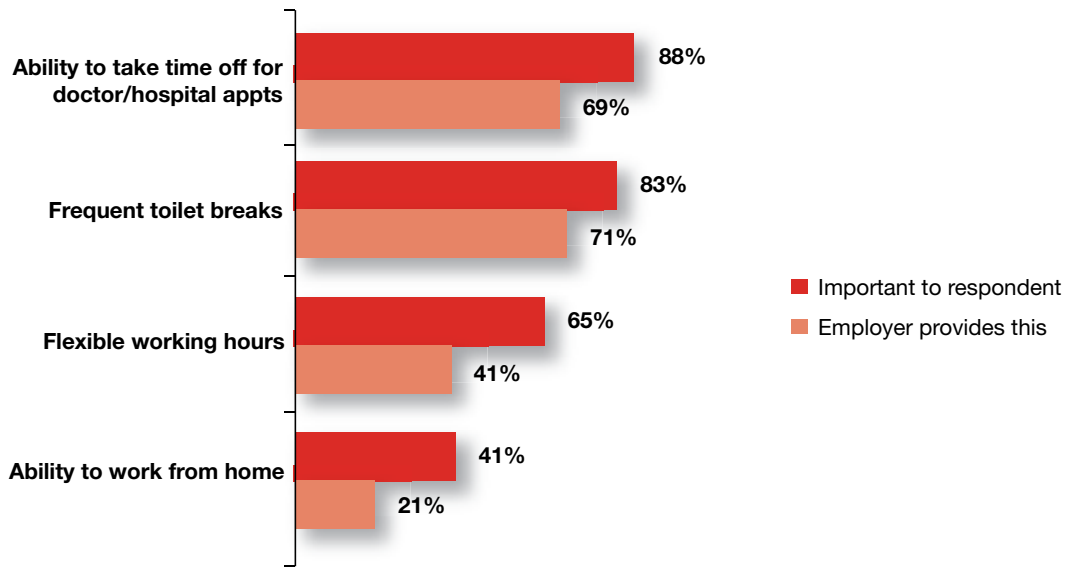
3.6 The need for reasonable workplace adjustments

The survey asked respondents about the levels to which they feel their employer supports them to carry out their job with their IBD. It revealed that one third of respondents worry about their employer not being flexible to their needs (33%, N=1,314. Respondents with Crohn's, 37%, N=744. Respondents with UC, 29%, N=570). Nearly two thirds do not feel fully supported by their employer to carry out their job with their IBD (64%, N=1,314).

When asked what support is important to them and what support their employer actually provides, discrepancies were highlighted as follows:

- Despite the vast majority of respondents stating that the ability to take time off for doctor/hospital appointments (separate from holiday allowance) is important to them (88%, N=1,314), nearly a third of employers are reported to not provide this (31%, N=1,314)
- Nearly one third of respondents said that their employer does not provide frequent toilet breaks (29%, N=1,314) yet the vast majority of respondents felt that this is important to them (83%, N=1,314)
- The biggest differential between a workplace adjustment of importance to respondents vs. reported provision by employers related to flexible working hours; 65 per cent of respondents felt this was important, 41 per cent of employers provide it (N=1,314)
- Two in five respondents stated that the ability to work from home is important to them (41%, N=1,314). One in five cited their employers providing the ability to work from home (21%, N=1,314)

Figure 6. Responses to question: "Which of the following is important to you? And, if you have an employer, which do they provide?"



Chapter four:

Early concerns of young people with IBD

This chapter examines the impact of IBD on employment considerations for young people aged 16-25 who have not yet entered full-time work. It looks at the impact of IBD on educational attainment, worries about future employment, and career choices and aspirations. All responses detailed below were from respondents aged 16-25 who had not yet entered full-time work, unless otherwise stated.

4.1 Educational attainment

The survey confirmed that having IBD can impact on the educational attainment of young people. Two thirds of respondents stated that their IBD has delayed or is delaying their education and/or training (67%, N=91). A higher percentage of respondents stated that their IBD has prevented them from reaching their full educational potential (69%, N=91).

4.2 Career confidence and aspirations

The survey responses revealed the significant impact of IBD on young people's career aspirations.

- More than half of the respondents suggested that due to their IBD, they would rule out some career options that they may otherwise have considered (56%, N=91)
- The vast majority of respondents noted that their IBD has affected their confidence and self-esteem (79%, N=91)
- Half of the pre-employed respondents revealed that their IBD has delayed them starting work or looking for employment (49%, N=91)
- More than two in five respondents stated that their IBD means they will find it more difficult financially in the future compared to other people (47%, N=91)
- Importantly, the majority of respondents stated that they would like career guidance which takes their IBD into account (60%, N=91)

"The report findings prove that IBD downgrades the aspirations of young people. Due to the nature of the illnesses' symptoms - prolonged tiredness, the urgent need to use a toilet, extreme pain etc, it is not unexpected that young people put limitations on the jobs that they seek. The perceived constraints may be logistical, in terms of not aiming for a job requiring frequent travel for example, or emotional, for example not stretching themselves in terms of their capability due to low self-esteem. Sadly, the research reveals that nearly half of young people with IBD have resigned themselves to the fact that they are likely to earn less than their peers. This is a terrific waste of potential. It is vital that careers advisors, teachers, lecturers etc. recognise the needs of young people with IBD, encouraging them to aspire to, and helping them to achieve, the career of their choice."

Dr Ian Barrison, Associate Dean, University of Herts School of Postgraduate Medicine

4.3 Worries about future employment

All respondents expressed concern about future employment. When asked about their specific worries:

- The vast majority expressed concern about managing their symptoms or flare-ups (82%, N=91)
- Two thirds of respondents worry about being able to carry out their work responsibilities adequately (66%, N=91)
- Two in three respondents worry about their employer not being flexible to their needs (65%, N=91)
- More than half worry about not being able to find a job that fits around their condition (57%, N=91)
- Over two in five expressed worry about losing their job as a result of their IBD (45%, N=91). Nearly two thirds expressed fear that their IBD would make them more vulnerable in terms of employability or job loss in a recession (64%, N=91)
- More than a third worry about being discriminated against (38%, N=91)

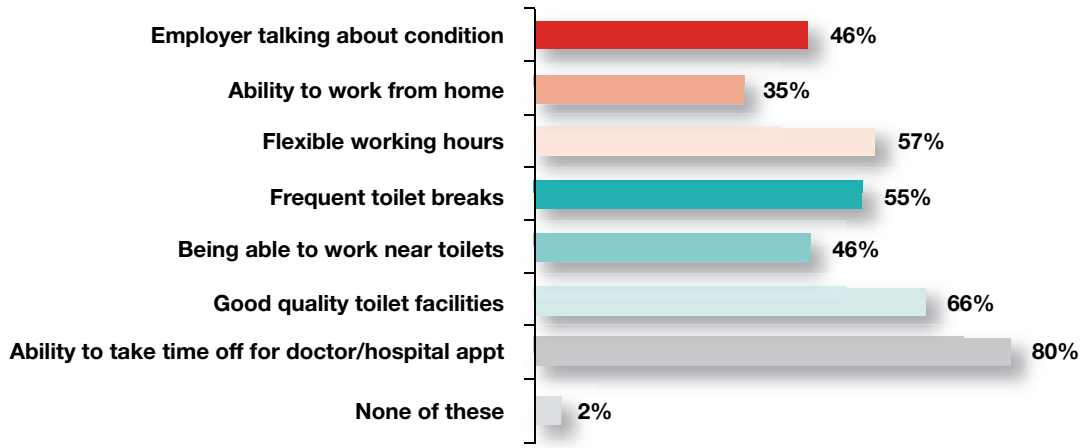
4.4 Job characteristics of importance

Respondents were provided with a list of job characteristics, and asked which they felt would be of importance to them in a job. Responses could be broken into three categories; working hours, toilet facilities and employer support.

> *"It is not surprising that young people with IBD have significant worries about commencing employment. It is common for IBD to first present in the teenage years, adding a burden into what can be, for some, a difficult transition time between childhood and adulthood. Entering into work, particularly for those who have recently been diagnosed with an LTC, can be a scary thought for young people."*
>
> **Helen Terry, Director of Information and Support, Crohn's and Colitis UK**

- Four out of five respondents stated that the ability to take time off for doctor/hospital appointments, separate from holiday allowance, would be important (80%, N=91). Nearly three out of five rated flexible working hours as important (57%, N=91), and more than one third expressed that the ability to work from home would be important (35%, N=91)
- Two thirds considered good quality toilet facilities to be important (66%, N=91). The ability to take frequent toilet breaks was important to more than half of the respondents (55%, N=91), with just under half also wanting to work near to toilets (46%, N=91)
- Nearly half of pre-employees stated that their employer taking the time to talk to them about their condition would be important (46%, N=91)

Figure 7. Responses to question: "Which of the following would be important to you in a job?"



4.5 Comparisons between pre-employed research respondents and those in employment

The RSG was interested to see which aspects of working life affected by IBD continued from pre-work into employment. People in employment aged 16-25 and people aged 16-25 who are yet to enter full-time employment completed different parts of the questionnaire. However there were some questions in the employed section and in the pre-employed section that were the same, allowing comparisons across the two groups. When tested using Pearson's Chi-squared, comparisons revealed some statistically significant differences. For example, pre-employed people were much more worried about not being able to find a job that fits around their condition compared to those in employment (Pre-employment, 57% vs. Employment, 36%, $p<0.0001$)

However, when asked about specific qualities that are important within a job, people who were in employment ranked various work characteristics as more important, compared to those in pre-employment (please see table two). This may be because they have experienced first hand exactly what it is like to work with their IBD, and which specific job characteristics are important.

Table two: Important job characteristics for those who are pre-employed compared to those in employment

Which of the following is / would be important to you in a job?	Pre-employed	Employed	P value*
The ability to take time off for doctor/ hospital appointments, separate from my holiday allowance	80%	93%	0.01
The ability to take frequent toilet breaks	55%	81%	P<0.0001
Flexible working hours	57%	70%	0.05

**Pearson's Chi-squared*

Both groups worried a great deal about managing symptoms and flares (Pre-employment, 82% vs. Employment, 88%).

Conclusions and calls to action

This research has been pivotal in understanding the effect of IBD on people pre, during, and at the end of employment. It identified three main factors:

- The effect of IBD on the career aspirations of young people, revealing that more needs to be done to encourage and help young people to secure and progress within the career of their choice;
- The impact of IBD on the productivity of workers, from career outset through to retirement, and the possibility of loss of potential if employees are not adequately supported within their work;
- The conscientiousness of workers with IBD.

In this study, the majority of respondents reported that their IBD had some impact on their working life, be it on their career choice, their career progression, their productivity or their job satisfaction. Overall, the findings of the report show serious shortfalls in employer awareness of the needs of people with IBD (as perceived by the research respondents) and patchy provision of reasonable workplace adjustments, such as access to a toilet when required. The research findings highlight the common issues faced by employees with IBD, which thus need to be addressed by all those involved in employment issues, including employers, the NHS, Public Health bodies, and employees themselves.

Career aspiration, progression and satisfaction, and the impact of reasonable adjustments

It is alarming that IBD has such a significant effect on working life before it has even begun. The report indicates that young pre-employed people with IBD find the prospect of gaining their first job a daunting challenge - a key factor since most IBD patients are diagnosed between the ages of 16 and 29, at the start of their higher education or working lives. That so many young people are lowering their career aspirations and underselling their work capability because of their IBD is saddening, and shows a clear need to provide support for young people and improve the quality of careers guidance. It also signifies a need for Government commitment to ensure that within the current labour market, all employment schemes (including apprenticeships and graduate schemes) consider and facilitate those with LTCs.

However, the report reveals that IBD does not just impact upon the career progression of young-people pre-employment. Those in employment also revealed that they are not necessarily in their career of first choice, nor do they feel that they are achieving their full working potential. Given the current economic environment, this is regrettable when simple workplace adjustments and appropriate treatment could assist employees to maximise their productivity (which this study has demonstrated as being greater than the general population's baseline work productivity when people with IBD feel well).

The research reveals the importance of reasonable adjustments, however, it is vital that employers are educated on the nature of fluctuating symptoms; plans to support employees must account for these stages of disease and as with all LTCs, support can not be 'one size fits all'. Despite the need for adjustments dependent on each individual, this need not be a high-cost intervention – the introduction of straightforward adjustments, such as easy access to toilets or time for doctor/hospital appointments separate from holiday allowance, could make all the difference to those either in work or looking for work.

From a healthcare policy perspective, the implementation of the IBD Service Standards[1] for patient treatment and care should be given priority.

Workplace worries and the need for ongoing support and financial stability

The workplace worries expressed by both those in employment and in pre-employment were multiple and varied. There were many parallels between workplace worries and career choices, for example worries about commuting and reluctance to choose a job involving a long commute, revealing the overlapping nature of the effect of the physical symptoms of IBD on people's confidence and emotional wellbeing, and on their choices related to their working lives.

The high percentages of people expressing worry over work are particularly concerning to the RSG, since such worries can greatly affect the wider wellbeing of a person. For example, a common worry to both those who are pre-employed and employed is managing symptoms and flares. The Government's recent strategies (such as *Personalised Care Planning*[8] and the *NHS Outcomes Framework*[6]) suggest that rather than focusing only on the management of disease symptoms, healthcare professionals should focus on the whole person including their social and working lives when considering treatment plans. The research findings reveal that people's worries are wide-ranging, from working hours through to office facilities through to the discrimination of colleagues, for example. Increased understanding amongst policy makers, patients, employers, and the NHS and Public Health bodies is therefore necessary, as are actions from all of these groups – working together collectively and coherently - to improve support for people living and working with these conditions.

Worries about losing work were prominent within the survey responses, particularly during periods of economic recession. However, also prominent was the finding that employees with IBD have a high work ethic, with the majority of people with IBD continuing to work, despite feeling ill, and admitting that they work harder to make up for any shortcomings as a result of their condition. However, due to the fluctuating nature of IBD symptoms, there may be times when working is not an option and it is vital that state benefits are made available to people with IBD for periods of ill-health, and that these are made well-known and are easily accessible, to avoid causing fear and even more worry amongst those people who may require them.

Calls to action

This research clearly demonstrates an urgent need to improve the working lives of those with IBD. The following calls to action are presented as a result of the findings of this report:

Employers

- To improve working conditions and policies for the benefit of employees with Crohn's and UC
- To offer reasonable adjustments to patients with Crohn's and UC to support them in the workplace, including the ability to take regular toilet breaks and flexibility to see a doctor when required
- To provide people with LTCs, including Crohn's and UC, high-quality work with opportunities for training, development and career progression
- To recognise the conscientiousness of workers with IBD and counteract the vulnerability felt by them by communicating their commitment to good working practices

Policy Makers

- A call for a programme of information aimed at employers to help them understand the needs of people with Crohn's, UC and other LTCs
- To ensure all elements of the system – NHS, welfare, employers – interact coherently and in a holistic manner to ensure optimal outcomes for people with IBD in their working lives
- To ensure there is an appropriate framework to provide support and treatment within the NHS to enable people with IBD, where appropriate, to return to and remain in work
- To ensure that people with Crohn's and UC receive adequate support through the benefits system to help them through intermittent and unpredictable periods of incapacity for work

NHS

- To engage in patient-centred conversations about working life as part of an assessment of a patient's overall wellbeing and treatment/management of their condition
- Healthcare managers are urged to ensure that adequate funding and resources are in place for Crohn's and UC patients to meet quality service standards for treatment and care within the NHS
- Commissioners (including shadow GP Consortia) are likewise urged to recognise the need for prioritisation as above when making commissioning decisions about services and care pathways in this area. They are also urged to understand how important work can be to people with IBD, and the impact this condition can have on their working lives, to ensure that those that can work are adequately and appropriately supported to do so
- For GPs to ensure full use of Fit Notes, with an understanding of the fluctuating nature of symptoms, including input into the report section which allows recommendations for reasonable adjustments

People with Crohn's and UC

- To play their part in raising awareness of Crohn's and UC in the workplace
- To be aware of employment rights inline with the Equality Act
- To utilise information provided by patient associations including Crohn's and Colitis UK to inform dialogue with employers
- To engage in conversations with healthcare professionals about working life as part of the assessment of their overall wellbeing

Career's Advisors and Educators

- To be better informed about Crohn's and UC, its impact on employment and young peoples' confidence and self-esteem
- To support students with Crohn's and UC so that they are able to complete courses of study/reach their full educational potential
- To encourage the aspirations of students who have Crohn's and UC
- To limit students' employment concerns by providing adequate and early careers counselling and support
- To persuade employers to be imaginative in making reasonable adjustments to help people to return to / stay in work
- To ensure workplace representatives are more aware of Crohn's and UC

Thank you for reading this report. We hope that whether you are an employer, employee, healthcare professional, parliamentarian or a career's advisor, this report has been interesting and will be useful to you in facilitating support for people with LTCs, to increase their employment prospects and keep people who want to work, in work.

It is hoped this report will provide the blueprint for further discussion to support all employees with chronic conditions. For further information on the research, or on IBD, please contact Crohn's and Colitis UK at **info@crohnsandcolitis.org.uk.**

Appendices

Survey questions as presented within the questionnaire, and the top-line findings

SECTION 1: A FEW INTRODUCTORY QUESTIONS

Q1. Which of the following conditions have you been diagnosed with? Please select one answer only.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Crohn's Disease	58	100	-
Ulcerative Colitis	42	-	100

For the rest of this survey, we will use "Inflammatory Bowel Disease" or "IBD" to refer to your Crohn's disease or Ulcerative Colitis.

Q2. What is your current age?

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
16-29	26	28	22
30-39	24	27	20
40-49	25	23	27
50-59	16	14	19
60+	9	7	12
Average (mean)	39	38	41

Q3. Are you a member of Crohn's and Colitis UK?

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Yes	73	71	75
No	27	29	25

If you have been diagnosed with neither Crohn's Disease nor Ulcerative Colitis, and you aren't aged between 16 and 65, you should not fill in this survey.

SECTION 2: YOUR CONDITION

Q4. As best you can remember, how many years ago were you diagnosed with Inflammatory Bowel Disease, or IBD? If it was less than a year ago, write in 0.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0	9	7	11
1-5	31	30	33
6-10	21	21	20
11-20	26	28	24
21+	13	14	11
Average (median)	8	8	8

Q5. How many surgical operations have you had specifically for Inflammatory Bowel Disease, or IBD? If none, write in 0.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0	63	47	85
1-2	25	36	9
3+	12	16	5
Average (median)	0	2	0

Q6. From the following list, which one best describes your IBD currently—that is, on average, over the past month? Please circle one number only.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0 – No symptoms/remission	13	10	17
1	11	10	13
2	12	13	12
3	12	12	12
4	9	9	9
5	9	11	8
6	9	10	7
7	10	10	9
8	7	7	7
9	3	4	3
10 – Very severe	3	4	3
Net: 0-2	37	33	42
Net: 8-10	14	15	13
Average (mean)	4.0	4.2	3.7

Q7. Are you currently experiencing or have you had a flare-up in your symptoms in the past seven days?

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Yes	43	46	40
No	57	54	59

Q8. Imagine that this scale represents your feelings about your health.
10 represents best imaginable health state. 0 represents worst imaginable health state.

We want you to make 2 marks on the scale below:

Write a "C" at the point that shows how you feel about your current health (during the past seven days).

Write a "P" at the point that shows where your health would be without symptoms of your IBD.

If you do not feel that your IBD symptoms have had an impact on your health, then your 2 marks should be in the same place.

Current health	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0 – Worst imaginable health state	2	2	2
1	3	3	3
2	7	8	6
3	9	9	8
4	15	15	15
5	14	15	12
6	11	11	11
7	12	11	14
8	12	12	13
9	7	6	9
10 – Best imaginable health state	4	3	5
Net: 0-2	12	13	10
Net: 8-10	23	21	26
Average (mean)	5.5	5.3	5.7

Without IBD	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0 – Worst imaginable health state	1	1	1
1	1	1	1
2	1	1	1
3	1	1	1
4	2	2	2
5	4	4	3
6	5	6	4
7	9	9	8
8	23	23	23
9	26	26	26
10 – Best imaginable health state	26	24	29
Net: 0-2	3	3	2
Net: 8-10	75	73	78
Average (mean)	8.2	8.0	8.3

Difference = Current health – Health without IBD	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
-10	*	*	1
-9	1	1	1
-8	2	1	2
-7	5	5	5
-6	8	8	7
-5	11	12	9
-4	12	14	11
-3	13	13	14
-2	15	14	17
-1	12	12	14
0	16	15	17
+1	1	1	1
+2 and more	3	4	2
Average (mean) difference	-2.8	-2.8	-2.8

Q9. How many flare-ups, if any, in your symptoms have you had in the last six months?
If none, write in 0.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0	26	24	27
1	25	23	28
2	15	15	15
3-5	20	21	19
6-10	8	10	7
11-20	2	3	2
21+	3	3	2
Average (median)	1	2	1

Q10. How many flare-ups, if any, in your symptoms have you had in the last 12 months?
If none, write in 0.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0	18	17	18
1	20	18	22
2	14	13	16
3-5	21	20	23
6-10	15	17	12
11-20	6	7	5
21+	5	6	4
Average (median)	2	4	2

The next three questions ask how much your IBD symptoms affect your ability to do your regular daily activities, other than work at a job.

By regular activities, we mean the usual activities you do, such as work around the house, shopping, child care, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like.

Q11. During the past seven days…

If IBD symptoms affected your activities only a little, choose a low number. Choose a high number if IBD symptoms affected your activities a great deal.

Consider only how much IBD symptoms affected your ability to do your regular daily activities, other than work at a job.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0 – IBD symptoms had no effect on my daily activities	19	16	22
1	13	11	15
2	12	11	13
3	10	11	8
4	6	6	5
5	8	9	7
6	8	8	8
7	10	11	8
8	9	10	8
9	4	5	3
10 – IBD symptoms completely prevented me from doing my daily activities	3	3	3
Net: 0-2	43	39	49
Net: 8-10	16	17	14
Average (mean)	3.8	4.0	3.5

Q12. During the past six months…

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0 – IBD symptoms had no effect on my daily activities	10	9	12
1	8	7	11
2	9	9	9
3	11	11	10
4	8	8	8
5	11	11	10
6	10	11	9
7	12	13	10
8	10	10	11
9	6	6	5
10 – IBD symptoms completely prevented me from doing my daily activities	4	4	5
Net: 0-2	28	25	32
Net: 8-10	21	21	21
Average (mean)	4.7	4.8	4.5

Q13. During the past 12 months…

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
0 – IBD symptoms had no effect on my daily activities	8	8	9
1	7	6	9
2	8	8	8
3	10	10	10
4	7	7	7
5	11	11	10
6	9	9	9
7	13	13	12
8	11	11	11
9	8	8	7
10 – IBD symptoms completely prevented me from doing my daily activities	7	7	7
Net: 0-2	24	22	26
Net: 8-10	26	27	25
Average (mean)	5.1	5.3	4.9

Q14. Have you been diagnosed with any of the following other long-term conditions?
Multiple responses permitted.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Mental health e.g. depression	19	22	16
Respiratory e.g. asthma	13	14	12
Cardiovascular e.g. angina	3	2	3
Metabolic conditions e.g. diabetes	2	2	3
Neurological disorders e.g. Multiple Sclerosis (MS)	1	2	1
Immune deficiency e.g. HIV / AIDS	1	1	*
Other long-term conditions not listed here	29	30	29
I don't have any other conditions	46	44	48
Don't know / No response	4	4	5

Q15. When you think of your IBD, do you consider yourself to have a disability?

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Yes	51	53	48
No	49	47	52

Q16. Are you currently in paid employment (including self-employment)?

	Total Employed (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Yes	69	67	71
No	31	33	29

SECTION 3: FOR THOSE IN PAID EMPLOYMENT

Q17. How many hours, on average, do you work per week?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
35 hours or more	62	61	64
Less than 35 hours	37	38	35

Q18. Have you ever had to reduce your working hours as a result of your IBD?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Yes	57	59	53
No	43	41	46

Q19. Which of the following best describes you?

If you have more than one job, think about the job you consider your MAIN job.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
You work in the public sector	41	40	44
You work for a private sector company	39	40	37
You are self-employed	12	12	11
You work for a non-governmental, non-profit organisation	6	6	6

Q20. What is your occupation?

Q21. What is your highest level of education?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
No formal qualifications	4	4	4
GCSE/O-Level/CSE	19	20	17
Vocational qualifications (=NVQ1/NVQ2)	8	8	7
A-Level/Scottish Higher or equivalent (=NVQ3)	16	17	13
Bachelor Degree or equivalent (=NVQ4)	29	29	30
Masters/PhD or equivalent	10	8	12
Other (e.g. professional qualifications)	14	13	15
Net: No degree	46	49	41
Net: Degree and above	39	37	42

Q22. For how long have you been employed or self-employed in your current job?
If you have more than one job, think about the job you consider your MAIN job. If less than a year, please enter 0 in the space below.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Under one year	10	12	7
1-5 years	39	41	37
6-10 years	22	23	22
11-20 years	18	17	20
21 or more years	11	8	14
Average (mean)	8.0	7.2	8.9

Q23. Which, if any, of the following statements are true for you? Multiple responses permitted.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Sometimes you go to work even though you don't feel well enough	80	83	75
Your job satisfaction has decreased because of your IBD	33	35	31
You feel you have control over your working conditions e.g. working time and order of tasks	32	32	32
You would work longer hours if you didn't have your IBD	32	34	29
You would look for a different job if you didn't have your IBD	24	27	20
You have been discriminated against because of your IBD	15	16	12
You work from home because of your IBD	12	12	11
You started your own business as a result of your IBD	4	5	3
None of these are true	7	5	9

Q24. During the past seven days (not including today), how many hours did you miss from work because of problems associated with your IBD symptoms? Include hours you missed on sick days, times you went in late, left early, etc. because of IBD symptoms.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
0 hours	71	71	71
1-5 hours	11	12	9
6-10 hours	5	6	5
11-25 hours	6	5	8
26-50 hours	6	5	6
Over 50 hours	1	1	1
Average (median)	0	0	0

Q25. During the past seven days (not including today), how many hours did you miss from work because of any other reason, such as vacation, holidays?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
0 hours	72	72	73
1-5 hours	4	5	4
6-10 hours	7	8	6
11-25 hours	8	8	8
26-50 hours	6	5	6
Over 50 hours	1	1	1
Average (median)	0	0	0

Q26. During the past seven days (not including today), how many hours did you actually work?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
0 hours	18	17	21
1-5 hours	3	3	2
6-10 hours	8	8	8
11-25 hours	23	23	23
26-50 hours	45	46	44
Over 50 hours	3	3	3
Average (median)	18	18	18

Q27. During the past seven days (not including today), how much did IBD symptoms 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. If IBD symptoms affected your work only a little, choose a low number. Choose a high number if IBD symptoms affected your work a great deal.

Consider only how much IBD symptoms affected productivity while you were working.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
0 – IBD symptoms had no effect on my work	28	25	32
1	14	13	15
2	11	11	10
3	11	12	9
4	5	7	3
5	6	6	5
6	7	6	7
7	6	7	4
8	3	3	3
9	2	2	2
10 – IBD symptoms completely prevented me from working	6	6	7
Net: 0-2	52	49	56
Net: 8-10	11	11	12
Average (mean)	3.1	3.2	2.9

Q28. How much does your employer do to support you as you carry out your job with your IBD?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Fully supported	31	33	29
Adequately supported	31	32	29
Minimally supported	18	17	20
Not supported at all	15	14	18

Which of the following is important to you? And, if you have an employer, which do they provide?

Q29. The ability to take time off for doctor/hospital appointments, separate from my holiday allowance

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
This is important to me	88	89	87
My employer provides this	69	69	69

Q30. The ability to take frequent toilet breaks

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
This is important to me	83	83	83
My employer provides this	71	72	69

Q31. Flexible working hours

	Total (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
This is important to me	65	65	65
My employer provides this	41	39	42

Q32. The ability to work from home

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
This is important to me	41	42	41
My employer provides this	21	19	23

Q33. Have you told your employer or HR department that you have IBD?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Yes	81	83	78
No	10	8	14
I don't have an employer / HR department	8	8	8

Answer only if you responded 'NO' to the previous question (Q33)

Q34. If no, why have you not told them? Multiple responses permitted

	Total Employed - Told Employer/HR (N=143)	Crohn's Disease (N=56)	Ulcerative Colitis (N=78)
Your symptoms are under control	62	64	60
I'd prefer them not to know	51	55	47
You feel there is no point as no-one can help you	22	21	23
You feel at risk of losing your job	18	21	15
None of these	7	4	10

Q35. Have you told your immediate boss or line manager that you have IBD, other than your employer?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Yes	76	79	73
No	11	9	13
I don't have an immediate boss or line manager	12	10	13

Answer only if you responded 'NO' to the previous question (Q35)

Q36. If no, why have you not told them? Multiple responses permitted

	Total Employed - Told Boss/Manager (N=134)	Crohn's Disease (N=69)	Ulcerative Colitis (N=74)
Your symptoms are under control	58	55	61
I'd prefer them not to know	53	55	51
You feel there is no point as no-one can help you	21	23	19
You feel at risk of losing your job	20	26	15
None of these	8	6	9

Q37. Have you told your co-workers that you have IBD?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Yes	77	80	73
No	16	13	20
I don't have any co-workers	6	6	6

Answer only if you responded 'NO' to the previous question (Q37)

Q38. If no, why have you not told them? Multiple responses permitted

	Total Employed - Told Co-workers (N=209)	Crohn's Disease (N=95)	Ulcerative Colitis (N=114)
I'd prefer them not to know	64	72	58
Your symptoms are under control	38	36	39
You feel there is no point as no-one can help you	22	25	20
You feel at risk of losing your job	6	4	8
None of these	8	5	11

Q39. Do you belong to a Trade Union?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Yes	31	29	34
No	68	70	66

Answer only if you responded 'YES' to the previous question (Q39)

Q40. If yes, has your Trade Union represented you in seeking adjustments or concessions?

	Total Trade Union (N=408)	Crohn's Disease (N=217)	Ulcerative Colitis (N=191)
Yes	12	12	12
No	88	87	88

Q41. How comfortable have you felt discussing your IBD condition at work?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Very comfortable	24	27	21
Somewhat comfortable	37	39	35
Not very comfortable	21	19	23
Not at all comfortable	8	6	10
I haven't discussed it at work	9	8	10

And if we discount those who select "I haven't discussed it at work":

	Total Employed and have discussed IBD at Work (N=1192)	Crohn's Disease (N=681)	Ulcerative Colitis (N=511)
Very comfortable	27	29	24
Somewhat comfortable	41	43	39
Not very comfortable	23	20	26
Not at all comfortable	9	7	11

Q42. Which of the following do you worry about in the workplace as a result of your IBD?
Multiple responses permitted.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Managing my symptoms or flare-ups	78	78	79
Not being able to carry out my work responsibilities adequately	62	65	59
Losing my job as a result of my IBD	36	39	34
My employer not being flexible to my needs	33	37	29
Not being able to find a job that fits around my condition	31	33	28
Being discriminated against	26	29	22
None of these	9	7	11

Q43. How difficult does your IBD condition make it for you to remain employed?

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Makes it very difficult to remain employed	6	6	6
Makes it somewhat difficult to remain employed	16	17	15
Makes it just a little difficult to remain employed	28	28	27
Does not make it difficult to remain employed	48	47	50

Q44. Which of the following, if any, make it difficult for you to remain employed? Multiple responses permitted.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
I need to take too much time off from work	28	31	26
It's difficult to carry out my work responsibilities	24	24	25
It is difficult getting to and from work	18	14	23
I receive too little support and understanding from my employer	11	11	11
None of these	50	51	49

Please indicate how much you agree or disagree with the following statements.

Q45 - Q53. Summary table – Completely agree

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
My IBD has restricted me from choosing a job involving a long commute.	28	28	27
My IBD condition has had an impact on my career progression.	26	29	23
I give more effort at work to make up for any shortcomings that result from my IBD.	25	29	21
My IBD has prevented me from reaching my full potential in the workplace.	23	25	19
I am earning less as a result of my IBD.	21	22	19
During a recession, my IBD makes me feel particularly vulnerable to unemployment or job loss.	20	22	17
My IBD has prevented me from pursuing my preferred choice of job.	19	21	16
Because of my IBD symptoms, I worry that my colleagues think I don't pull my weight at work.	18	19	16
As a result of my condition, I feel at risk of losing my job.	14	14	13

Q45 - Q53. Summary table – Agree (Completely + Somewhat)

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
I give more effort at work to make up for any shortcomings that result from my IBD.	52	57	45
My IBD condition has had an impact on my career progression.	51	54	47
My IBD has prevented me from reaching my full potential in the workplace.	50	53	46
My IBD has restricted me from choosing a job involving a long commute.	47	47	48
During a recession, my IBD makes me feel particularly vulnerable to unemployment or job loss.	41	43	38
Because of my IBD symptoms, I worry that my colleagues think I don't pull my weight at work.	40	42	38
My IBD has prevented me from pursuing my preferred choice of job.	36	40	32
I am earning less as a result of my IBD.	35	37	33
As a result of my condition, I feel at risk of losing my job.	33	35	31

Q45. My IBD condition has had an impact on my career progression

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	26	29	23
Somewhat agree	25	26	24
Neither agree nor disagree	16	16	17
Somewhat disagree	7	6	9
Completely disagree	24	22	27
Net: Agree (Completely + Somewhat)	51	54	47
Net: Disagree (Completely + Somewhat)	32	29	35

Q46. My IBD has prevented me from pursuing my preferred choice of job

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	19	21	16
Somewhat agree	18	19	16
Neither agree nor disagree	21	19	23
Somewhat disagree	10	10	10
Completely disagree	32	30	35
Net: Agree (Completely + Somewhat)	36	40	32
Net: Disagree (Completely + Somewhat)	42	40	45

Q47. I am earning less as a result of my IBD

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	21	22	19
Somewhat agree	15	15	14
Neither agree nor disagree	17	17	16
Somewhat disagree	9	9	9
Completely disagree	39	37	42
Net: Agree (Completely + Somewhat)	35	37	33
Net: Disagree (Completely + Somewhat)	48	46	51

Q48. My IBD has prevented me from reaching my full potential in the workplace

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	23	25	19
Somewhat agree	27	28	27
Neither agree nor disagree	15	15	15
Somewhat disagree	9	8	9
Completely disagree	26	23	28
Net: Agree (Completely + Somewhat)	50	53	46
Net: Disagree (Completely + Somewhat)	34	32	38

Q49. Because of my IBD symptoms, I worry that my colleagues think I don't pull my weight at work

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	18	19	16
Somewhat agree	22	24	21
Neither agree nor disagree	15	16	15
Somewhat disagree	11	10	13
Completely disagree	32	30	34
Net: Agree (Completely + Somewhat)	40	42	38
Net: Disagree (Completely + Somewhat)	43	41	47

Q50. I give more effort at work to make up for any shortcomings that result from my IBD.

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	25	29	21
Somewhat agree	27	28	25
Neither agree nor disagree	21	18	24
Somewhat disagree	6	6	6
Completely disagree	20	18	23
Net: Agree (Completely + Somewhat)	52	57	45
Net: Disagree (Completely + Somewhat)	26	24	29

Q51. As a result of my condition, I feel at risk of losing my job

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	14	14	13
Somewhat agree	19	21	18
Neither agree nor disagree	17	15	18
Somewhat disagree	12	13	11
Completely disagree	37	35	39
Net: Agree (Completely + Somewhat)	33	35	31
Net: Disagree (Completely + Somewhat)	49	48	50

Q52. During a recession, my IBD makes me feel particularly vulnerable to unemployment or job loss

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	20	22	17
Somewhat agree	21	22	21
Neither agree nor disagree	17	17	18
Somewhat disagree	10	10	11
Completely disagree	30	29	32
Net: Agree (Completely + Somewhat)	41	43	38
Net: Disagree (Completely + Somewhat)	41	39	43

Q53. My IBD has restricted me from choosing a job involving a long commute

	Total Employed (N=1314)	Crohn's Disease (N=744)	Ulcerative Colitis (N=570)
Completely agree	28	28	27
Somewhat agree	20	19	21
Neither agree nor disagree	19	19	18
Somewhat disagree	9	9	8
Completely disagree	24	23	25
Net: Agree (Completely + Somewhat)	47	47	48
Net: Disagree (Completely + Somewhat)	33	32	34

Q54. If you have any additional comments about IBD and employment, please feel free to use the space below or a separate sheet to elaborate.

SECTION 4: FOR THOSE NOT IN PAID EMPLOYMENT

Q55. Which of the below describes you best?

	Total Not working (N=499)	Crohn's Disease (N=305)	Ulcerative Colitis (N=194)
You are retired from work	33	30	39
Full-time parent or carer	15	17	12
Full-time student	5	5	5
Full-time volunteer	2	2	2
You do not have paid employment for another reason	43	46	40

Q56. At what age did you retire from work?

	Total Retired (N=167)	Crohn's Disease (N=92)	Ulcerative Colitis (N=75)
Under 40 years old	13	21	4
40-49	17	14	20
50-59	46	43	49
60-65	23	21	27
Over 65 years old	1	1	-
Average (median)	55	55	55

Q57. To what extent did your IBD play a part in your decision to retire when you did?

	Total Retired (N=167)	Crohn's Disease (N=92)	Ulcerative Colitis (N=75)
A great deal	53	66	36
A moderate amount	12	9	16
Just a little	11	9	13
Not at all	23	14	35

Q58. Which of the following describes the reason you do not currently have paid employment?

Multiple responses permitted.

	Total Not working (N=499)	Crohn's Disease (N=305)	Ulcerative Colitis (N=194)
My IBD makes it hard for me to work at all	40	46	31
My IBD makes it hard for me to find a suitable job	27	28	25
I could work, but I choose not to	12	9	16
I cannot find a job that matches my skills and requirements	10	9	11
My IBD treatment makes it hard for me to get through the process of applying for jobs	10	9	13
None of these	28	25	33

And if we look at responses among those who are not retired, nor full-time students, volunteers, parents or carers:

	Total Not working, with exclusions (N=224)	Crohn's Disease (N=142)	Ulcerative Colitis (N=82)
My IBD makes it hard for me to work at all	51	54	46
My IBD makes it hard for me to find a suitable job	42	37	50
My IBD treatment makes it hard for me to get through the process of applying for jobs	14	9	22
I cannot find a job that matches my skills and requirements	13	13	15
I could work, but I choose not to	4	4	5
None of these	15	15	13

Q59. From which of the following sources do you currently receive financial support?
Multiple responses permitted.

	Total Not working (N=499)	Crohn's Disease (N=305)	Ulcerative Colitis (N=194)
State benefits (e.g. state pension and tax credit)	55	58	49
My partner	36	35	38
My savings	21	18	26
From another friend or family member	7	7	8
Statutory sick pay	4	4	5
Independent income	4	3	6
Insurance payments	2	1	3
Other sources (e.g. occupational pension)	22	18	29
I don't receive any financial support	3	2	4

Q60. If you have any additional comments about how your IBD affects you, please feel free to use the space below or a separate sheet to elaborate.

SECTION 5: FOR THOSE AGED 16-25 AND NOT YET ENTERED WORK

Q61. When you think about employment, which of the following do you worry about, if any? Multiple responses permitted.

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Managing my symptoms or flare-ups	82	79	88
Not being able to carry out my work responsibilities adequately	66	60	76
My employer not being flexible to my needs	65	60	74
Not being able to find a job that fits around my condition	57	56	59
Losing my job as a result of my IBD	45	46	44
Being discriminated against	38	37	41
None of these	-	-	-

Q62. Which of the following would be important to you in a job? Multiple responses permitted.

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
The ability to take time off for doctor/hospital appointments, separate from my holiday allowance	80	79	82
Good quality toilet facilities	66	60	76
Flexible working hours	57	56	59
The ability to take frequent toilet breaks	55	49	65
My employer taking the time to talk to me about my condition	46	51	38
Being able to work near to toilets	46	37	62
The ability to work from home	35	39	29
None of these	2	2	3

Please indicate how much you agree or disagree with the following statements.

Q63 - 71. Summary: Completely Agree

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
My IBD has affected my confidence and self-esteem.	56	51	65
My IBD has delayed or is delaying my education and/or training.	42	46	35
My IBD has prevented me from reaching my full educational potential.	41	42	38
I would like career guidance which takes my IBD into account.	40	42	35
I fear my IBD will make me more vulnerable in terms of employability or job loss in a recession.	37	44	26
My IBD has delayed me starting work or looking for employment.	35	40	26
I think it's likely I will tell my future employers up-front about my IBD.	33	39	24
My IBD means I rule out some career options that I might otherwise consider.	32	32	32
My IBD means I will find it more difficult financially in the future compared to other people.	26	32	18

Q63 - 71. Summary: Agree (Completely + Somewhat)

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
My IBD has affected my confidence and self-esteem.	79	75	85
My IBD has prevented me from reaching my full educational potential.	69	75	59
My IBD has delayed or is delaying my education and/or training.	67	70	62
I fear my IBD will make me more vulnerable in terms of employability or job loss in a recession.	64	68	56
I think it's likely I will tell my future employers up-front about my IBD.	63	65	59
I would like career guidance which takes my IBD into account.	60	65	53
My IBD means I rule out some career options that I might otherwise consider.	56	58	53
My IBD has delayed me starting work or looking for employment.	49	53	44
My IBD means I will find it more difficult financially in the future compared to other people.	47	53	38

Q63. My IBD has delayed or is delaying my education and/or training

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	42	46	35
Somewhat agree	25	25	26
Neither agree nor disagree	9	11	6
Somewhat disagree	7	2	15
Completely disagree	14	14	15
Net: Agree (Completely + Somewhat)	67	70	62
Net: Disagree (Completely + Somewhat)	21	16	29

Q64. My IBD means I will find it more difficult financially in the future compared to other people

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	26	32	18
Somewhat agree	21	21	21
Neither agree nor disagree	26	25	29
Somewhat disagree	12	12	12
Completely disagree	11	7	18
Net: Agree (Completely + Somewhat)	47	53	38
Net: Disagree (Completely + Somewhat)	23	19	29

Q65. I think it's likely I will tell my future employers up-front about my IBD

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	33	39	24
Somewhat agree	30	26	35
Neither agree nor disagree	19	19	18
Somewhat disagree	11	12	9
Completely disagree	4	-	12
Net: Agree (Completely + Somewhat)	63	65	59
Net: Disagree (Completely + Somewhat)	15	12	21

Q66. My IBD has prevented me from reaching my full educational potential

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	41	42	38
Somewhat agree	29	33	21
Neither agree nor disagree	5	4	9
Somewhat disagree	11	7	18
Completely disagree	11	11	12
Net: Agree (Completely + Somewhat)	69	75	59
Net: Disagree (Completely + Somewhat)	22	18	29

Q67. My IBD means I rule out some career options that I might otherwise consider

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	32	32	32
Somewhat agree	24	26	21
Neither agree nor disagree	15	18	12
Somewhat disagree	8	5	12
Completely disagree	18	16	21
Net: Agree (Completely + Somewhat)	56	58	53
Net: Disagree (Completely + Somewhat)	25	21	32

Q68. I would like career guidance which takes my IBD into account

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	40	42	35
Somewhat agree	21	23	18
Neither agree nor disagree	26	19	38
Somewhat disagree	4	7	-
Completely disagree	5	5	6
Net: Agree (Completely + Somewhat)	60	65	53
Net: Disagree (Completely + Somewhat)	10	12	6

Q69. My IBD has delayed me starting work or looking for employment

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	35	40	26
Somewhat agree	14	12	18
Neither agree nor disagree	19	21	15
Somewhat disagree	8	5	12
Completely disagree	21	18	26
Net: Agree (Completely + Somewhat)	49	53	44
Net: Disagree (Completely + Somewhat)	29	23	38

Q70. I fear my IBD will make me more vulnerable in terms of employability or job loss in a recession

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	37	44	26
Somewhat agree	26	25	29
Neither agree nor disagree	19	16	24
Somewhat disagree	7	4	12
Completely disagree	8	9	6
Net: Agree (Completely + Somewhat)	64	68	56
Net: Disagree (Completely + Somewhat)	14	12	18

Q71. My IBD has affected my confidence and self-esteem

	Total Pre-Employed (N=91)	Crohn's Disease (N=57)	Ulcerative Colitis (N=34)
Completely agree	56	51	65
Somewhat agree	23	25	21
Neither agree nor disagree	8	7	9
Somewhat disagree	4	5	3
Completely disagree	5	9	-
Net: Agree (Completely + Somewhat)	79	75	85
Net: Disagree (Completely + Somewhat)	10	14	3

Q72. If you have any additional comments about how your IBD affects you, please feel free to use the space below or a separate sheet to elaborate.

SECTION 6: A FEW FINAL QUESTIONS

Q73. Are you male or female?

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Male	30	26	34
Female	70	74	65

Q74. Who do you currently live with? Multiple responses permitted.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
With a partner or spouse	63	62	65
With other family member/s	16	16	16
With a parent(s)	15	16	13
Alone	12	12	12
Other	3	3	3

Q75. Which of the following best describes the area in which you live?

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Suburban / small town	43	45	41
Urban / city	29	29	30
Village	20	19	22
Rural	7	7	7

Q76. Where do you live?

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
England	82	81	83
Scotland	9	9	9
Wales	3	3	3
Northern Ireland	3	3	3
Other	2	3	2

Q77. Which of the following state benefits, if any, do you currently receive? Multiple responses permitted.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
Tax credit	11	13	10
Disability Living Allowance – Care Component	8	10	4
Incapacity Benefit	7	8	4
Council Tax Benefit	6	8	5
State pension	5	4	6
Disability Living Allowance – Mobility Component	5	7	3
Housing Benefit	5	6	3
Jobseekers Allowance	2	2	1
Employment and Support Allowance (ESA) – Work related activity group	2	3	2
Employment and Support Allowance (ESA) – Support Group	2	2	2
I receive state benefits but I don't know which ones	*	*	*
Other benefit/s not listed here	4	4	4
I don't receive any state benefits	63	60	68

Q78. Would you be willing to share your story publicly—for example, by talking to a reporter writing a story on Crohn's Disease or Ulcerative Colitis? There is absolutely no obligation to do so, and your answers to this survey will remain completely anonymous no matter what.

	Total (N=1906)	Crohn's Disease (N=1107)	Ulcerative Colitis (N=799)
No	55	49	62
Yes	44	49	37

Contact details (name, email address and telephone number supplied in separate document)

Thank you very much for your time and participation in this survey.

RSG Biographies

Dr. Ian Barrison holds the post of Associate Dean in the School of Postgraduate Medicine at the University of Hertfordshire.

He was previously Consultant Gastroenterologist at the West Hertfordshire NHS Trust (1988-2010), Chair of Clinical Services at the British Society of Gastroenterology (2006-2009), Chair of the Joint Royal Colleges Training Board Speciality Advisory Committee in General Internal Medicine 2008, and holds the President's Medal from the British Society of Gastroenterology for 2008.

Karen Bean is a Senior Health Economics and Outcomes Research (HEOR) Advisor at Abbott.

She has a first class degree in Pharmacology from Kings College London and an MSc with distinction in Health Economics from City University. She has a special interest in outcomes research, particularly in health related quality of life and the impact of health on work. She has a wealth of experience in outcomes research with other LTCs.

Stephen Bevan is Managing Director of The Work Foundation where he also previously held the post of Director of Research.

Stephen has carried out research & consultancy for the No. 10 Policy Unit, HM Treasury, the Cabinet Office and the European Commission. He has also advised many 'blue chip' companies and several research councils and charitable trusts. His areas of specialism include health and wellbeing at work, employee engagement and retention and reward strategy. Stephen has recently been appointed Honorary Professor at Lancaster University.

Ross Carroll is a Government Affairs Manager at Abbott.

He is a qualified pharmacist, elected NHS Foundation Trust Governor and is a senior policy analyst and author on the Bow Group think tank's Health & Education Policy Committee. Ross has published work on the development of the Northern Irish economy, the role of pharmacy, public health and military healthcare amongst others.

Suzi Clark is the Director of Marketing and Fundraising for Crohn's and Colitis UK.

In this role, she is committed to raising awareness of the charity, so that the little-known conditions of Crohn's and Colitis become better recognised and understood. In particular she strives to ensure more people know that the services of the charity are available, and that they do not feel "alone" in coping with their condition. Suzi was diagnosed with Ulcerative Colitis at the age of 20.

RSG Biographies continued

Dr Martin Gay is National Vice Chairman of Crohn's and Colitis UK.

When diagnosed with Crohn's he became a member of the organisation within 12 months of its formation, over 30 years ago. He has been a Trustee for 8 years and prior to that a committee member for 5 years. As a doctor he had to rethink his career path because of his Crohn's so understands the impact of IBD on work from personal experience. With a special interest in Disability Assessment Medicine he also has an interest in the impact of these diseases on others and their ability to work.

Professor Amanda Griffiths is Professor of Occupational Health Psychology and Deputy Head of the Institute of Work, Health & Organisations, University of Nottingham, UK.

She is a Chartered Occupational Psychologist, Chartered Health Psychologist, a Health Professions Council registered Practitioner Psychologist, and an Academician of the Academy of Social Sciences. Her expertise concerns the dynamic relationship between work and health. In particular she is concerned to understand and reduce work incapacity via improvements to the design and management of work. As a result of her earlier research for Crohn's and Colitis UK, Amanda contributed to their web-based guidelines for employers and employees on working with IBD.

Peter Purton, BA (Hons), DPhil. (Oxon) has been the Policy Officer for disability and LGBT rights at the TUC since 1998.

He also previously held the same role at the equality unit in National Association of Teachers in Further and Higher Education (now part of University and College Union). Prior to that Peter worked in the voluntary sector. He was trade union adviser to the Disability Employment Advisory Committee from 2008 until its abolition. His work has involved engagement with ministers, government departments, a wide range of disability organisations and trade union officers and members to promote a better understanding of disability issues in the workplace. He has written the TUC guidance on Disability and Work and helped produce similar advice on mental health and dyslexia.

Helen Terry BA (Hons), CQSW is Director of Information and Support of Crohn's and Colitis UK and a member of the Association's Senior Management Team.

Her specific responsibilities include managing the Association's information and support services, including the Helplines and production of Crohn's and Colitis UK's publications. She is also editor-in-chief of NACC News and takes the staff lead in Crohn's and Colitis UK's programme of research and campaigning on issues related to living with IBD. She is the staff lead for Crohn's and Colitis UK's Information and Support Committee, Personal Grants Panel, Living with IBD Research Awards Panel and Crohn's and Colitis Support Managing Team, and sits on the IBD Public Affairs Committee.

Further reading

The following reading may be of interest to you.

Websites
Crohn's and Colitis UK: http://www.crohnsandcolitis.org.uk/content/home.asp

Fit for Work Europe: http://www.fitforworkeurope.eu/

The Work Foundation website: http://www.theworkfoundation.com/

Documents
Crohn's and Colitis UK, *Ulcerative Colitis and Crohn's Disease*: *a guide for employers*.
Accessible at: http://www.crohnsandcolitis.org.uk/downloads/factsheets/employers.pdf

The Government Equalities Office, *Equality Act 2010*. Accessible at: http://www.equalities.gov.uk/equality_act_2010.aspx

The Work Foundation, *Body and Soul: Exploring the connection between physical and mental health conditions*. Accessible at: http://www.theworkfoundation.com/assets/docs/publications/260_body_soul160910FINAL.pdf

Contact information

Crohn's and Colitis UK
Registered charity in England and Wales no. 1117148
Registered charity in Scotland no. SC038632
A company limited by guarantee in England: company number 5973370

Website: www.crohnsandcolitis.org.uk
Email: info@crohnsandcolitis.org.uk
Telephone: 01727 830038 (general enquiries)
Information Service: 0845 130 2233
Crohn's and Colitis Support: 0845 130 3344

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