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Working Well:

Promoting job and career opportunities for those with IBD

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The Work Foundation transforms people's experience of work and the labour market through high quality applied research that empowers individuals and influences public policies and organisational practices. For further details, please visit www.theworkfoundation.com.

Executive summary

This report focusses on Inflammatory Bowel Disease (IBD) and the effect that this condition has on an individuals' ability to work, and what can be done to improve the workforce participation of those with IBD from both the employee's and employer's perspective.

IBD is the name for a group of diseases that cause inflammation of the gastrointestinal tract. The two main types are Crohn's Disease (CD) and Ulcerative Colitis (UC), and the prevalence of IBD in the UK is estimated to be 300,000. Both Crohn's Disease and Ulcerative Colitis are fluctuating chronic long-term conditions, characterised by flares, or periods where symptoms are more acute. Diagnosis can occur at any age, but IBD commonly first presents itself in an individual's teens and early twenties. As well as the difficulties associated with primary symptoms of IBD, those who experience IBD may also have associated anxiety or depression, fatigue, and other symptoms that can have an impact on their quality of life normalising limited patterns of living and limiting education and employment opportunities.

It is important therefore to consider the social and employment implications that IBD can have on an individual. CD and UC have the potential to disrupt and have an impact on an individual's education and employment in a number of ways. Young people with IBD can face challenges completing their education and transitioning into employment, with concerns regarding managing symptoms in the workplace, self-confidence and whether they would be able to undertake their duties effectively. The timing and the age of onset of IBD, happening at this transition to adulthood can also have implications about individual career decisions, especially if they have little practical help available to help with these decisions. Evidence suggests that those with IBD were more likely to be out of the labour force, had increased sickness absence and fewer opportunities for career progression and reaching their full employment potential. IBD has also been reported to have an impact upon an individuals retirement age, with the median age of retirement for those with IBD being 55 years.

The research consisted of interviews with employees who have experience of working with IBD, taking a life-course history approach where participants were asked about how IBD had affected their life, and its role in employment decisions. As previous research has neglected the employer's perspective and how to manage an employee with IBD, this study also included perspectives of employers who work in occupational health and have experiences of managing individuals with IBD.

A summary of the results from the interviews follows:

- IBD was characterised by stomach cramps, blood in stools and an urgency of needing the toilet, however it was associated with other side-effects, the most commonly discussed being fatigue. The nature of IBD (it being a fluctuating

condition, having hidden and often embarrassing symptoms) was seen to have implications for employment and how IBD was managed at work.

- Individuals with IBD also experience increased anxiety and depression and reduced wellbeing both as a result of receiving the IBD diagnosis and adjusting to the condition. Psychosocial factors associated with IBD were seemingly related to age at diagnosis, the presence and nature of IBD symptoms and the role of medication.
- Being referred to an IBD specialist at the earliest opportunity post diagnosis reduced associated anxieties for those with IBD. Healthcare professionals were primarily seen as important for finding the correct method of IBD treatment, rather than discussing work or employment as an outcome.
- Specialist IBD nurses were unanimously praised for their role in providing support and information to individuals especially when access to consultants was limited. However, their role in discussing education and employment provided mixed responses from active provision of information to referral to other parties (most commonly Crohn's and Colitis UK).

Exploring IBD and employment in more detail, the interviews suggested that:

- There are a range of factors that lead to the career choice and work patterns for those with IBD, for example: the level of symptoms they experience, the length of a commute, the level of stress experienced in their role. However, for others job satisfaction not wanting to allow IBD control their employment was also a factor for many. Finally, an individual's financial circumstance was also considered important regarding whether to enter or leave an employment situation.
- The importance of the employer-employee relationship, usually established by the line manager was seen as vital in helping an individual with IBD at work. Characteristics of good line managers included: being sympathetic, understanding, having an awareness of how the condition could affect the individual (emotionally and physically). It also involved developing a relationship where there was two-way trust and communication, a provision of reasonable adjustments and the awareness of other services that could also provide a level of support.
- Disclosure of their IBD by employees to employers was seen as beneficial especially if time off for hospital appointments or longer sick leave was required. Participants acknowledged that due to the nature of IBD disclosure could be difficult, but often reported employers being grateful when disclosure occurred, as this helped develop a positive employment relationship and open communication.
- There was evidence for a number of reasonable adjustments implemented by employers, including: flexible working, time off for appointments, reduced hours and ensuring necessary facilities were in place. Factors for not asking for reasonable

adjustments included being in remission, the ability to self-manage, or because they did not feel able to ask for reasonable adjustments.

- In terms of future employment opportunities and IBD, those who had a positive employment relationship, or whose IBD was manageable displayed optimism regarding their future employment. However, some participants still questioned their ability to progress up the career ladder, and also discussed considering retirement earlier than their peers.
- Participants discussed a number of ways through which the management of IBD can be improved from a range of perspectives. Employers could improve management at work through developing the line manager and employee relationship, providing flexible workplace practices, improving facilities and developing the roles of occupational health and HR. Individuals with IBD can improve their awareness of the condition themselves, learn how to self-manage and develop a self-perception of their disorder. Healthcare professionals could also help with earlier provision of information about IBD and offering both medical and psychological support.

A summary of the results from the employer's perspectives showed that:

- Employers were able to discuss a number of policies and practices that they have in place to help manage employees with long-term health conditions, however many were reliant on line managers recognising that a problem was occurring and referring employees to occupational health. Employers noted that some organisations provide line managers with training to conduct trigger point and return to work interviews and the best methods for managing individuals with long-term conditions.
- Line manager have an important, some would argue critical role in the management of long-term conditions (including IBD) at work. Employers discussed the importance of developing an employment relationship based upon open and honest communication and trust so that the employee could disclose to their line manager directly. Organisations can provide line manager training to help with people management roles.
- Employers were able to identify a range of reasonable adjustments that they have implemented for employees with IBD, including flexibility in hours worked and place of work, being located close to appropriate toilet facilities, office relocation, redeployment and adjusting work expectations. Employers also discussed rare occasions where reasonable adjustments could not be made, but this was very much situation based.
- Employer perceived barriers to the management of IBD in the workplace included the nature of the disorder (fluctuating and embarrassing), a reluctance to disclose, organisational culture and the employment relationship. Employers also

emphasised that individual employee barriers may also have a role to play in relation to how they cope with the diagnosis and how having IBD affects them psychologically.

- Employers reported that improvements to the management of IBD in the workplace could be made from a range of stakeholders, but clearly highlighted that joined up practice is needed and is the most preferred option for improving the management of IBD at work and reducing any stigma associated with it.

The research highlighted that individuals with IBD want to work, and in many cases have the health to work, however a range of factors including individual constraints, healthcare related support and organisational management structures still provide a number of barriers to the management of IBD at work. The report provides a number of recommendations for relevant stakeholders that could be implemented to improve the management of IBD at work. These include:

For the individual:

- Seeking help and equipping yourself with information
- Understanding how the conditions affects you and your work
- Having the confidence to disclose
- Learn self-management techniques

For the employer:

- Improving line management
- Line management training
- Provision of functional adjustments
- Provision of flexible working
- Developing a supportive culture
- Increased awareness and availability of Occupational Health
- HR to understand their role and implement policies and practices effectively
- Introducing Employee Assistance Programmes
- Understanding physical and mental health affects

For healthcare professionals:

- Information provision at diagnosis
- Discussing an individual's work life
- Improving the speed to receiving specialist support
- Provision of more specialist nurses
- Consideration of other symptoms
- IBD standards
- Co-ordinated access to key professionals
- Early identification of most challenging patients
- Shared decision-making

For patient charities:

- Increasing the dissemination of information to raise awareness among employers and other employees
- Continue raising the awareness of IBD

For policy makers:

- Access to work
- Fit for work service
- Fit note
- Increase the number of specialist IBD centres
- Eligibility criteria for state benefits
- Further investment in IBD specialist nurse posts
- Cross departmental strategy
- Better understanding and recognition of urgency and chronic fatigue as a symptom

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Chapter 1 Long-term conditions and employment: the policy context

As the UK labour market begins to recover from the recent economic downturn it is important that sections of the workforce who are particularly at risk are not left behind, and that action is taken to support them in attempts to stay in, or return to work in a way that is dignified, rewarding and meaningful for them (Bevan, 2010). This includes people of a working age with long-term chronic conditions. This report looks specifically at Inflammatory Bowel Disease (IBD), the effect that this condition has on an individuals' ability to work and what can be done to improve the workforce participation of people with IBD from both the employee's and employer's perspective.

Strategies around the management of long-term conditions are gaining increasing focus and emphasis in health policy (Gay et al., 2011) as encouraging and helping people with long-term conditions to enter and remain in employment maximises their economic productivity, and can also be beneficial for their mental health and wellbeing (especially if they are employed in an understanding work environment). Employment and health are intrinsically linked; being out of work is associated with poor physical and mental health as well as mortality (Bates, Baldwin & Jones, 2013). Waddell and Burton (2006) reported that employment promotes full participation in society, minimises the harmful effects of long-term sickness absence and unemployment, improves quality of life and wellbeing and can lead to better health outcomes by promoting recovery and rehabilitation.

The NHS's "*Five year forward view*" (2014) highlighted a commitment to develop and support new workplace incentives to promote employee health and to cut sickness-related unemployment. The review also highlights the merits in extending incentives for employers in England who provide effective NICE recommended workplace health programmes for their employees (including mental health). This emphasis around managing long-term conditions and encouraging employment for those who suffer with them runs alongside an increasing appreciation of the importance of creating good quality working environments. In 2008, Dame Carol Black's review, '*Working for a Healthier Tomorrow*', made recommendations for policy makers and employers to improve employment and working life for the working age population as improved workplace health has potential not only to make significant contributions to the economy but also to protect the health, and prevent future ill-health to the working population. The Work Foundation's Good Work Commission (2011) undertook research to discuss what 'good work' involves. The report concluded that good quality work is a benefit to employees, employers and society alike and that it is possible to make work rewarding for all involved. It is important to understand that to achieve 'good work' for all, adjustments to the work environment will have to be made for individuals with long-term conditions. To ensure that everyone has the opportunity for good employment the

agenda for good work and the agenda for managing long-term conditions need to be brought together.

This joined up approach for long-term conditions and work is beginning to build momentum. In *'Personalised Care Planning: An 'at a glance' guide for healthcare professionals'* (2011), the Government published a strategy with the aim of improving support, and the social and working lives of people with long-term conditions. The strategy recognised that the wellbeing of people with long-term conditions should be considered from a number of perspectives, including education and employment, and extend beyond a purely biological conception of illness. This report focuses on a specific long-term condition, IBD, and aims to develop current understanding on how employment situations for those with IBD can be managed to create 'good work'.

Chapter 2 About Inflammatory Bowel Disease (IBD)

IBD is the name for a group of diseases that cause inflammation of the gastrointestinal tract (the gut). The two main types of IBD are Crohn's Disease (CD) and Ulcerative Colitis (UC). The prevalence of IBD in the UK is estimated to be 300,000 (Royal College of Physicians, 2014). Within this total figure, CD affects approximately 115,000 people in the UK, and UC affects up to 146,000 people in the UK. It is estimated that Crohn's Disease affects about one in every 650 people in the UK (Crohn's and Colitis UK, 2013a), and one in every 420 people in the UK has Ulcerative Colitis (Crohn's and Colitis UK, 2013b). The conditions affect men and women equally. In terms of age of diagnosis, IBD commonly first presents itself in the teens and early twenties (Gay et al., 2011), however it has been reported that diagnosis can occur at any age (median age at diagnosis is 29.5 years). This onset age can be very difficult for young people, as it comes at a time when key education and work transitions and decisions are being made (Gay et al., 2011). The incidence of IBD among children is increasing, with now over 25 per cent of new cases being diagnosed among those under the age of 16 (Goodhand, Hedin, Croft & Lindsay, 2011).

CD and UC are autoimmune conditions where the body's immune system attacks itself. Clinicians believe that IBD is caused by the immune system mistaking organisms which are naturally occurring in the intestines (e.g. bacteria), for foreign bodies, triggering an immune system response. As part of the process, white blood cells move into the lining of the intestines, where they produce chronic inflammation and ulceration. IBD is often confused with, but is a different condition from, Irritable Bowel Syndrome (IBS), and IBS requires different treatment. IBD is not infectious (Crohn's and Colitis UK, 2014a).

Although CD and UC are grouped together, there are distinct differences between the two conditions. CD 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 gastrointestinal tract and often occurs in patches. The main symptoms are urgent diarrhoea, pain in the abdomen, loss of weight and fatigue. CD can be treated with anti-inflammatory drugs, symptomatic drugs, and/ or antibiotics, as well as with surgery to remove damaged parts of the gut (it is estimated that about seven out of ten people with CD will need surgery at some point in their lives) (Crohn's and Colitis UK, 2013c).

UC, on the other hand, affects the colon and the rectum. In UC, inflammation and small ulcers develop on the inside of the colon, resulting in pain, bloody diarrhoea and continual tiredness. The condition may vary according to the proportion of the colon affected (Gay et al., 2011). Typically UC is treated with anti-inflammatory and/ or symptomatic drugs, but again surgery may be considered to remove parts of the bowel in more serious circumstances.

The symptoms for both CD and UC can vary from mild to severe between different patients, and at different points in time for one individual, meaning that people must employ different coping strategies at different times. CD and UC can also present with additional symptoms such as liver complaints, arthritis, and conditions that affect the skin and eyes. CD and UC are also both fluctuating conditions, and are characterised by flares, or periods where symptoms are more acute. IBD is also associated with psychiatric morbidity, and in particular anxiety and depression (Casati & Toner, 2000). Several studies have also identified fatigue as one of the most troubling symptoms and the most prevalent concern among IBD sufferers (Czuber-Dochan et al., 2013a, 2013b). As well as the difficulties caused by the primary symptoms of IBD, these additional symptoms also affect physical, cognitive, emotional and social functioning, which can have an impact on both the sufferers quality of life and employment opportunities. It has been suggested that individuals with IBD often regard their illness as embarrassing, discussing body image concerns, feeling dirty, not having the ability to reach their full potential and often having to plan their lives around toilet availability as a result of the fear of unpredictable bowel urgency. Hall et al., (2005) in a qualitative study investigating the experiences of individuals living with IBD, reported that being healthy and 'normal' implied the absence of IBD, and that managing their condition so that they could maintain an outward appearance of 'normality' was especially important to them.

There are still no known cures for CD or UC, meaning that people must learn how to cope with, and manage their condition for the rest of their lives (Gay et al., 2011). Management of IBD can occur through treatment plans, medication and surgery; however, sufferers may also experience frequent hospitalisation (Wilson et al., 2013). Drugs to suppress the immune system and to induce and maintain remission are the most common form of treatment. However, those who fail to respond to these (approximately 30 per cent of the IBD population), may be considered for biological therapies (anti-TNF- α) (Gay et al., 2011).

Costs of IBD

As a result of the nature of the disease, the time needed to manage the condition and the implications this can have for the employment and productivity of IBD sufferers, researchers and economists have attempted to estimate what the economic costs of having IBD are. It has been calculated that the lifetime costs for IBD are comparable to other major diseases such as heart disease and cancer (Luces & Bodger, 2006). Floyd et al., (2014) in their systematic review highlighted that although the incidence of CD is smaller than those of diabetes, coronary heart disease, hypertension, asthma and chronic obstructive pulmonary disease, the related costs per patient per year were higher in CD than in any other of these diseases.

Costs relating to IBD can be divided into direct and indirect costs. Direct costs include healthcare costs and other resources used by patients and their families; such as expenditure on additional transport, or specialist dietary requirements. Luces and Bodger (2006), conducted a study looking at the economic burden of IBD in the UK, finding that in-patient hospital costs were incurred by a minority of sufferers but accounted for approximately half of total healthcare costs, while drug costs contributed to less than a quarter of total healthcare costs. However, this distribution of costs is set to change as the

development of biological therapies means they will have an increasing role in IBD treatment, which will reduce hospital and surgery costs (Lucas & Bodger, 2006). A recent study has focused on the costs of IBD following the introduction of biological therapies (van der Valk et al., 2014). The study, set in the Netherlands, found that anti-TNF- α (anti tumour necrosis factor- α) therapy accounted for 64 per cent of healthcare costs among CD patients over a three month period, while surgery accounted for 19 per cent of healthcare costs (van der Valk et al., 2014). Among UC patients, whose mean healthcare costs were significantly lower than CD patients, 59 per cent of healthcare costs could be attributed to medication use, with mesalazine and anti-TNF- α therapy accounting for 54 per cent of healthcare costs.

Floyd et al., (2014) conducted a systematic review looking at the economic and quality-of-life burden of CD in Europe and the United States between 2000 and 2013. The review found that CD in the USA and Europe together had total annual costs of nearly €30 billion, of which more than half were due to indirect costs. In the UK the average annual cost of care was found to be £550 per patient in remission, £1,356 per patient experiencing a flare in symptoms and treated by ambulatory care, and £10,888 per patient when they were hospitalised. Further analysis indicated that increasing the length of a hospital stay, surgery, the severity of an illness and certain comorbidities were significant predictors of IBD costs. However, the review also presented other factors that could influence the costs of CD, and the most common cost drivers included the diagnostic procedures and disease onset, surgery and the associated hospitalisation and the use of biological therapies.

Benedini et al., (2012), in their study reported that in Italy the mean total cost per patient with CD was €31,043 during the 24 months they observed individuals with IBD. Of this total, 76.3 per cent was accounted for by direct costs, with drug treatment being the most significant percentage (60.3%), followed by hospitalization (10.9%) and laboratory examinations (2.6%). However, they also reported that the loss of productivity accounted for 17.9 per cent of total costs. Stone (2012) noted that caring for and treating IBD patients is a challenging aspect of a gastroenterologist's practice, and that IBD care is expensive. In fact, IBD is among the top five most expensive gastrointestinal disorders (alongside reflux, colorectal cancer and gallbladder disease) despite having a lower prevalence. However, Stone (2012) argues that costs can be controlled and avoided only by effective IBD management using pharmaceuticals – which can be costly themselves, but could offset costs of hospitalisation and surgery, as well as improving the quality of life for the individual. However, it was suggested that future cost-analysis studies need to help reveal how and when to use drug treatments so that there is a balance of cost savings for patient care. There is need for more research investigating the healthcare costs related to IBD since the widespread use of biological therapies in the UK context.

Both Floyd et al., (2014) and Benedini et al., (2012) reported how the economic costs of IBD are also related to an individual's health related quality of life. For example, Benedini et al., (2012) concluded that costs were strongly correlated with a decreased quality of life. They also reported that expenses incurred for CD treatment were significantly higher for patients with a poorer quality of life than for those with a better quality of life. The authors noted that an increase drug treatment improved the individual's quality of life, which reduced their

hospitalisation costs. Floyd et al., (2014) discussed how individuals with CD were associated with a reduced health related quality of life in comparison with the general population. Disease activity was related with quality of life, for example, individuals who reported being in remission were associated with improved quality of life compared to those whose IBD were active. Thus, the authors concluded that the burden of CD with both high direct and indirect costs results in the reduction in an individual's quality of life.

Indirect costs refer to lost productivity, which are incurred due to having to take leave from work, being less productive at work because of one's illness, or being unable to work altogether due to disability or premature death. Reaching a concrete definition of indirect costs is a difficult task. There exist only a few studies that have attempted to measure the indirect costs of IBD (Marri & Buchman, 2005). The studies that do exist often employ different measurements of productivity (Lucas & Budger, 2006) or use different combinations of factors making it difficult to reach a consensus. For example, sick leave, early retirement, unpaid employment, and labour force participation can all be included in indirect cost estimates, but are often not included consistently across studies (Marri & Buchman, 2005).

The Work Foundation used Australian data to estimate that the total cost of CD to the UK economy (including direct and indirect costs) (Bevan, 2010). In what was termed a "*crude application of these figures*" (page 15) the annual cost of CD to the UK economy was found to be in excess of £300 million (not accounting for differences in labour and healthcare costs) (Bevan, 2010). Blomqvist and Ekbon, (1997), using data from Sweden, found that 68 per cent of all IBD related costs were attributable to indirect costs, of these costs, 47 per cent were related to sick leave while 53 per cent were attributable to early retirement. However, this study employed a definition of indirect costs which did not include a measure of reduced productivity (i.e. presenteeism), highlighting the difficulty in calculating indirect costs. The challenge of defining what indirect costs involve, results in difficulties in attempting to calculate the total costs of IBD in the UK. This was highlighted by t Crohn's and Colitis UK, when they recommended that the cost of IBD to business and the economy needs to be quantified (Gay et al., 2011). More recent estimates from the IBD standards (2013) suggest that the cost of IBD could be in the region of £470 million per year as a result of the fluctuating nature of the disorder meaning healthcare costs can be comparable to other chronic conditions such as diabetes and cancer. The IBD standards (2013) argue that as a result of these large direct healthcare costs, there are strong arguments for focus for prompt detection of IBD, and improved outpatient management when a patient suffers a flare, and for the effective maintenance of remission.

Education and IBD

Although a proportion of IBD research has focused on the economic costs of the disorder, it is important to also consider the social impact that IBD can have on an individual. The chronic and fluctuating nature of IBD, combined with the fact that symptoms often begin when people are children or young adults, means that UC and CD have the potential to disrupt and have an impact upon individual's education and employment in negative and multifarious ways. Children and adolescents tend to be more severely affected by IBD than adults; the condition can have a negative effect on growth, education, psychosocial and

sexual development, as well as on employment outcomes (Goodhand et al., 2011). When IBD is diagnosed during childhood, it can lead to behavioural adaptations that can interfere with both psychosocial and social development and as a consequence of the disorder the individual will also have to develop a range of coping behaviours. Adolescents with IBD often report poorer quality of lives and increased psychological distress than unaffected peers (Goodhand et al., 2011).

Young people with IBD can face various challenges as they complete their education and transition into the world of work, however the impact that IBD can have on education is unclear. A review of the IBD literature has found mixed results in terms of the educational attainment of people with IBD. For example, Boonen et al., (2002) found fewer IBD patients had finished higher education (31.5 per cent had low, 47.9 per cent had medium and 20.6 per cent had high education) in comparison with the control group (29.5 per cent low, 43.4 per cent medium and 27.1 per cent high education). Similarly, Bernstein et al., (2001) reported that fewer IBD patients had completed education to the secondary level, and they required more time to complete their education. Conversely, Longobardi et al., (2003) used census data of patients with IBD and found that those who had not reported any IBD symptoms in the previous year were more likely to attain educational targets than those who had experienced symptoms. Mayberry et al., (1992) found that individuals who had been diagnosed with CD did not differ significantly in their level of education (i.e. secondary and tertiary levels) than those in the comparison group. The report also noted a similar achievement in formal qualifications gained through education between those diagnosed with CD and the control group. However, the study did report that patients when diagnosed at school lost at least 2 weeks of schooling as a result of admission into hospital, 17 per cent had been unable to sit exams because of the illness and 14 per cent felt that CD had prevented them from obtaining their desired level of education. This disruption to education was also reported in a recent study conducted by Crohn's and Colitis UK (2013c) who stated that 67 per cent of young people with IBD felt their illness had delayed their education or training, and 69 per cent responded that their IBD had prevented them from reaching their full educational potential.

When students are having difficulties with their health, then the academic environment and a teacher's perception and awareness of IBD plays an important role (Marri & Buchman, 2005). However limited research into teacher support has been undertaken. Mayberry et al., (1992) in their study of CD, reported that 21 per cent of participants responded that their teachers were indifferent to the disease, and 8 per cent reported hostility (although the results were based on a population of only 58 students).

Transitioning between education and employment

A survey conducted by Crohn's and Colitis UK (2013c), asked young people living with IBD about their experiences and expectations of work. The results indicated that there were a number of concerns among the respondents who were yet to enter work. For example, 66 per cent of respondents were worried that having IBD would prevent them from carrying out employment duties adequately; 65 per cent were already concerned about whether employers would be able to be flexible enough in employment patterns to meet their needs,

and 82 per cent were concerned about managing their symptoms or flare ups in the workplace. Furthermore, 79 per cent of respondents said that their condition affected their confidence and self esteem, which is especially concerning as self confidence is key to an individual being able to advocate for themselves and therefore successfully manage their condition.

As young people are managing their transition into work, they are also often managing the transition from paediatric to adult healthcare, which creates an additional burden. It has been suggested that adult gastroenterologists often have inadequate training in adolescent medicine and so are ill-equipped to ensure a smooth transition (Sebastian et al., 2012). It has also been noted that the links between young people with IBD's experiences of education, and their subsequent employment type is poorly understood (Gay et al., 2011). The IBD audit reported by the Royal College of Physicians (2014) reported that dedicated clinics and support for young IBD patients who were undergoing transitions from paediatric to adult services are offered by 53% of services (equating to 92/173 services). The audit made the recommendation that more work needs to be undertaken to share best practice and to help role out services to sites that are yet to establish their own transition processes. This was highlighted when 60 per cent of young people with IBD reported that they would like career guidance which takes into account their IBD. It therefore seems necessary to develop a greater understanding of the challenges that young people face when moving from education into employment.

In summary, CD and UC are autoimmune conditions that can affect the body between the mouth and the anus, but most commonly affect the intestines and the colon. The prevalence of the conditions has been estimated to be 240,000 in the UK, with age of onset and diagnosis predominantly occurring between 10-40 years of age. Symptoms of IBD can vary between individuals, and other symptoms are often noted including liver complaints, arthritis and fatigue. Individuals may also be affected psychologically and socially as a result of the fear of unpredictable bowel urgency. There are currently no cures for IBD, and treatment management occurs through treatment plans, medication and surgery. IBD can have implications for employment and productivity, but reaching a concrete estimation of the costs of IBD to the UK economy is a difficult task. Additionally, research has been undertaken on the social implications of IBD for the individual, for example IBD can have an impact on an individual's education, and they can also face various challenges in the transition between work and employment, as they often reported concerns regarding whether employers would be understanding, provide flexibility in working hours, and how employers will manage flares in the condition.

Chapter 3 IBD and its impact on employment

As a result of the timing and age of onset for IBD, the condition can have an impact on the individual's entry into the labour force and the career decisions they make (Gay et al., 2011). Boonen et al., (2001) indicated that labour force participation is important both in terms of the social-esteem and quality of life it offers the patient, but also in terms of the productivity and costs for the organisation and society. As with IBD and education, research provides mixed evidence concerning the employment opportunities and occupational distribution of patients with IBD (Marri & Buchman, 2005). However, trying to address these differences could make a substantial difference to the health of individuals and to business costs (Gay et al., 2011).

Career Choices

In their survey of young people with IBD, Crohn's and Colitis UK (2013c) reported that 56 per cent of their respondents suggested that due to their IBD they ruled out some career options that they may otherwise have considered. Almost half of respondents (49 per cent) revealed that the disorder had delayed them in starting or looking for employment. Moody et al., (1992) also highlighted that patients with IBD are worried about employment prospects, but reported there being little practical help available to help them with employment decisions. Ferguson et al., (1994), discussed that in an interview study with IBD patients, it was reported that over half of the participants had changed their career plan in light of their condition. Gay et al., (2011) when investigating what the impact of living with IBD has on an individual's working life reported that two in five respondents with CD and one third of those with UC agreed completely or somewhat that their IBD had prevented them from pursuing or entering their preferred choice of job, and nearly a quarter of respondents admitted they would look for a different job if they didn't have IBD.

Looking more closely at specific job characteristics, a survey conducted by CCUK found that 62 per cent of respondents with IBD were worried about being able to carry out certain work responsibilities adequately (Gay et al., 2011). It has also been found that IBD is more prevalent among white collar workers, and that men with IBD were rarely found to be working in jobs that required much physical exertion (Marri & Buchman, 2005). Jobs that are based indoors are strongly associated with IBD, while jobs that are outdoors or involve exposure to sunlight are correlated with a lower prevalence of IBD (Marri & Buchman, 2005). The nature of the relationship between IBD and type of work is unclear here, and it has been suggested that environmental factors related with manual work are in some way protective or preventative of IBD (Marri & Buchman, 2005), although it may also be that individuals with IBD seek out jobs that are not of a physical nature because such work is not compatible with the symptoms of their condition.

Workforce Participation

As Gay et al., (2011) highlighted, there are very few pieces of research regarding IBD and

working life (in the UK), and consequently research discussing the participation of IBD patients in the workforce comes from other countries. Mayberry et al., (1992) found that a significant number of CD patients in their study experienced long-term unemployment exceeding 6 weeks (in comparison to controls) as a result of difficulties with obtaining work. Longobardi et al., (2003) reported the analysis of employment effects related to IBD from the Canadian National Population Health Service. They found that 28.9 per cent of those who reported IBD were not in employment, with the corresponding figure for the non-IBD group at 18.5 per cent. Their study reported that IBD sufferers were 20 per cent more likely to be out of the labour force. Similarly, in a study of the Dutch population, Boonen et al., (2002) found that individuals with CD and UC were more economically unemployed (6.5 per cent lower compared with the control group).

Sickness Absence

Workforce participation cannot only be measured by levels of employment vs unemployment, but also the amount of sickness absence that those with IBD take. Boonen et al., (2002) found that IBD patients reported sick leave more frequently than control employees, however, those with IBD had less non-specific sick leave compared with the controls. Within the IBD cohort, those with CD reported somewhat more sick leave than UC patients. Longobardi et al., (2003) reported that absence was also related to the level of pain, the presence of IBD symptoms and the need for hospitalisation. However, the recent report by Gay et al., (2011) also reported sickness absence, with three quarters of IBD employees reporting that IBD had affected their work in the previous seven days, with one in twenty reporting that their symptoms had completely prevented them from working in the last seven days. However, the report also suggested that those with IBD displayed a level of presenteeism (attending the workplace when ill). In their survey four out of five participants reported sometimes going to work even when they feel they are not well enough to do so, and more than half reported that this meant they gave more effort at work to make up for any shortcomings that resulted from their IBD.

Career Opportunities and Progression

Gay et al., (2011) found that IBD also had an impact on the career choices that individuals made. Half of the respondents reported that their IBD had prevented them from reaching their full potential in the workplace and that IBD also had an impact on how far they progressed in their career. More than a third reported that they perceived earning less as a result of their IBD, and one third also indicating reduced job satisfaction. These findings support research by Lesage et al., (2011), who undertook a national survey on the quality of life of patients with IBD. The patients described several ways in which the disease had an impact on their occupations, including; having to modify their work schedule; abandon their desired occupation; change occupation and discontinue occupational activities. Evidence from an older piece of research suggested that individuals with IBD are more likely to remain in their same role (57 per cent) in comparison to the control group (Wyke, Edwards and Allan, 1988). Changes in work tended to occur as a direct result of their IBD, usually involving modifications to their current role or re-training. However, Wyke et al., (1988) also reported that IBD employees who were asymptomatic experienced fewer problems with their employment.

Retirement

In a recent report published by Crohn's and Colitis UK (2014b), it was highlighted that the median age for retirement for those with IBD was 55 years, in contrast to 64.6 years (for men) and 62.3 years (for women) in the general population. Additionally, approximately 30 per cent of the respondents with IBD retired before the age of 50, and those with CD were more likely to retire below 50 than those with UC (35 per cent and 23 per cent respectively). Overall, 61 per cent of those with IBD who retired before 50 reported that their IBD had a great impact on their decision to retire when they did, in comparison to 53 per cent of all those with IBD who had retired at any age. Reasons provided for early retirement included finding it hard to work (34 per cent) and finding it hard to find a suitable job (11 per cent). Although the sample in this study was small, it still highlighted that IBD had an affect on the decision to retire at an earlier age, especially for those who retired before the age of 50.

Is IBD a barrier to employment?

Gay et al., (2011) concluded that more work and research is needed to ensure that people with IBD are able to reach their full working potential. In the same report, Dr Martin Gay, commented that: *"it is particularly saddening that IBD has such an impact on a person's career choices and opportunities..."* (page 10). However, is the IBD a barrier to employment, or do the barriers come from other factors associated with having the condition?

Knowledge and awareness of IBD

An individual's own knowledge and awareness of their condition is a crucial enabler or barrier to employment. Casati and Toner (2000) reported that: *"the lack of information coupled with the shame and stigma of having a bowel disorder is frustrating and distressing for clients"* (page 391). Becoming aware of one's condition is a complex and lengthy process. Some have discussed how people with CD often grieve in response to receiving a diagnosis, as they begin to accept and then to understand their condition and the impact it has on their lives (Casati & Toner, 2000). This grieving process may include emotions such as denial, hostility, despair and sadness, and the individual has to learn how to cope and adapt to the ups and down of having the long-term condition. This is, of course, easier when access to information about the disorder is readily available and understood. Casati and Toner (2000) indicated that a lack of information about IBD was also seen in the medical community, especially in reference to the etiology and cure of the disorder and the psychosocial aspect of the condition.

Sebastian et al., (2012) researched the transition between paediatric and adult healthcare services for patients with IBD from the perspectives of adult and paediatric gastroenterologists. One of the key findings was that patients lacked knowledge about their condition, its treatment and how to co-ordinate care. The IBD audit by the Royal College of Physicians (2014), reported that although the provision of support has increased, there is still room for improvement. The audit found that although services are good at providing patients with written information about their condition (e.g. 88% of services reported that they provide educational material for all patients who are newly diagnosed), the provision of formal education sessions remains low (only 42% of services reported that they provided regular

education opportunities for patients and their families. Successful transitions between services included having knowledge and understanding about IBD, and the ability to take their medication independently. This lack of knowledge about the conditions may potentially compromise coping abilities and interfere with treatment compliance (Casati & Toner, 2000). This was highlighted by Goodhand et al., (2011) who reported that only 22 per cent of adolescent patients could recall the location of their disease and only 55 per cent could recall when they were diagnosed. Consequently, improving an individual's knowledge about the condition, and communicating information, especially during periods of transition may improve the treatment of IBD and reduce employment barriers.

Psychosocial factors

Psychosocial factors play an important role in determining how people will cope and manage chronic and disabling diseases, thus it is important to be aware not only of the physical side effects of IBD, but the impact that psychological and social effects have as well. Positive mental wellbeing and positive physical wellbeing are closely linked: someone with good mental health is better able to look after their physical condition and to care for themselves to ensure they receive the appropriate treatment (Moussavi et al., 2007). It has been argued that healthcare professionals do not give adequate attention to the psychosocial factors involved in managing IBD (Casati & Toner, 2000), which should be seen as integral to the successful treatment and management of physical symptoms both inside and outside of the workplace.

Cooper et al., (2010) discussed how having a sense of personal control is important for psychological functioning, and this predicts both physical and mental wellbeing. In a qualitative study, Cooper et al., (2010), aimed to explore how people with IBD perceived themselves before and after their diagnosis and what the impact of the condition had on their quality of life. Participants often discussed that trying to maintain a degree of personal control was important to them, which often meant having to adapt to the uncertain and unpredictable nature of the condition. For some, this lack of control was very distressing. Participants in the study who were determined not to let the IBD 'beat them' often displayed more resilience and were able to incorporate practical solutions so they could maintain control over their quality of life. However, the individuals who were more able to accept the uncertain nature of IBD were also those who had been given clear information about the condition, highlighting the importance of self-knowledge and patient-specialist communication. A better knowledge and understanding of the psychosocial issues can help clinicians to improve their understanding about how to treat patients with IBD to improve their quality of life (Casati & Toner, 2000).

Self-stigma

Self-stigma can be understood as negative and unjustified beliefs about oneself and one's abilities, and is evident among some people living with IBD. Self-stigma reduces self-confidence and the ability to manage one's condition effectively, which can in turn damage employment prospects. A survey conducted by Crohn's and Colitis UK found that the *expectation* of negative experiences at work among young people with IBD who were yet to enter employment were worse than the *actual* reported experiences of those who were in

work (Crohn's and Colitis UK, 2013c). Self-stigma remains a poorly understood area, and more research is needed to explore the effects of self-stigma on people with IBD, and in particular young adults with IBD as they enter the world of work (Gay et al., 2011).

Symptoms and treatment of IBD

The characteristics of the symptoms and treatment of IBD mean that they can often present a challenge for people with IBD who want to work. IBD is a fluctuating condition, meaning that symptoms can go from being under control to flaring up and becoming acute. Flares can be common for some people with IBD. A survey of people with IBD from across Europe found that 35 per cent of respondents had experienced a flare in the last three months (Wilson et al., 2013). A survey conducted by Crohn's and Colitis UK found that 78 per cent of respondents were worried about managing their symptoms or flare ups in the workplace (Gay et al., 2011). Longobardi et al., (2003), found that those who reported more pain in relation to their IBD also indicated increased non-participation in the labour force, compared to those with no pain. Additionally, Wilson et al., (2013) highlighted that respondents who said they experienced constant flare-ups in their condition were most likely to be unemployed as a result of their IBD.

Furthermore, for some people with IBD, fatigue is a constant feature of everyday life (see <http://www.crohnsandcolitis.org.uk/whats-new/fatigue-in-ibd>). Fatigue prevalence in those who suffer from IBD ranges from 41 to 48 per cent when the disease is in remission, to 86 per cent when it is active (Czuber-Dochen et al., 2013a). A study conducted by Czuber-Dochan et al., (2013b) found that fatigue had a debilitating effect on the social and emotional wellbeing of participants, and also limited their employment opportunities. Employed individuals who experienced fatigue often used short naps and took staggered breaks to manage their tiredness. Others had developed methods of planning ahead, and attempting to develop methods to prevent IBD related fatigue including normalising the behaviour, and 'being in control' through managed rest periods and frequent, healthy eating (although it is important to note these were patients with more experience of the disease). A Crohn's and Colitis UK (2014a) information sheet highlighted that students with fatigue may find studying difficult, and worry that their fatigue may limit their achievements and job aspirations. Some respondents, however, also indicated that their employer and colleagues lacked understanding and were unsupportive or not empathetic toward their fatigue (Czuber-Dochan et al., 2013b), possibly related to a poor understanding of the disease by the general population and the impact that IBD can have for sufferers. Working part time or reduced hours is an intervention that a workplace can implement to help employees manage fatigue, however, this can have major financial implications for the sufferer, which can increase an individual's anxiety or depression (which are factors associated with fatigue) (Crohn's and Colitis UK, 2014b). Lastly, for some this lack of energy influenced participants to change jobs, to make the decision not to work at all, or to take early retirement (Czuber-Dochan et al., 2013b).

Surgery and hospitalisation can also disrupt an individual's ability to work. A European survey of people with IBD found that 85 per cent of respondents had been hospitalised in the past five years due to IBD, and that of these respondents 37 per cent had been in hospital

for 1-5 days and 48 per cent had been in hospital for longer than 5 days (Wilson et al., 2013). The same survey found that 60 per cent of respondents had been operated on for IBD, and that those who were less able to work because of their condition were more likely to have been operated upon than those in full-time employment (Wilson et al., 2013). Similarly, Longobardi et al., (2003) reported that those who had been hospitalised in their survey were 81 per cent less likely to be in the labour force, compared to those who experienced no pain in relation to their condition.

The role of healthcare professionals

Healthcare professionals also have a role to play when discussing people with IBD partaking successfully in the labour market. It has been researched in a previous study that, “A key barrier to ensuring greater personal control and self-management was a lack of knowledge and awareness by non-specialist health care staff, employers and wider society” (Cooper et al., 2010, page 1500). Healthcare professionals may lack the appropriate knowledge about the full impact that IBD can have on their patients’ lives in order to support them effectively, especially in the context of work. It has been suggested that the medical community needs to develop a better understanding of the effect that IBD can have on educational and employment related issues and that the patient-clinician relationship would be strengthened if this were achieved (Marri & Buchman, 2005). In 2012, the Royal College of Physicians reported that GPs have called for more information about both Crohn’s and Colitis. GPs also wanted more information about the local services available for their patients.

Wilson et al., (2013) reported that 83 per cent of the respondents in their European study had access to a specialist gastroenterologist, but only 45 per cent reported having a nurse who understood and specialised in IBD. A majority of the respondents thought they had adequate access to their IBD professional (69 per cent), but 24 per cent felt they did not. Results from the IBD audit by the Royal College of Physicians (2014), highlighted that although the availability of IBD nurses has shown that there has been improvement in specialist IBD nurse provision, only 27% of services (equating to 46/173 services) met the full requirements for the core IBD team as reported and established in the IBD standards. Additionally, 14% have no services. Gay et al., (2011) highlighted that healthcare professionals and specialists should focus on the whole person including their social and their working lives when considering treatment plans and made the recommendation that healthcare specialists need to engage in patient-centred conversations about working life as part of their assessment of a patient’s wellbeing and how they treat and manage their condition. If this integrative approach is implemented then this could help people to respond to their symptoms and improve their quality of life and employment opportunities (Casati & Toner, 2000).

The Role of the Employer

There is limited evidence regarding employer attitudes towards employees with IBD and whether employers can be barriers to employment. However, this is important to study, as how employers react could have implications for whether an individual with IBD can participate in the workforce. Moody et al., (1992) undertook a survey of employers’ attitudes towards employees with IBD. Personnel officers from only two companies said they would

reject a job application from an IBD patient, and four were ready to employ a patient regardless of their IBD status. Of those who responded to the survey 60 per cent said they would consider offering lighter duties to an employee with IBD, 70 per cent said they would provide paid leave for employees to attend clinics and 16 per cent said they would pay for private care for an employee with IBD. Additionally, most personnel managers felt that ill-health did not influence promotion, and employees would be assessed individually. However, 8 per cent reported that CD and UC could jeopardise promotion in some cases. The study also suggested that IBD sufferers neglected to tell employers of their IBD when applying for jobs for fear of discrimination, and that companies employed significantly fewer people with IBD than would be expected. However, this study had a very low response rate, of only 27 per cent of all companies asked to participate. Some reasons for non-participation were provided, including companies with no employees with IBD, some had never heard of IBD, and others had no records available. The findings must therefore be treated with caution as the results may be biased in some way; for example, only employers who had positive attitudes towards employees with IBD might have been motivated enough to respond. As the authors point out such a low response rate “*suggested at best disinterest in the subject*” (Moody et al., 1992, page 459), and that there was not a wide enough recognition of the nature of IBD among employers (Moody et al., 1992).

Other findings corroborate that employers can have a positive attitude towards employees with IBD. An interview study of young people with IBD found little evidence of rejection by employers because of IBD (Ferguson, Sedgwick and Drummond, 1994). However, this must be qualified by the fact that some interviewees said that they did not disclose their illness to potential employers, suggesting anxiety that this could compromise their job opportunities. Wyke et al., (1988) reported that the attitudes of other colleagues in the workplace were ‘generally helpful’. In the same study, 77 per cent of IBD patients who had disclosed their condition found that their employers were helpful, with only 4 per cent reporting unhelpful behaviour. Once again, 19 per cent had failed to disclose their IBD to employers. Lack of disclosure was also found in the research conducted by Mayberry et al., (1992) who reported that 37 per cent of their participants felt that employers should not know about their diagnosis and 30 per cent were actively concealing their disease, despite the fact that CD had not led to greater dismissal among individuals who experience IBD at work on health grounds. However, as the research was survey based the results did not indicate why individuals did not disclose to employers and what other factors could have influenced the decision not to disclose. Gay et al., (2011) found that 81 per cent of respondents with IBD had told their employer or HR department about their condition, while 76 per cent had told their immediate boss or line manager. However, they also found that 61 per cent of respondents said they felt very or somewhat uncomfortable discussing their condition at work, pointing to the issues of embarrassment and self-stigma which comes with disclosing IBD at work. Other research reporting employer reactions to IBD disclosure at work has not been as positive. For example, Cooper et al., (2010) reported findings that employees found work challenging as a result of the lack of awareness of IBD and support provided by employers. Angelberger et al., (2009) conducted a poll to assess the public awareness of IBD in an Austrian population, finding that poor knowledge of the disorder was reported among the public, and this could contribute to the taboo surrounding the symptoms of IBD.

This lack of awareness was highlighted by Gay et al., (2011), who recommended a call for a programme of information aimed at employers to help them understand the needs of people with IBD in the workplace.

A measure of the extent to which employers are a barrier to employment to those with IBD could be the level IBD employees feel that their employers support them to conduct their role and implement workplace adjustments. Gay et al., (2011) revealed that a third of their respondents reported concerns that their employers were not flexible to their needs in the workplace, with two thirds stating that they felt unsupported by their employer to carry out their role effectively. For example, in their study 88 per cent of respondents thought it was important for an employer to allow someone with IBD to take time off work to attend doctors' or hospital appointments, however, nearly a third of employers did not provide this. Another adjustment viewed as important by a large majority of the sample (83 per cent) was the ability to have regular toilet breaks at work, which 71 per cent of respondents said they were actually offered. From the survey the largest discrepancy between an adjustment that would help an IBD employee and reported employer provision was in relation to flexible working hours, where 65 per cent of respondents reported this as important, when only 41 per cent of employers provided it. As an example, 41 per cent responded that working from home is helpful and important, but, only 21 per cent cited that employers provided them with this flexible work option. These results (from the employee's perspective only) highlight a need for employers to improve the working conditions for the benefit of employees, and to make reasonable adjustments for individuals with a lived experience of IBD, so they are supported in the workplace (Gay et al., 2011). The call for flexible, supportive and non-discriminatory work practices was also recommended by Wilson et al., (2013), with the aim to improve the quality of work life for those with IBD.

In summary

As a result of its timing and age of onset, IBD can have a great impact on individual's career decisions and their entry into the labour force. Previous research has indicated that people with IBD were more worried about their employment prospects and their IBD had prevented them from pursuing their preferred choice of job, and that people who experience IBD were more likely to be out of the labour force. However, research has highlighted that those with IBD report sick leave more frequently than control employees, although sickness absence was related to the presence of symptoms, increased pain and hospitalisation. On the other hand, individuals with IBD also display presenteeism (attending work when unwell), in an attempt to make up for their level of sickness absence, however presenteeism can also have negative implications for organisational productivity. IBD patients have previously also reported reduced job satisfaction, career progression, having to change their desired occupation and discontinue occupational activities, and retiring earlier than control groups (and IBD was an important factor in the retirement decision).

There have also been questions to establish whether and to what extent IBD is a barrier to employment. For example an individual's own knowledge and awareness of IBD is crucial when communicating information, especially during transitions in employment. Having an improved understanding regarding how IBD can affect an individually psychosocially can

help in their treatment, improve their quality of life and increase their employment opportunities. The symptoms and the treatment of IBD can often present challenges for individuals, as IBD is a fluctuating condition which affects workforce participation, especially if surgery and hospitalisation is necessary. Additionally, the associated fatigue can have a debilitating effect on the social and emotional wellbeing of IBD patients. Healthcare professionals are considered important to deliver an integrated approach of care to enable individuals with IBD to understand their condition and improve their quality of working life. There is currently limited qualitative evidence regarding the attitudes of employers with IBD, however recent quantitative work has suggested that patients with IBD felt unsupported by their employer to undertake their role, there was little opportunity for flexible work and there was a need for further reasonable adjustments to be made to ensure suitable support in the workplace.

Chapter 4 Research aims

Having identified gaps in the current literature regarding employment and IBD, this study aims to:

- Explore the employment decisions of those with IBD, discussing what factors (and their relative importance) affected the individual's employment decision;
- Highlight enablers and barriers to employment for those with IBD;
- Explore how IBD is managed in the workplace (from both the employee's and employer's perspective);
- Consider how the management of IBD and employment decisions can be improved; and,
- Develop recommendations for improving employment outcomes and employee wellbeing of individuals who suffer from IBD.

Chapter 5 Methods

Semi-structured interviews were conducted with individuals who have experience of working with IBD. The interviews took a 'life-course history approach' where the participants were asked about how IBD had affected their life and the role that IBD had in making their employment decisions. Participants were also asked to provide examples from their employment history for when IBD had been an influencing factor in decision making and what other factors were taken into consideration. For example; participants discussed how they coped with the initial diagnosis of IBD, how or if IBD was a factor in deciding to undertake their current employment role and what other factors affected this decision, how their current employment differs from any previous employment they may have had, and participants were also asked to discuss the role that IBD may have in their future employment decisions. In addition and as a result from their experiences, participants were asked to discuss ways in which they thought that employment with IBD could be improved. The approach was judged most appropriate to use in this study as the semi-structured life-course history method encourages the opinions and behaviours of the participants to be explored in more detail and elicits additional concerns or issues that had not previously been considered or anticipated by the researcher.

As previous research had neglected the employers perspective regarding how they manage IBD in the workplace, what an employer's role should be, and what employers think could or should be implemented and improved to help those with IBD remain in the workplace, semi-structured interviews were also undertaken with employers who worked in occupational health and have had experiences of managing employees with IBD.

The participants in this study, providing the employee voice included those who had received a diagnosis of either Crohn's Disease or Ulcerative Colitis, who were currently in work, or had worked previously (see Appendix 1 for advert). Participants were recruited through an advert placed in the Crohn's and Colitis UK newsletter, and if they expressed an interest to take part they were sent an information sheet detailing further information about the nature of the study and what participation will involve, and a consent form for the participants to sign to show they were happy to take part. Interviews were conducted over the telephone and were recorded digitally (with the participants consent) to ensure an accurate record of the interview to aid analysis, and to limit disruptions in the flow of the interview due to note taking. The interview data was transcribed and thematically analysed to identify common themes reported by the participants. This was an iterative process to ensure that themes were updated throughout the analysis. The thematic analysis was inductive in nature, meaning that the themes were determined through close examination of the data, and not prescribed before analysis was undertaken. The interviews and the analysis were undertaken by two researchers at The Work Foundation. This was especially helpful to ensure rigour in both the interviews, but especially the analysis and meant that inter-rater reliability could be established when discussing and verifying the themes and overcoming

any doubts within the thematic framework by interrogating and assimilating one another's interpretations of the data and arriving at agreed conclusions. Using two researchers to analyse the data also adds further validity and rigour to the results by reducing the possibility of individual researcher bias.

Qualitative semi-structured interviews with those who have a lived experience of IBD in the workplace were chosen as an appropriate method to use in this study for a number of reasons. Firstly, the qualitative approach allowed for the participants with IBD to interpret their social role, and provide an in-depth understanding of the role that IBD has had in their individual social and employment context, and reached aspects of behaviours, attitude and reasons for why certain decisions were made that a quantitative method would not have achieved. The approach also meant that specific employment circumstances could be explored in greater detail – highlighting what other factors (other than IBD) may have had a role in influencing career decisions, and where employment situations have or haven't worked well, and crucially why. The in-depth approach also meant that it was possible to ascertain from participants where they felt improvements for managing IBD in employment could be made. This study follows on from the surveys conducted by Crohn's and Colitis UK discussing education and employment, retirement and the research focussing on employment aspirations and reality. These were predominantly quantitative, and so this qualitative study provides a greater understanding of the processes and factors that lead to employees with IBD making the decisions they do, and a more in-depth understanding of the impact of their decisions. (The interview schedule can be found in Appendix 3)

The participants providing the employer perspectives were recruited through contacts at The Work Foundation, who were known to work in Occupational Health or employee wellbeing positions in organisations. Once again, interviews were conducted over the phone, digitally recorded and transcribed and analysed thematically, in a similar process to the employee interviews. Employers were asked about their policies and practices regarding managing IBD in the workplace, to provide examples of when they have had to manage some with IBD, what they did (or didn't provide) and the decisions around their actions, and how this management could be improved to help those with IBD remain in employment. (The interview schedule can be found in Appendix 4). It must be highlighted that these employers can be viewed as 'experts' when considering the management of IBD (and other long-term conditions) in employment and consequently their experiences may not be fully representative of other employers, but can indicate elements of best practice when managing IBD at work.

In total, 15 interviews were conducted with participants with experiences of working with IBD (4 male, 11 female, with age ranging between 25 and 58). Interviews were conducted until the researchers felt they had reached saturation, i.e. when there were no substantially new themes emerging from the interviews being conducted. The researchers found that it was more difficult to engage employers in this research, consequently only 3 employer interviews were conducted. However, these interviews also provided similar themes and suggestions.

The research was reviewed by Lancaster University's Research Ethics Committee, where it

was granted full approval. Before all interviews, participants received an information sheet outlining the study, making it clear that they could withdraw from the study at any time. Respondents also provided their written and verbal consent for participation.

A number of biases can be identified in this sample. All participants had roles that were predominantly desk based, and consequently some of the barriers to employment and improvements needed may not be generalisable to more active, less sedentary manual roles. As participation was based on responding to an advert, the individuals involved may have had exemplary cases that they wished to share, or have the increased confidence and willingness to discuss their experiences, and consequently may not be fully representative of all those who experience IBD at work. Finally, the sample was predominantly female, and gender could be viewed as a factor influencing how individuals view their IBD, their choice of employment, and how willing they are to ask for reasonable adjustments in the workplace.

Participants with both Crohn's Disease and Ulcerative Colitis were interviewed in this study. It is important to note that although previous research has highlighted that there are differences between Crohn's Disease and Ulcerative Colitis, during the analysis it was noted that there were no significant differences in what the participants were reporting in relation to their condition and employment, consequently the term IBD will be used throughout the remainder of the report.

Chapter 6 Results: The employee perspective

The following section presents the results of the thematic analysis of the interview data with the participants with experiences of working with IBD.

Nature of IBD

All participants were willing to discuss what the impact of having IBD had on their life (both employment wise and socially), and described the physical nature of their condition. Common symptoms of IBD included experiencing blood in their stools, increased frequency in needing the toilet, stomach cramps and pain.

“I experienced bleeding, diarrhoea and bleeding and stomach aches.”

— Participant 10

Some participants also mentioned that these symptoms were exacerbated at certain times of the day, particularly around meals, which also lead to difficulties in eating and subsequent weight-loss. Others explained how their IBD was worse in the morning, and that they usually had to get up earlier than they would have liked so that they were able to prepare themselves as best they could for the day ahead:

“I always wake up early in the morning, a lot earlier than I probably should, because I have to – I’d rather prepare myself before I go to work and that takes a while. You don’t want to be unwell on your way to work to make sure that everything is ok.”

— Participant 3

A number of participants discussed how the IBD had an impact on other parts of their body, especially noting swelling and pain in joints and some also suffered from osteoporosis and arthritis related to the condition. For example:

“I also suffer from swollen joints as well and it can be different ones, like last year my knees swelled up really bad. Before that my jaw swelled and I couldn’t speak, my wrists have been swollen and my hips and ankles.”

— Participant 7

“Physically, it [IBD] does have an impact, for example it leads to arthritis, osteoporosis. I’ve got osteopenia in my lower back – this is the step before osteoporosis, so when you have brittle bones – you can’t treat the fractures...but that leads to chronic back pain, so I’ve got that.”

— Participant 3

Although participants discussed a commonality of symptoms, some were keen to mention the individualistic nature of the condition, and that people can suffer in different ways. They

were also keen to raise the awareness that IBD should not be considered only as the disorder that meant an individual experienced blood in their stools. This highlighted the difficulties that the participants had in helping others to understand the nature of the condition:

“So, not everyone is the same, and people can suffer from it in different ways and have different symptoms. There can be different causes and different effects. It’s not just black and white, you’ve got Crohn’s or Colitis that means that you need to be near a toilet. It’s the urgency. It’s the stomach cramps. It’s the triggers.”

— Participant 2

One side-effect that almost all participants raised was the nature of fatigue associated with IBD, even when they were in remission from physical symptoms. Some participants discussed how they were fatigued because they experienced many symptoms at night, which meant that they went through extended periods of disturbed sleep patterns, and little opportunity to rest. Others reported that it could be related to diet and digestion, and the body being deficient of necessary vitamins:

“...They did some tests on me and found that I was Vitamin D deficient. It can be a symptom of Crohn’s, but the deficiency of Vitamin D also causes tiredness.”

— Participant 2

In many cases however, this tiredness or fatigue was often discussed to be as bad as, or in some cases worse than the physical symptoms. Many participants discussed that in many cases they were lucky that stomach cramps, bleeding and the urgency for the toilet were controlled by a range of medication, or in some cases surgery, but the fatigue was harder to combat. This fatigue therefore had major implications on how the individual coped with the disease both socially and at work. One participant summarised this when they said:

“I can’t stress enough how much fatigue is such a big impact. And I’m not talking about, oh, I’m a bit tired today, I’m talking about exhausting, where you feel like you can’t even walk up the stairs...I was barely able to get out of bed because I was so weakened by it...Tiredness doesn’t even sum it up, fatigue doesn’t sum it up really, it’s beyond that when it hits. It’s pure exhaustion basically.”

— Participant 11

A number of participants discussed that managing IBD in their daily lives (and especially in relation to their employment) was very difficult because of the unpredictable and fluctuating nature of the condition. This meant that individuals found it very difficult to plan holidays, long-term career plans, or even days out:

“With this type of illness and my Crohn’s Disease, it’s so unpredictable. You could be fine one minute and then the next minute you could be in total pain and that’s the worst thing, because I couldn’t plan ahead. I couldn’t plan for the next week or the next month because you just never know if you’re going to feel up for it.”

— Participant 1

Participants also noted that because of the individual nature of the condition, and that it could fluctuate and flare (often without any warnings), that when you are diagnosed with IBD there is no way of knowing the severity or the course of the IBD, what symptoms you may experience on any given day, and how your body will react to the condition:

“At the time of diagnosis you have no concept as to how it’s going to change throughout time. You expect especially with something like IBD that it’s going to get worse, that your system is going to slowly break down and that you’re going to be stuck with things.”

— Participant 14

Some participants also mentioned that alongside the frustrating fluctuating nature of the condition, it was difficult to understand why they had developed IBD as there is no known cause for the condition, and at the moment, there are also no cures. Participants discussed the lack of understanding about the condition as a barrier to being able to cope with the disorder:

“Nobody else in my family has got it...There’s no reason for me to have it. And so not only could they not say why I had it, but nor could they say how serious it would be, nor how long it would last.”

— Participant 6

At the time of data collection, media stories were published suggesting that eating junk food was a cause of, or could trigger IBD. This was raised in a number of interviews as being ‘horrific’, and participants felt that there was the implication that individuals with IBD brought the condition upon themselves. One participant described how such stories not only confuse individuals with IBD who are still struggling to understand and discover why they have the condition, but that such media coverage can have a detrimental impact on how others view the condition and potentially why certain individuals have it:

“My consultant shrugs at me when I ask him a question because sometimes he just doesn’t know the answer. So, the doctors are still trying to fathom exactly what triggers it and nobody really knows. So to have somebody go, well yes, it’s junk food isn’t going to help...it did, I think, have a detrimental effect in the way people perceived it.”

— Participant 15

As well as having an unknown course or progression, for many participants the fact that IBD was an internal condition, and for many does not show physically on the outside as a disability was a difficulty they had to overcome. The hidden symptoms made it difficult for individuals to discuss, or even persuade to others that they are ill. The nature of IBD can

then be very difficult for others to understand, which, as will be discussed later in the results has implications for how IBD is managed at work:

“It’s very hard to articulate...people were saying oh you look really well. My insides were getting ruined. It’s very hard because nothing’s falling off, you’re not limping...there is nothing visible and it’s quite hard to get over to people that it is a serious disease.”

— Participant 8

In summary, IBD is a disorder that is often characterised by individuals experiencing stomach cramps, blood in the stools, an urgency of needing the toilet and pain. However, the condition can also be associated with other side-effects, including fatigue, which can occur even when an individual is not symptomatic. IBD has no obvious cause, and as of yet no cure, and because of its fluctuating nature, planning for social events and employment is very difficult. As the condition has hidden symptoms, many participants felt that they had to explain that they had a chronic condition or disability because of the lack of physical symptoms, and sometimes had difficulties in doing so. The nature of IBD was seen to have implications for employment, and how IBD was managed at work, and this will be discussed later in the results.

Psychosocial implications of IBD for the individual

As well as experiencing physical affects of IBD, all participants discussed the psychosocial impact that being diagnosed with the condition had on them and how the condition had implications on the way in which they lived their lives. As a result of the nature of the condition, participants often mentioned feeling embarrassed about discussing what IBD was, and when they experienced a severe flare explained how the nature of the condition often resulted in a loss of confidence and self-esteem:

“I started to feel really sad about it, especially because I was having periods of incontinence and that was really embarrassing for me. And I got really embarrassed about using a toilet in public and things. So it kind of destroyed my confidence really.”

— Participant 1

This loss of confidence often resulted in social implications, where participants would: reduce their time in social situations; only go out where they could plan where toilet facilities were in case of an emergency; or stop going out completely. The physical symptoms were not however the only reasons why a participant’s social life had been affected. Many discussed how the fatigue associated with IBD meant that even if they wanted to go out, and had the confidence to do so, they did not have the physical energy to:

“On my day off, I just lie on the sofa all day. I don’t go out. I don’t have a social life. Since I have been ill with IBD I have had no social life. I literally lie on the sofa on my days off asleep...I don’t get to see my friends as often, and my husband and I never go anywhere.”

— Participant 10

For one participant, the symptoms had a great effect on their life, as they developed an

anxiety about going outside for fear of having an accident in public. Their IBD was severe, and they had mentioned that they had rarely been in remission, but they described instances of not wanting to or being able to go out. Over time they had developed some coping mechanisms for this, including knowing where the available public toilets were, and timing when they went out, but this case highlighted just how socially disruptive the condition could be:

“When you’re outside the door of your house, you’re anxious immediately. At one point I almost became agoraphobic, and it’s quite hard to fight against that because the instinct is to just not go out.... You’re always trying to make sure that you’ve emptied your bowels before you step outside the door, and if you eat anything during the day you don’t go out immediately afterwards...it’s certainly mentally damaging.”

— Participant 8

Other participants discussed becoming depressed as a result of the diagnosis and the consequent symptoms and outcomes associated with IBD. The participants noted that they thought that IBD was going to take over their lives, and felt that their outlooks were going to be bleak, and could not see a way out of the shock of their diagnosis and how the symptoms affected them.

“I have had periods where it has completely affected my confidence, and it affects my emotional health and psychological wellbeing. I do sometimes have terrible, terrible lows, to the extent of where I am being told you have depression...I’ve been through a bad patch and feel the world is completely against me.”

— Participant 12

Another participant was also medicated for depression however, once they had their IBD medication under control, and had learnt how to keep their IBD under control, they explained that:

“I was just really being a bit stupid, not really thinking that once my medication was under control, that actually I would just lead a normal life again.”

— Participant 15

This notion of ‘normality’ was echoed in other interviews, and suggested that individuals with experiences of IBD perceived themselves to be ‘abnormal’ or less worthy than those without the experience of IBD. This supported the literature that had found that those with IBD often reported reduced self-belief and have unjustified beliefs about their abilities.

Other participants highlighted that the impact of IBD on their mood and wellbeing was symptomatic, dependent on whether they were experiencing a flare, and how well their medication was working. Participants who were in remission often reported feeling better, happier and having the ability to maintain a positive lifestyle in comparison to those who were experiencing IBD symptoms or who were changing medication. One participant said:

“It’s very cyclical. So when I am symptomatic obviously there’s a huge impact and then shortly afterwards you’re wary and very careful about what you’re doing and it’s on your mind. And then you go through a prolonged period of time where you’ve been well and taking other medication, and tend not to think about it much.”

— Participant 4

The age of the initial onset of symptoms and diagnosis could also have social implications for individuals. For example, a participant who was diagnosed with IBD when still at school commented that physical development held them back, they were not selected for the school sports team, and felt that they were different from their peers. Another discussed how they felt they missed out on spending time with their friends because they were often too ill to go out, and this affected social relationships that they had with their peers:

“So other people were being involved in school teams and that kind of thing, and I had the experience that many teenagers can have of being told that you’re different and that you desperately want to be the same as everyone else.”

— Participant 6

“I was in my last year at middle school, and it did have a really big impact on me then because when you get to that age when you’re going out with your friends a lot, there’s a lot of sleepovers and things like that, and being ill I wasn’t able to do a lot of things and I was missing out on spending time with my friends.”

— Participant 13

In summary, the results indicate that people with experiences of IBD not only experience physical symptoms, but may also display increased anxiety and depression and a reduced sense of wellbeing as a result of both receiving the IBD diagnosis and coming to terms with the physical symptoms of IBD. The psychosocial factors associated with IBD were seemingly related to age at diagnosis, the presence and nature of IBD symptoms and the role of medication. Participants discussed how IBD could take over their lives, and how when a suitable medication or treatment had been found they were ‘normal again’, indicating that IBD led to feelings of reduced self-belief. It is therefore important to also consider the psychosocial wellbeing of individuals with IBD in the context of work, which will be discussed later in the report.

However, the physical and psychosocial effects of IBD on individuals could be related to the role of healthcare professionals, and how they manage the diagnosis and communication of IBD to an individual.

The role of healthcare professionals and IBD

All participants discussed the role of healthcare professionals in diagnosing their IBD, and how this affected them. The participants in this study were diagnosed with IBD between the ages of 13 and 53, and there were a range of both positive and negative experiences related to length of time it took to diagnose IBD, and the helpfulness of the medical professionals treating the participants. Some participants explained that they had a very quick diagnosis,

that their GP realised that their symptoms were severe and could be related to IBD and so provided a quick referral to a gastroenterologist. However, speed of diagnosis was seemingly related to a number of factors. For example, one participant described that their diagnosis was quick as a result of the severity of their IBD:

“I went to the doctors, and then they referred me on, and I was diagnosed within like a month or so. So I got diagnosed pretty much straight away because my inflammation and stuff was really bad at the time. So they were able to diagnose me straight away.”

— Participant 1

Another factor for getting a quicker diagnosis appeared to be the persistence of the individual in communicating to their GP that something was seriously wrong, and that a referral to a specialist was necessary. One participant had an increased awareness of IBD as somebody in their family had also been diagnosed with the disorder, and as a result pushed for tests to be conducted by their GP, who then referred them to specialist consultants. In this case it was clear that knowing people who had an understanding of the disorder was helpful in the speed of their diagnosis:

“I said, look I need something done, more than just taking blood and samples and nothing being done about it. She then referred me to a consultant at the local hospital to go and have a talk to see if they could work out what was wrong with me...I gave her the push...I did have to push for it, and basically got the colonoscopy and then that’s how they found out that actually my insides were pretty buggered to be quite honest.”

— Participant 15

Age was another factor that affected the speed of diagnosis. One participant in the sample had been having symptoms of IBD from the age of 13, but was only diagnosed at 15. Although throughout this time they reported sickness, an increased need to go to the toilet, dramatic weight-loss and fatigue they reported that:

“Everybody thought I was really lazy and just didn’t want to get up. I went through a number of different diagnoses from that, from IBS, to in the end everyone thought that I was bulimic and doing to myself...but I wasn’t, I had no control over it.”

— Participant 7

Their IBD was eventually diagnosed as a result of a bowel infection, which ended up with an extended period of hospitalisation. During this period of diagnosis the participant reported finding it hard to explain what was actually occurring and how it was affecting them. However, when the diagnosis was reached and a referral was made to a lead IBD specialist at a different hospital, treatment from the medical profession improved.

Similarly, another participant who was diagnosed when they were in their teenage years explained that they felt that their GP did not listen to them, and would not conduct tests, as they believed that the IBD pain was period pain or growing pains related to the age of the individual:

“They kept taking me back to the doctor, and they were no good, saying it was period pain, even though this was no way near, it was every single day of the month...I’d go back again and they would say it would be growing pains and now you’re making up the pains in your head...no one actually did any tests, they would just listen and send me away with a you’re making it up sort of thing.”

— Participant 13

In this case, it was only until one GP recognised that the individual was seriously anaemic and in a potential need for a blood transfusion that further tests were undertaken and a diagnosis of IBD received. This resulted in a very angry and anxious time for the individual, which did not help the IBD, and a led to a distrust of doctors that still exists. Treatment improved only after a move was made to specialist hospital, with a consultant who specialised in IBD and understood what needed to be undertaken and had up to date knowledge of any new treatments.

However, older participants also reported difficulties in diagnosis, especially as the symptoms for IBD are similar to other disorders. For example:

“I’d been in and out of hospital several times in great pain and was getting told things like oh, women your age, its irritable bowel, all that kind of nonsense. It was about 5 years (the gap between experiencing symptoms and diagnosis). In the course of one year I was in and out of hospital 5 times.”

— Participant 12

Another participant diagnosed at the age of 45 found that the length of time it took to reach a diagnosis led them to feel tired, worn out, miserable and depressed, and the symptoms that they were experiencing were similar to bowel cancer, which was a cause of great anxiety. Referral took a long time as:

“I went back three times before they decided that I was actually in need of some further examination and that is when I got referred to the wrong specialist at the wrong hospital, who then referred me to the right specialist at the right hospital.”

— Participant 10

After diagnosis, the main role of the healthcare professionals was to help those with IBD find a medication that worked for them, to help to reduce the occurrence of flares, which meant that the individual could return to, or remain at work:

“The main focus was getting the symptoms under control...so they were just focusing on what the symptoms were and how we can get them under control.”

— Participant 9

Participants often discussed a range of medications that they had been offered to try, and in many cases, relevant medical treatment was successful. However, for one participant, although they were stable on medication, the hospital has since stopped providing it, as

NICE guidelines have reported that it is too expensive and should only be administered three times. As a result the participant reported sliding back into the IBD symptoms they had experienced before the medication, and was waiting to discuss with consultants what would happen next. Although, their IBD symptoms were not yet at a stage to have an impact on their working patterns, if a replacement medication was not found, then this could have been the case.

However, for others although finding a medication to control the IBD was important, they argued that other services were also required to help those recently diagnosed with IBD come to terms with the diagnosis:

“I guess it is about support for people immediately on diagnosis, and that may not be the consultant...but somebody who can hold that space in the face of that uncertainty and shock. And then the opportunity to have a more considered follow-up conversation with someone who can explore the medical side of things, whether that is dietary or medication or treatment or prognosis.”

— Participant 6

This need for support was important, however it was discussed by the participants that the medical staff were often very busy, and sometimes appointments were hard to secure, meaning that staff had limited time to spend with a patient. One participant identified that:

“There have been times where at hospital I’ve felt that I have been completely ignored...and I just feel that I’ve been treated like a lump of meat and not as a human being.”

— Participant 12

One group of healthcare professionals who came under great praise for the help that they provide those who have been diagnosed with IBD were specialist nurses. Many participants often described their GPs or consultants as being too busy to see or to talk to if an issue with their IBD arose, and as a result IBD nurses provided an invaluable support, would be a point of regular contact and somebody who was able to chart the progress of an individual more closely. For example:

“I’ve got a really good specialist IBD nurse – in my opinion she’s a lot better than my actual doctor who I rarely see because he is so busy...she tends to see me more regularly, and tends to listen to any of your concerns. She sees me a lot more (than the consultant) and is able to see my progress and if there have been any problems I can tell her. She’s one of the biggest people who has been able to support me.”

— Participant 3

The importance of the specialist nurse was highlighted by one participant who was diagnosed with IBD over 30 years ago, at a time when specialist nurses were not in place. They explained that when they were diagnosed, IBD was treated as a disease that had to be medicated, but was not contextualised, and the wider psychosocial and employment implications of IBD for the individual were not discussed. As a result, there was little

information regarding how to best manage stress, diet or even the psychological impact of handling the diagnosis. However, after a recent flare and hospitalisation, the participant was transferred to a major teaching hospital and had access to a specialist IBD nurse:

“Getting the support from the specialist nurse is the most fantastic thing I have done. I’ve learnt so much about how to self-manage my own condition, and have received so much support and information from the specialist nurse. I just wish I had known all this stuff 30 years ago, but we weren’t in the same position as we are now...It’s far removed from the traditional consultant role and it provides an invaluable bridge between the actual patient and the consultant...which is incredibly valuable.”

— Participant 8

As well as being an important source of support, IBD nurses were seen as having an invaluable role for the provision of information when receiving an IBD diagnosis. One participant described how after being diagnosed with IBD it was the longest and worst two months of their lives until they were referred to a specialist nurse, who was then able to explain the condition in more detail. The IBD nurse was often the person who introduced the participants to the Crohn’s and Colitis UK Charity website, and discussed where other sources of information about understanding IBD could be found:

“The IBD nurse was able to explain what it was, they also gave me the pack from Crohn’s and Colitis UK...it was just unfortunate that it took so long to get a first appointment. But now I feel very supported by the IBD clinic.”

— Participant 14

The IBD nurse was also a first point of call for participants when they had a relapse, as they were reliant and reliable specialists to contact, and they also have closer contact with the specialists to book appointments at clinics or respond to queries regarding medication. However, participants often responded that it was the practical experience of treating IBD patients of all age ranges which was the best feature of specialist nurses, as they then had a wealth of experience to offer regarding the self-management of the disorder, practical implications and solutions to solve re: commuting and travelling, and the moral support that they provided.

Participants were asked if at any stage throughout diagnosis or initial treatment of their IBD, if they were provided with any information regarding how IBD could affect their employment (or education if the participant was diagnosed when still at school), and who gave this information to them. The results were mixed, and was once again, usually connected to the information that was provided by the specialist nurse. For example, one participant wanted to train for the nursing profession, and was concerned how the diagnosis would affect their education and employment opportunities. However, they explained how the specialist nurses were very supportive and provided real and honest advice:

“...The specialist nurses were really really supportive and they would be there to help talk about education and things like that. We spoke about it [employment decision with IBD] and

they said that I was still able to do it with this type of illness. And even when I wasn't able to become a nurse, they provided me with help to find a space that I could work in within healthcare...that was good to know."

— Participant 1

A participant who was diagnosed with IBD whilst still at school described how the specialist nurse always asked how school (and now work) was going, as they were keen for the participant to maintain a healthy work-life balance, as stress was something that exasperated their IBD. The participant discussed that they had suffered a lot of emotional stress when at school, but they had learnt anxiety and stress techniques to reduce the level of stress they experienced at work. However, in terms of career advice as a result of their diagnosis, the participant explained that as there was so much conflicting advice about IBD and research, they found it best to undertake independent research, and choose employment they thought they were best suited to. Another participant also provided a case where work was often discussed by their GP and gastroenterologist, because for them their stress and sleep levels seemed to trigger an IBD flare, and these were both factors that could be affected by an individual's workspace. Therefore, this participant explained that:

"They've always asked about what work environment are you working in and what's your work set up like? They do tend to ask about that, and most of them advise that I do something different."

— Participant 4

This participant also said that the GP offered help with statutory forms regarding sick leave or that they could provide contact with employers regarding the nature of the condition, and stating that time may be needed off work. This highlighted other ways in which healthcare professionals could provide employment related help to those diagnosed with IBD.

Others explained that no direct information about IBD and employment was given to them, but at the same time, they didn't ask for the information either. This response was given from participants who were already in stable employment roles, and didn't feel that they would have any further problems associated with their employment. However, some participants did mention that the specialist nurse advised them to disclose the condition to their employer in case there were problems that needed to be addressed in the workplace. Additionally, participants also mentioned that at the point of diagnosis, specialist nurses provided information regarding the advice Crohn's and Colitis UK produce which they could access for all the necessary information re: IBD and employment (from both the employee and employer perspective) and they researched any effects for employment themselves through the use of internet forums or discussion groups:

"If I'd have asked it could have been likely that I'd have been given information, but I know that Crohn's and Colitis have got a leaflet on it, and I went on forums quite a lot when I was first diagnosed...reading what other people had responded, and it did reassure me that it wasn't going to massively affect my employment likelihood."

— Participant 14

However, some participants felt that it was not in the role of the IBD specialist nurses, or healthcare professionals to provide information and advice around IBD and education and employment. In these cases individuals reported that the only information that would have been helpful concerned the role of medication, and which would be best for them to be able to continue to work effectively and remain in employment. Others felt that it was the role of the healthcare professionals to deal with medical related issues and concerns (for which they were already busy enough with), and it was the role of other charity bodies and the individual to be more proactive in the decisions that they made:

“I don’t think that it is their problem [the healthcare professionals]. The hospital is there to deal with you medically, it’s up to you then to take on board what you’ve got, contact people like NACC and be a little more proactive. You can’t expect a hospital, they’re busy enough, and they’ve got to deal with the illness only, that’s their job.”

— Participant 10

“It is the role of the medical team to find some kind of medical resolution to get me through...The medical team was the medical team, and my work was my work. I didn’t feel that I needed a bridge between them.”

— Participant 5

Some participants voiced concerns regarding what would happen when their specialist nurse would retire as some of them were approaching retirement age. They were worried as it appeared that the hospital had nobody else being trained to replace them, and this would be a huge loss to other IBD patients, and a loss of the valuable knowledge accrued:

“The distressing thing is, is that my specialist nurse and my surgeon are getting older and there is no-one to line up to replace the specialist nurse. She has seen over a thousand patients in her time, and all that body of knowledge would be lost. Because it looks very doubtful that this hospital will have somebody to train up alongside her to take her place when she finally goes...which is gutting.”

— Participant 8

In summary, healthcare professionals were seen as very important in the initial diagnosis of IBD, and although some participants reported having a short diagnosis period from the initial onset of IBD symptoms, this was generally related to the severity of their IBD and the individual having an understanding of their symptoms and pushing for a diagnosis. Being referred quickly to an IBD specialist also decreased the length of time for diagnosis, and reduced the associated anxiety for the individual with IBD. However, for certain participants (especially females in their teens, and late 30’s onwards), a delayed diagnosis was reported as the symptoms for IBD were often confused with, or mistaken for other physiological or hormonal changes that could occur at that age. The role of the healthcare specialists was primarily seen as finding a medication that reduced or removed the symptoms of IBD, which played a role in an individual’s ability to remain in or return to work. Some participants noted that healthcare professionals should also provide some psychological care, especially at the point of diagnosis, so that individuals can better understand what having IBD means for

them. Specialist IBD nurses were unanimously praised for their role in providing support and information to individuals, especially when it was difficult to arrange consultant appointments. Their wealth of experience meant that they were often a source of advice if an individual noticed a change in their condition. When asked whether education and employment was discussed with the participants, once again there were mixed responses, with some indicating that they took an active interest in providing help and advice, some responding that they were a link to the provision of other services (e.g. Crohn's and Colitis UK) who had detailed information on these matters, and others who believed that this was not part of their role.

IBD and current employment decisions

The participants in this study held various roles, and worked a number of different employment patterns. Four participants were either self-employed or a contractor (including one who took early retirement, and had since started working self-employed part-time), one participant was a NHS-bank agency shift worker (a specific agency service for health professionals), seven participants were in full-time employment working the regular 9-5 (but some had adjusted or flexible work patterns to help them to remain at work), one participant was full-time but worked to shift patterns, one participant was part-time, and one was retired.

For some, their experience of IBD was a major factor for their choice of work – both the working pattern and the career they chose. For example, the participant who worked as a NHS-bank agency worker was currently symptomatic and believed that this working pattern worked well for them as they could choose when they wanted to work, and the NHS-bank provided the flexibility needed to decide how much work they thought they were able to offer. They had chosen a career in healthcare which meant that NHS-bank work was an option. This was especially important at the time of the interview as their IBD was unpredictable and choosing shifts meant the participant felt like they were not letting anyone down:

“It works for me really well, because I can choose when I want to work and when I don't want to work....with Crohn's Disease being really unpredictable it meant I couldn't plan ahead because you just never know if you're going to feel up to it...you don't have a set contract and you don't have set days when you go to work.”

— Participant 1

One participant chose part-time work as their IBD was currently in a transitional state as they were settling into new medication, and were waiting to see if they could manage on it, or whether they were required to go on a second tier of drugs. As a result the participant was still experiencing IBD symptoms and felt anxious when leaving the house. Their role and work pattern meant that their commute to work was reduced to a level that was manageable, and toilet facilities were available if needed:

"I can go by bus now, and it's just a short bus ride, so that is ok, then it is sort of middle-distance trains which all have loos on board, and that is actually very manageable for me. It [the IBD] was a consideration, I have to be able to get there. If it was a longish journey by a suburban train, then it just wouldn't be doable."

— Participant 8

For two of the participants who were self-employed or worked on a contractor basis, having IBD was a role in their decision making. The stress of their previous role and the prolonged commute were factors that influenced their decision in both cases. One participant chose their role, because although they had previously retired, it working helped them financially, and the new work was acceptable in terms of the location (reduced commute), and environment (improved toilet facilities). Additionally, the participant explained that there was now reduced stress and pressure on them, in comparison to their previous role. Reducing the level of stress was important for this participant as this limited the opportunities for triggering their IBD:

"I thought that I couldn't do this long-term and I felt that staying there was stressing me out, because I wasn't happy and that's when I felt things could trigger again, so I decided to leave...I would rather manage on what I have got than put myself through the risk of having a flare up by going into a full-time stressful job."

— Participant 11

The experience of working with IBD was also important in one participant's decision to retire (although not the only reason, as their partner had also just retired), and this was related to the fatigue that participants experienced with their IBD. The participant discussed becoming very tired, to the extent of not being able to stand for a shower:

"I'd have a shower and then lie down, which is when I said that I have to do things in slow time. I was just getting worn out by getting up....and I had actually reached that point of just thinking Sundays were horrible because I was thinking I have to get up on Monday and do this...and I realised I was going to be on my knees soon."

— Participant 9

One participant had mentioned that although job satisfaction was important in any career choice that they made, IBD did play a role in the choice of their current role as they perceived that some employers had seen their job history (they had been in and out of previous roles as a result of hospital appointments), and if they disclosed either on the application form, or in an interview that they had IBD, then they felt employers would not hire them. Although they now enjoyed their role, they explained that it may not have been the direction they would have taken at first:

"I was in and out of hospital, and I'd been applying for jobs and as soon as they say that you had Crohn's Disease, no, they weren't interested in you...you would go for interviews and they would ask quite deeply about the Crohn's..."

— Participant 12

However, for a proportion of the participants IBD was not a major factor in their employment decisions although, it may have had an impact on the working hours for individuals (for example, some participants worked flexibly both in terms of time and location). Participants argued that job satisfaction was important for them, and even though they may have been symptomatic, and finding working with their IBD difficult, their choice of career was more important, and they wanted to remain in that role. For one participant who was diagnosed with IBD when still at school, the IBD did not influence their choice of academic subjects, and this attitude remained into employment. This participant said that even with IBD (that they had regular hospital appointments for), they did not want the IBD to control them, and so would pursue what job role they could, and importantly wanted to do:

“I took the subjects that I wanted to take, so the ones that I enjoyed. These decisions weren’t really based on the IBD...I applied for the job because I had the background needed, and the experience. I was interested in the role, I have a background in social media and events and this was what the organisation needed...so it wasn’t really based in this is a good place to work when you have IBD...I don’t want the Crohn’s Disease to control me as such...I try to pursue everything I can.”

— Participant 3

Similarly, the participant who worked in a shift work pattern at the time of the interview, was experiencing symptoms of IBD but had always wanted to pursue a career in media, and consequently, even when they were diagnosed with IBD whilst employed in their role, they wanted to stay in the role, because they were determined to continue in their chosen profession, had hoped that their IBD would improve with medication. Additionally, the participant wanted to remain independent and not let having IBD control their employment decisions:

“Why did I choose it? You have to go back to when I was 18, I just always wanted to work in media...I didn’t have IBD when I became a sound engineer, but it has been very hard work...”

— Participant 10

Factors other than IBD were evident when it came to choosing a career. Finance was one factor that was discussed by a number of participants, in that individuals chose work, or chose to remain in work because they needed the money, and if a role came up that was convenient and they had the skills and were able to undertake the work, it was necessary to take the role. Although at times, some of the participants felt that they did not feel particularly valued as they felt that they could do more with the skills they had, they remained in the role because of financial reasons, and because they had been treated well whilst in their roles and symptomatic:

“I don’t think it did at the time [IBD playing a role in deciding their current job], because I just needed a job, I needed the money and it was just convenient...I stay here more now for convenience for the illness rather than because I like it.”

— Participant 13

In summary, there are a range of factors that led to the career choice and work patterns for those who experienced IBD in employment. For some, the nature of IBD and whether they were symptomatic was a major consideration in the type of working hours that they chose and how flexible they needed to be. In such cases, individuals chose working patterns that they had more control over (i.e. bank/agency work, self-employment). Others discussed that their commute was a major factor in their employment choice, often choosing employment that reduced commuting times, or where the individual knew that they had facilities on their route. Stress was also considered as a factor, as some participants had left previous roles as a result of the stress they experienced in them, to enter less stressful roles, in an attempt to reduce the chance of triggering an IBD flare. However, for a number of participants remaining in a role they enjoyed, that they had always wanted to do, or matched their experience was more important than how their IBD affected them. These individuals often discussed not wanting their IBD to control their decisions and having the determination to continue in their chosen career. Some were diagnosed whilst in their current role and did not want to change what they were doing (although their work patterns may have been adjusted to accommodate their IBD). Finally, the need for an income was also discussed as a factor that sometime preceded IBD when making a decision regarding whether to enter or to leave employment, and what role the participant chose to undertake.

Factors that affect employment with IBD

For participants who had changed their career or employment pattern as a result of their IBD, they often compared their experience in their current role, to their previous employment. This highlighted a number of factors to be taken into consideration when discussing how IBD can affect employment, and what organisations and individuals can do to improve the management of IBD in the workplace.

The role of line management

Line management and support provided by senior management was often discussed by participants. In many cases, participants often left previous roles as they had felt unsupported by line managers, or explained that a line manager's lack of awareness or sympathy of IBD increased the level of stress they experienced.

One participant discussed how a line manager had originally been supportive of the individual and their experiences of IBD and after an extended period of sick leave agreed a phased return to work. However, when the participant was back full-time, they realised that they were unable to cope working full-time. As a result, there was an attempt to negotiate reduced hours, but this was refused. This refusal by the line manager to negotiate working hours, even though occupational health had been approached and suggested that the request was reasonable led to the participant feeling that they had no choice but to resign. Although, the participant recognised that a line manager's role can be busy (and in this case the line manager was undertaking many roles), the participant felt that the line manager was more interested in an employees outputs and ensuring that tasks were completed to the required standards rather than the 'people management' component of understanding health, wellbeing and stress. This perceived lack of people management skills led to embarrassing situations for the employee when having to describe their symptoms, and

sometimes led to leaving that work situation:

“They wouldn’t let me [have reduced hours] so I was forced to resign. They said that they don’t like people working odd hours – that was the reason given. That was it, she wouldn’t negotiate. She wasn’t sympathetic. I was forced to sit there and talk about my bowel habits to her, which was highly embarrassing and humiliating...I think she was quite happy when I resigned...it was just my line manager.”

— Participant 11

The limited support and sympathy from line managers that many participants discussed may have been in relation to their general lack of awareness of IBD and how it could affect an individual’s attendance at work. Two participants discussed how, even though they had disclosed the nature of their condition, and explained that they might need to take time off work if they were experiencing a flare or to attend hospital appointments, throughout the course of their employment, they faced disciplinary procedures from their line managers regarding their sickness absence. For example:

“I had a different manager who wasn’t very supportive and told me that I looked alright and that I don’t look poorly, and that made me feel really uncomfortable. I was put on level 1 sickness and I should never have been because it was a disability. I was just asked to go into a meeting, and I wasn’t informed about what type of meeting it was, and it was a disciplinary meeting.”

— Participant 7

Another participant had a similar experience, and they approached both HR and occupational health for advice about what to do. Although they did receive helpful support from both sources of employee support, the behaviour of the line manager and how they had managed the situation led to them wishing to leave their employment:

“They started taking out disciplinary proceedings against me for the amount of time I’d had off, which I thought was pretty disgusting because I had been open and honest with them, and they didn’t have a problem when I was first diagnosed...so that was a factor for me deciding to leave, because I just really wasn’t happy and I thought it was all very badly handled...it was the line manager and the senior manager – I didn’t feel it was an organisation that I could carry on with.”

— Participant 15

Some participants described that line managers could blur the distinction between IBD as a health issue, or IBD as a disability, and how line managers perceived the condition affected the way they reacted towards them. Alongside this, they also mentioned that even if line managers were aware of the physical nature of the condition, they were often unaware of how IBD can affect an individual’s emotional wellbeing and confidence. For some participants, this lack of support played a large factor in leaving a role as this had implications for their overall job satisfaction and health and wellbeing:

“They [the line manager] were very militant to the point that health issues were differentiated from disability issues....I was seen as someone who merely had a health issue. To make such a differentiation is just really backwards discrimination, and I was discriminated against...He couldn’t support me...They don’t seem to grasp that it can affect your emotional wellbeing. It can affect your confidence levels.”

— Participant 12

This lack of line managerial support also increased the level of stress that participants experienced in the workplace. Many participants discussed how stress played a role in triggering flares of IBD. Consequently, when limited support was reported, partnered with a line manager’s limited awareness of IBD, participants had to find other ways of coping with stress, usually through approaching other members of the organisation who could support them (i.e. occupational health, HR, senior managers and trade unions), and provide ideas for recommended adjustments to enable them to remain in employment. Although some may argue that this self-management is a positive step for individuals so that they begin to take control of their condition at work, there is still an important people management role that line managers should undertake to reduce the negative implications of stress and reduced employee wellbeing, for both the individual and the organisation:

“My line manager is rubbish, so I just go around him now. I don’t bother with him at all. I just go straight to the HR person...It’s just him personally. He’s just crap, he’s a rubbish manager and he’s a control freak as well. I prefer to just go to HR now, this is one of my strategies to reduce my stress, so I just go straight to HR, because ultimately they are the ones who will make the recommendations.”

— Participant 8

One participant discussed that even when they had a supportive line manager, the organisational culture and hierarchical nature of the management structure at their organisation meant that senior managers over-ruled any recommendations that the line manager and occupational health wanted to implement, which meant that the participant’s work began to affect their health and trigger their IBD. In this case, the line manager was seen to follow correct organisational protocol for helping an individual with a chronic condition, as they had referred the participant to occupational health, raised concerns with senior managers and also attended union meetings with the participant, but the lack of compassion and support from senior managers ultimately led to the participant tendering their resignation:

“My immediate line manager was very supportive, very helpful. But the senior manager didn’t really seem to have any reaction, there was no suggestion of doing anything differently. My line manager raised a few concerns, she put me in contact with the union, she came along as a support person to the meetings. But then her manager overruled her. All I wanted was more understanding from them...I just needed to get out and leave, purely because how they were treating me.”

— Participant 2

However, the results indicated that when there was a positive employment relationship with the line manager (which included understanding how IBD affected the individual, providing the individual with support, and implementing reasonable adjustments when necessary) participants were able to remain in employment and have a positive experience of working with IBD in the workplace. In some cases, the participant had been in their employment before their IBD diagnosis, which provided an opportunity for a social exchange relationship to develop resulting in high quality relationships. When positive employer-employee relationships are established, this is not only helpful for improving employee productivity and reducing organisational turnover, but is also important and necessary for maintaining positive employee wellbeing and satisfaction:

"I have been with the same employer throughout my working career. They were very accommodating with my work, but to be honest it is down to the individual bosses and team that you work with...There was never any question of you being made to feel threatened by the fact that you were ill at all...I was never made to feel that there's a fear of doing anything other than what you need to be doing, you should get yourself well and make sure that you are as healthy as can be. They made it so easy to get on with my illness....The personal relationship made it easy because they knew that I was not pulling wool over anybody's eyes."

— Participant 5

Having a long-term employment relationship with a line manager was also very important when communicating the nature of the disorder to them, and helped to develop a trust relationship between the employer and the employee. This was once again demonstrated by another participant who remained in the same employment throughout their diagnosis. Having this relationship and the confidence to communicate the nature of their disorder to their line manager meant that managers could be more sympathetic and understanding towards the employee, and reduced the level of anxiety that participants felt. This was highlighted when the participant was asked whether they felt their job security was at risk as a result of their level of sickness absence:

"I did feel that if it came to a choice between A and B, and A had nothing wrong with them and would always be able to turn up for work on time and not have to go home halfway through the day, it made me worry that A would be chosen. But as I say, just knowing my boss, that would never have been an issue, so that was a self-imposed thing...she was very sympathetic, and understanding, and if I couldn't get moving very quickly in the morning, I could text her and say I'm coming in in slow time and that was fine."

— Participant 9

One participant worked for a smaller firm, and as a result thought that the communication with their line manager and their personal relationship was especially strong in terms of how they managed IBD in the workplace. Working in a smaller firm was seen as positive by the participant because people knew them and what was occurring. The HR staff were stable and consequently the participant could talk to the same people to receive continuity in any adjustments that were needed, and they felt that when there was an understanding about

the disorder from HR and the line manager they were less anxious about their sickness absence and job insecurity and how they were perceived at work. The participant had worked in the same role since diagnosis, but as a result of the positive communication and the relationship with their line manager was able to communicate with them on an almost daily basis. They found this communication especially important at the time of diagnosis as a result of the nature of the disorder:

"I had a very good relationship with my boss...I was in contact with him daily letting him know what was going on...at that stage you don't know how it is going to affect you longer term, so it is good to get some factual information to them...the relationship with my current employer with respect to my illness is much better because it's a more personal one. I think because it's a smaller firm and because I have been with them for longer."

— Participant 4

However, participants who had changed roles throughout their IBD diagnosis and had experienced different management techniques when employed with IBD, discussed characteristics that they found helpful in line managers when working alongside somebody with IBD. Having a supportive line manager was key. Even when a participant had not disclosed the full nature of their IBD, but simply explained that they had a chronic condition, the support that was received in terms of being flexible in terms of hospital appointments, providing the flexibility to work from home and reducing an individual's anxiety regarding their condition was highlighted as most important:

"My line manager knows that I have a chronic condition and I need to go to hospital, I haven't exactly told him what it is. But they are very supportive, if I ever feel sick or need to work from home there is no pressure. It is really important to just make sure that there is some kind of support and that you don't feel anxious or stressed."

— Participant 3

When somebody had mentioned to their line manager that they had IBD, a line manager who had some understanding or awareness about the nature of the disorder was seen as really important. One participant mentioned that their line manager was sympathetic when they mentioned that they were tired, and allowed opportunities for rest, so the IBD did not worsen. Additionally, having a line manager that was sympathetic regarding the use of facilities was important, especially as this was something that many participants found embarrassing. When participants found line managers who had awareness of IBD, they felt more comfortable in disclosing the full nature of their condition and how it could affect them, which also therefore allowed for further discussions regarding what reasonable adjustments could be made:

"No-one has ever said anything horrible or made me feel uncomfortable...I'm surprised my job hasn't sacked me really because of the time off I've taken, but because they understand my illness they have accepted me as a worker with an illness."

— Participant 1

Additionally, some participants discussed how their line managers also directed them to other sources of support in the organisation that they believed were helpful. For example, some participants were made aware of counselling services or employee assistance programmes that could provide an extra source of support, or a confidential helpline if something arose that the participant felt they did not wish to disclose to anybody at the organisation. One participant discussed how their line manager paid for some dietary tests to be conducted as the line manager was aware that diet may trigger IBD in some people. The most common sources of further support provided by line managers were referral to the staff trade union, to HR and Occupational Health.

“We do have an occupational health that we can access at any time. My manager wanted to make sure that I was fit for work. She did, with my approval do an occupational health referral to make sure that I was fit for work...but they do need to know how work is going to affect me also.”

— Participant 14

In summary, the importance of the employer-employee relationship, usually established by the line manager was seen as vital in helping an individual with IBD at work. Good line management included being sympathetic and understanding to the individual, and being aware of how the condition could affect them, both physically and emotionally. It also involved developing a relationship where there was trust and communication (both ways), so that individuals could say when they felt unwell, or ask for adjustments in the workplace if they were necessary. Additionally, having a line manager that was aware of other services that could help an employee was also seen as important. Participants seemed to advocate that in their opinion a good line manager was someone who displayed good people management skills. When participants provided examples of poor employment relationships, factors usually included unsympathetic managers, unaware of the needs of their employees, having a culture where employees were fearful of communicating the extent of the disorder for fear of job loss and when employees felt discriminated against because of the nature of their IBD.

Disclosure

However, on some occasions the reaction of the line manager could have been understandable, especially if the individual did not disclose that they had a chronic condition. Some may argue that it is the role of the line manager to notice when an employee's wellbeing is reduced and implement steps to mitigate this. However, as the role of the line manager is two-fold, both people and task management, the role that an individual has in disclosing their condition could help develop an employment relationship that was more supportive and understanding.

Some participants believed that disclosing their IBD was necessary for them to undertake, as they felt it was important to be honest with their employers in case there were problems that arose during their period of employment. Disclosure also gave employees the opportunity to discuss what the condition meant for them. There was also some indication from the participants that disclosing their IBD could help with the employment relationship, in

a sense that 'honesty is the best policy' throughout:

"I felt that it was only right that my employer knew about my health condition...I want to be honest with them and I don't want them to say down the line, oh, you didn't tell us about that..."

— Participant 14

Others noted that disclosure could be difficult because of the embarrassing nature of the condition, and they felt that they had to be careful to who they disclosed to. In such cases they would only disclose to those they thought they could trust, and have most interaction with, especially if they were symptomatic and their employment would be affected. However, it was recognised that having a personality where individuals were determined to work despite of their IBD (being headstrong, and remaining optimistic) that they would be able to remain in employment, was helpful for disclosure:

"I always say that it is one of the things that I know I have to mention now in interviews, because I know that it's going to be something that's going to affect me in my employment at some point...I am quite open about it really because you have to be, and people don't really understand straight away that something is wrong with you."

— Participant 1

This participant continued to say that after disclosure they were able to bond with those they had disclosed to. They admitted that that it had taken some time to develop the confidence to discuss IBD with their employers, but remarked that it was the best option, otherwise it could have affected their psychosocial wellbeing due to the anxiety they would have experienced if they didn't disclose.

Other participants decided to disclose to their employer as a result of negative experiences with other employers. When disclosing their condition they used this as an opportunity to discuss their needs for time off or flexible employment, and provide employers the chance to ask questions about IBD to improve their awareness of the condition:

"I made it known in my first interview and when I first started that I had Crohn's Disease, and said that I will need time off for infusions every 8 weeks...Because of the problems I had with my last one, I thought that it would be best to be open and honest about it and we could have a frank discussion about it and they could mention any issues that they had with me having time off. And I could give them an opportunity to ask questions about it."

— Participant 15

Some participants were wary of disclosure, and reporting that they only disclosed when they were flaring, as they were concerned that if they disclosed at interview that this would affect their chance of being chosen for the role. However, this participant said their IBD was currently stable, and as a result they thought this disclosure strategy was best for them:

"It shouldn't affect people's judgements and it shouldn't affect people's decision making"

process, but it's incredibly difficult not to let things like that shadow judgement...but I'm lucky to some extent that my illness is under control sufficiently that I don't feel I need to raise it."

— Participant 4

In one case, a participant chose to disclose using a letter from their doctor which explained what IBD was, and this was presented to their line manager in the presence of their union rep. They had decided to disclose in this manner for 'safety' purposes, so the union knew that they had disclosed in case the participant needed any backing in the future over any employment practice disputes.

In most cases, participants suggested that employers were usually thankful that they had disclosed their IBD, and that this had opened the discussion regarding what employers can do for their employees, thus developing the important employment relationship based upon trust, honesty and communication. From these interviews, it was clear that although the line manager was important for support, the employee also had a role in developing this relationship.

However, line managers were not the only individuals that the participants felt they had to disclose their IBD to. Many participants discussed the importance of colleagues in the workplace and some explained why they were willing to disclose their IBD to co-workers and the implications of their disclosure. For example, a number of participants reported that they were able to disclose their IBD because they worked in a tight-knit team, and as a result believed it was important to mention their condition so they could ask for support if and when necessary (in one case co-workers provided information regarding the relevant policies and practices that the organisation should be implementing for them), and so they were able to cope when managing their workload in the office:

"We were quite a tight group, we had been working together for a number of years as a small team before we merged into a larger one. There were probably about four or five of us, so we were a very close team. They were very supportive. They helped me, and advised me for meetings, they helped me find the recommendations as to the policies and procedures that the [employers] should be implementing. This meant that I was well prepared when I turned up for meetings."

— Participant 2

"Because I have been in the department for so long, and it's a reasonably stable team that we've got, the individual's around me are aware. It's not like I shout it from the rafters, but most of my immediate team certainly know. I had to be able to explain my absences. But they have made it so easy for me to get on with my illness, there is no way I could have coped if I didn't have that sort of support."

— Participant 5

Another participant explained that it was only fair to the rest of the team that they disclosed their IBD as they worked in a small team, so it was noticeable when they were absent, and they did not want to let their team down. The benefit of working in the small team was

evident, as the participant had an allocated 'buddy' who knew what to do in the case of an emergency:

"I share my IBD with everyone. They were all very understanding. My very close worker friend, she knew where my emergency bag was, and so she knew that if I went running off she would come running after me with that. But it was important to tell them, especially when you work in a small team, because it is very noticeable when somebody isn't there and you like to do your best for people, and you don't want to let them down."

— Participant 9

A number of participants cited disclosure as a method of improving the awareness of IBD in the workplace. When informing their work colleagues that they had IBD, they took this opportunity to attempt to remove some of the misconceptions about the condition, and provide information regarding what having IBD can mean to an individual, and allowing for further discussions about IBD to occur.

"Most of my colleagues have been very supportive, they will bend over backwards to support me if they can. I've always been fairly open with people about this condition, I think it is quite important that people know about it and the consequences it has. You have to be careful though about trying to inform people and overstating it, but it is important that they have a bit more information not just about your situation but anyone else they may come across. Whilst you don't have to go into graphic details, but I think it is something that should be discussed."

— Participant 8

One participant discussed a benefit from disclosing their IBD to fellow workers, when they explained that the organisation undertook some charity fundraising events. Additionally, raising awareness surrounding one chronic condition, also led to others disclosing other illness that had an impact on work, which provided the opportunity for mutual support and an exchange of self-management at work techniques:

"Some people are very understanding, there were some staff who went to go and climb the big hills or mountains or something to raise some funds. But there are also other members of staff, and one who takes the same medication as me for arthritis, so we have been able to give each other bits of information about how to manage things at work."

— Participant 12

For some however, even though they felt able to disclose to their work colleagues, they reported that in general there was a limited awareness of what IBD was and how it affected an individual, and the consequences IBD had for employment. Although, some participants mentioned they did not receive support from their co-workers, they were keen to point out that if somebody they worked alongside knew somebody else with IBD, this resulted in a greater level of understanding:

"There was not much awareness within the team. You might have the odd person saying,

oh my aunty has got that or something. But you certainly did have a better understanding from those who knew somebody else that has got IBD.”

— Participant 11

Some of the participants described a struggle in disclosing to co-workers because of the embarrassing nature of the condition. Disclosure also became increasingly difficult if a person was symptomatic or was experiencing reduced confidence. One participant reported that although the co-workers they had chosen to disclose to have been sympathetic and understanding, this was likely to have been related to the profession they were employed in (the caring profession):

“I don’t necessarily tell everyone, I’ll disclose to the staff that I feel that I can disclose to, because it is kind of embarrassing, and not the easiest thing to talk about. You have to have the confidence to disclose, because you can fall into a pattern of feeling really down about it all, and then not being able to disclose properly. Nobody has ever made me feel uncomfortable...but I think the people that are within that job are caring people, so maybe in a different situation, in a different role they might not be so understanding.”

— Participant 1

Another interviewee spoke about their concerns when disclosing to colleagues because of comments that have been made regarding both the hidden nature of IBD, and that co-workers had remarked that the individual did not appear to look ‘unwell’, and because co-workers had also commented on having to undertake extra workload. This was often connected to the perceived lack of understanding around IBD and its implications for the individual, their wellbeing and employment situation. A reluctance to disclose to co-workers was also evident as a result of animosity experienced when participants had disclosed in previous roles. For example, participants who had previously felt uncomfortable disclosing because there had been laughter about the condition described a reluctance to disclose:

“I didn’t tell them about the illness, because in my last role the sort of people who worked there, including the managers, they were the sort of people that mocked disabled people as they left the building. So I didn’t feel comfortable telling them and quite often I would go in tired. I’m still quite shy about it, I don’t like to shout it around that I’ve got an illness because even though I’m working with other adults there are still people here that will have a good snigger about it. And I don’t want to broadcast it for that reason.”

— Participant 13

Finally, a few participants also reported that disclosure to colleagues although very difficult, should occur to reduce the animosity from teams regarding any time off, or the chance that on some occasion’s colleagues may have to cover workloads. There had been discussions from some participants who reported that they had received comments from co-workers in reference to their increasing workload, or who had noticed increased absences. For some, this led to a reluctance to disclose for fear of further animosity, but one participant explained that they took this opportunity to inform colleagues of the nature of IBD and to try and understand how the disorder has implications for their working life:

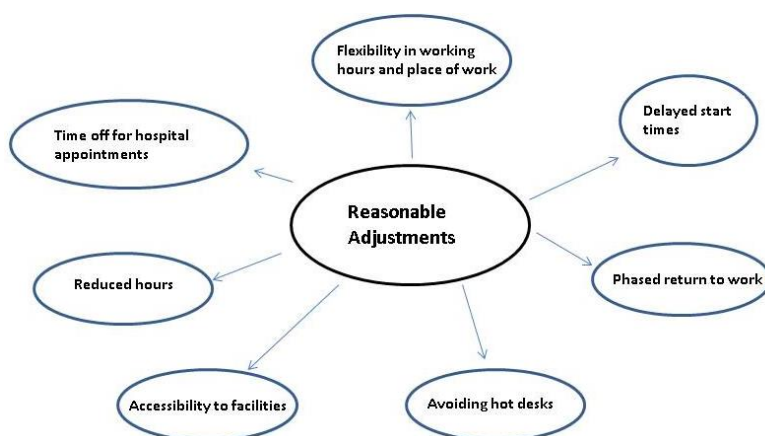
“In previous teams there has been some animosity from my teams towards the fact that I was having doctor’s appointments, or that I was phoning in to say that I was ill in the night and couldn’t come in first thing. I gave out fact sheets and said, look if you want to chat with me about it then do. I sat down with my team and told them that my working hours had been adjusted and things like that and they were a little more feeling about it.”

— Participant 15

In summary, participants realised that there were benefits to disclosing their IBD to their employers, especially as they may need to take time off for hospital appointments or need longer sickness leave. Disclosure provided individuals with the opportunity to raise awareness of how the IBD affected them, and in some cases allowed the employer to ask questions regarding what they could do to help. Participants acknowledged that disclosure could be difficult as a result of the embarrassing nature of IBD however; they usually noted that employers were grateful that they did disclose. There was also evidence to suggest that disclosure could help with developing the employment relationship with a line manager as this begins the exchange of honest communication between the employer and employee. There were mixed reactions regarding the disclosure of IBD to co-workers. Many participants felt willing to disclose to fellow work colleagues because they worked in a close-knit team, had worked with the team for an extended period of time, and felt that they would receive the necessary support. Others felt disclosure was important so they can raise awareness of IBD among colleagues, and used disclosure as an opportunity provide information sheets or ideas for ways co-workers could practically support them. Unfortunately, a few participants had previously experienced animosity after having disclosed in previous roles, and were either hesitant in disclosing, or chose who they would disclose to carefully.

Reasonable adjustments

As discussed in the previous two sections, participants revealed that a characteristic of a good line manager was one that discussed and approved reasonable adjustments. Additionally, the disclosure of IBD also aided discussions regarding what flexible provisions or adjustments could be offered to those with IBD. Throughout the course of the interviews it was evident that a number of employers had made reasonable adjustments for their employees. Reasonable adjustments included:



- Flexibility in working hours and in place of work (i.e. working from home):

"I can work flexi-time, so I can put extra hours in one day and leave early another if I have to...my flexi-hours are an adjustment...this flexibility has been really helpful."

— Participant 15

- Delayed start times:

"Flexibility about start times have been important to me twice [IBD can be worse in the morning]...it's all about employers being flexible."

— Participant 6

- Phased return to work after an extended period of sick leave:

"I went back to work with a phased return...so I only worked a few hours a couple of days a week."

— Participant 11

- Having a fixed desk so they did not have to hot-desk:

"They gave me my own desk, which gave me a lot of relief, I hated hot desking, because you had to carry your life around with you [Participant had an emergency bag in case of an accident] and set up in a strange place, go and find the new toilets...so having my own desk and being surrounded by people who knew what was happening was much, much better."

— Participant 9

- Accessibility to facilities:

"They were very conscious that I needed to access the loo...and there was an understanding that if I need the loo, I need the loo."

— Participant 12

- Reduced hours:

"I was going back home and back to bed at 4pm every day and this was not much of a life, so I asked them if I could reduce my hours and they were fine about it, so now I do 9-1 on Monday-Friday, and I get all of the school holidays off. I can leave work and not feel drained...I can have a life."

— Participant 13

- Time off for hospital appointments:

"I said that I have to go to the hospital for appointments every 8 weeks because I have a chronic condition, and they were fine with this...there is no pressure."

— Participant 3

For many of the participants, adjustments were made as they had either a referral from occupational health, or they had discussed their employment needs with their line managers. Some participants however, chose not to ask for reasonable adjustments to be made. In some cases this was because their IBD was in remission, and they did not feel the need to ask for adjustments. However, importantly in these cases the participants felt that if anything needed to be changed, then they had a supportive environment to ask for this:

“At the moment I don’t think I need to ask them to do anything else, and there is nothing else that I can do because I am in remission and there’s no major problems. They are supportive.”

— Participant 3

For others, although they had received some reasonable adjustments, they felt they did not need to request anything further as they had developed their own self-management techniques to help them. For example, one respondent felt that they did not need to be moved near toilet facilities as they knew the layout of their workplace and that there were toilets in regular places. This participant also discussed that if they were ill, then work would be understanding and they would not have to come in. They also discussed one self-management technique if they were relapsing:

“If I’m in a relapse and not well then I don’t eat or drink anything during my shift at work...And if I don’t eat or drink anything it’s not a problem...but it’s vary rare.”

— Participant 13

One participant however, had not asked for any reasonable adjustments as they believed that they had been signed up to work in a certain way, they knew what they had been getting into, and consequently did not think that adjustments had to be made for them. This participant worked shifts that could be changed at the last moment, and had been attempting to work with their IBD around their working pattern – which they admitted had been difficult, and if they could they would change their shift patterns to avoid early mornings as this is when their IBD was currently causing most problems. During the interview, the participant was asked whether they had been referred, or self-referred to occupational health. They did not know whether the organisation had one, but acknowledged that if their IBD worsened, this is something that they would consider doing.

“I don’t feel like I can ask for them [adjustments at work]. I signed up for a job that is shift work, irregular hours and under a lot of pressure. If I can’t hack it, then I’ll just have to give up the job.”

— Participant 10

Other participants described situations where what would have seemed to be reasonable adjustments were turned down, or not appropriately implemented. For example, one participant had suggested a reasonable adjustment to work from home, as this would provide them with the flexibility they required to stay in employment and manage their condition. However, this could not be implemented as the organisation did not have the

technology required for this to work:

“We talked about working from home, but our IT construction is not particularly 21st century shall we say. It was decided that that wasn’t terribly practical and I can see their point, but for me this would have been the best option...we haven’t got an ideal solution.”

— Participant 8

Although not in their current employment, a number of participants discussed how occupational health had recommended reasonable adjustments to be made with regards to increased workplace flexibility and reduced hours. Requests for these were made as a result of fatigue from the IBD and to reduce commuting time especially if participants were experiencing a relapse. In some cases responses from line management or senior management were that changes to working hours would be disruptive, and in two cases no alternative adjustments were made:

“They basically just dismissed it [what occupational health were saying], and said that it doesn’t fit with what they want, mainly to ensure continuity of service...no alternative was offered, no mediation.”

— Participant 2

In summary, there were cases where reasonable adjustments had been made by employers to help the individuals remain at work with their IBD. Adjustments included flexible working, allowing time off for hospital appointments, reducing work hours, and making sure the participants had the facilities they need (i.e. being close to toilets or having their own desk). Participants who asked for adjustments in the most cases had a good relationship with their line manager and so felt they would be supported if adjustments had been made. Reasons for not asking for reasonable adjustments included the IBD being under control or in remission, the individual being able to self-manage their condition (however, it must be emphasised that no matter how good somebody is at self-management the IBD can flare at any time, and not all of those with IBD may have the capability to self-manage), or because they did not feel able to ask because they had signed up to a particular contract. In some cases occupational health had been referred to when adjustments were needed, but there were mixed responses with regards to whether the recommendations were implemented.

Presenteeism

Although many participants acknowledged that increased stress and pressure aggravated their IBD, many also reported attending work when they were ill (known as presenteeism), adding to their stress. Participants provided a number of reasons for attending work when unwell, however the most common was not wanting to let their co-workers down. The participants discussed that they realised that if they didn’t go into work, their colleagues would have to take on additional work to cover for them. Some participants indicated that both managers and co-workers didn’t comment about any added pressure, but they admitted that the pressure to attend work when unwell came from them:

“Yeah, definitely, I go into work when unwell. I get really upset if I have to call in sick

because I feel like I am letting that person down. But the pressure comes from myself, there's no one really pushing me to come in when I am ill, not in this employment."

— Participant 1

However, others reported that they did feel pressure from their line manager to attend work when unwell. In these cases, the participants had described their line managers as unsympathetic towards them and their IBD, often as a result of the lack of understanding about the nature of the condition and the physical and psychological affects that IBD can have on an individual's wellbeing. In such cases, participants would attend work even if they knew this would have further negative implications for their health:

"I have to fight to push myself to go into work, because you know that it's not actually in your best interests health wise...I always get the feeling, certainly with my line managers that he thinks part of it is skiving."

— Participant 8

How IBD was classified also had an affect on whether individuals attended work when unwell. For example, in the case of the participant who's line manager defined IBD as a 'health issue' and not a chronic condition or disability, they explained that as a result of this distinction, the line manager gave no slack at work, and the participant would often attend work when unwell, and described occasions when they had signed themselves out of hospital to do so:

"There were times when I was going into hospital at 2 in the morning to get morphine, signing myself out at 5 in the morning, going home, having a cup of tea or a sleep, and then my husband driving me into work in a very ill state. Because I knew that if I didn't go in, I would get the worst word that could come out of anyone's mouth for being off. It was absolutely no slack. It was a health issue and not a disability."

— Participant 12

For others, it was the lack of awareness of the nature of the disorder from co-workers, and co-worker comments about having to take on extra work roles, duties and tasks that made participants attend work when relapsing. The participants understood that their absence would cause colleagues extra stress, but attending work when unwell didn't help their stress and IBD as a result of the extra pressure they would have put on themselves. In some cases, the participant had not disclosed their condition to their co-workers, which may have provided an additional barrier to co-workers understanding the condition. However on many occasions, it was the hidden nature of the illness, in that an individual could look well even when experiencing symptoms that made the issue of presenteeism harder:

“I went back against my doctor’s advice, and somebody on my team asked me if I had had a nice holiday break. And I said that I had been off sick, and they said, we had to pick up all your cases. That upset me quite a lot, it made me feel really bad, so I feel pressure to go in. I know what it is like when other people are off and everybody gets more work. It’s hard for people and stressful. But because I don’t look very poorly it doesn’t go down well.”

— Participant 7

One participant discussed how they attended work when unwell, but explained that this was not just IBD related, and they would go to work when they felt ill from other conditions also. They attended because their work was short staffed and that if any member of staff was absent then their office would not be able to cope with the workload. Additionally, although it had never been mentioned by their line manager, there was an underlying fear that if they took periods of sickness absence then they were at risk of losing their job. However, they did understand that attending work when unwell also had an affect on their productivity and their quality of work, something that line managers should be aware of:

“I feel sorry for myself at times, but I try not to sit around and mope, I try and keep working. I have been to work loads of times when I have felt unwell. Yes absolutely, but not just with IBD, with other things as well. We’re so short of staff that if somebody does goes sick it falls down like a pack of cards. I know I’m not as sharp and as quick and all round as good at my job when I am unwell compared to when I am well. But I don’t want them to ring up and say get rid of this person, I don’t want to lose my job.”

— Participant 10

Other participants discussed how they attended work even when they felt unwell because they enjoyed work, and they would rather be working as this makes them feel better, in comparison to remaining housebound and often ‘feeling sorry for themselves’. However, this was especially the case when reasonable adjustments had been put in place to make the workplace and their role easier for them to manage. This supports the work conducted by Parker and Bevan (2009) when they provided a model of what constituted good work which included strong working relationships, and job satisfaction:

“I have attended work when I felt unwell. I don’t want to take time off work if I can avoid it. If I feel able to work generally speaking I’d rather be there as long as I’m doing something still useful within the place, and I was able to manage it to a level where it didn’t particularly affect my performance at work. I love my job.”

— Participant 14

The results also provided some evidence of how changing employers and an improved employment relationship reduced the level of presenteeism experienced by employees with IBD. One participant described how when working for an unsympathetic line manager they would feel extremely stressed, and would often attend work when unwell (as a result of the limited awareness from the line manager), which made their IBD worse as they were not listening to the affects of this added work pressure on their illness. However, since they had changed jobs, and there had been an improvement in their employment relationship, the

stress had dissipated, and there was no longer a need to attend work when unwell:

“With my current employer I haven’t had any time off work at all, I have never had to go in when unwell, because I am not in a stressful situation. I’m a completely different person, I have no flare up, I’m not stressed, I’m not being sick all the time because I have got to go into work.”

— Participant 15

In summary, the participants did provide evidence of attending work when unwell for a variety of reasons. For some, there was a self-imposed pressure to attend work as they felt guilty about their co-workers having to take on their work. However, others reported that as a result of the comments they had received from co-workers they felt they should come into work. However, in these cases, this was partnered with a limited understanding regarding the nature of IBD and that the participants may not have disclosed their condition to all of their co-workers. For some, presenteeism was related to the employment relationship, as they felt pressure from their (usually unsympathetic) line manager to attend. Others perceived job insecurity if they were absent from work when they were ill, once again, suggesting that improved communication with their line manager is a factor that led to presenteeism. However, others enjoyed their work and attended work when unwell as they felt it was better for them to be at work than not, although they did realise that this could have an impact on their job performance.

IBD and future employment

The participants were asked how they thought that IBD would affect their future employment, and how they felt about the options that they had. For many participants the unpredictable nature of their IBD and whether or not it will worsen meant that they were unsure as to what their future held, both employment wise and medically. For some this uncertainty created anxiety, and others were resigned to the idea that their IBD will continue to constrain their work plans:

“You don’t really make any plans for the future, you don’t know what is around the corner...it’s hard because you could be in a position where your condition is very unstable. You don’t make long-term plans, or even medium ones. I am sure that IBD will continue to constrain the type of employment, the kind of roles I pursue, because you can’t line yourself up for the roles that you will not be able to deliver.”

— Participant 8

For others, their ability to remain at work was dependent on other factors related to IBD or the workforce. For example, a number of participants were optimistic that they would be able to stay at work if their IBD was stable and managed appropriately with medication or in some cases surgery. Some participants even considered to opt for private treatment if they thought this would improve their chance of stability in the future, even though this would be financially difficult for them.

“The future really depends on whether I can get back on the treatment that was working for me. If I could get back on that then I will be all optimism. If I can’t, then I really don’t know. I’m at the point of considering going private, but that may take up half my income.”

— Participant 10

If however, their IBD was to worsen and could not be controlled medically there were concerns about how they will be able to remain in the same employment, or if they would have to find new employment, which would become increasingly difficult:

“Sometimes I worry about what will happen if I am really sick, and I have to take a lot of time off. I worry if an employer would accept me, or give me the time off. Would I be able to recover quickly and then return to work normally as before?”

— Participant 3

Finding new employment in the future also was a cause of concern, especially as some participants perceived that there was still a stigma around chronic conditions and disabilities, and how employers would view IBD. There was a hope that future employers would be understanding and sympathetic especially as some participants noted that knowledge and awareness of IBD was improving, but the stigma of disability was still evident:

“I am concerned about how future employers would view me. I read a report the other day that the generally people treat those with disabilities significantly worse. Even after the Olympic Games there is still a stigma about being, and having any form of disability. So I would just hope that I would be able to explain to a future employer that it doesn’t affect me day to day and they are understanding.”

— Participant 14

Many participants discussed that they had to reconsider their career progression as a result of their IBD. One participant explained that stress had been a factor in deciding which direction they wanted their career to progress, and they felt that moving up the career ladder was something they are not going to aspire to because of the extra stress this would entail and the resulting implications that this would have on their IBD symptoms. For one participant, career progression was a short-term, yet salient consideration, as they were struggling to decide whether to continue with medical treatment, or to undertake surgery that would lead to at least 12 months out of employment. This made their future career options difficult to predict, which had was having clear implications for their wellbeing:

“I can have the treatment route of having an operation. So career progression for me is not really as I would like it to be, and if I go down other routes it means taking 12 months out of my career then trying to get back into it again. So it’s a bit difficult for me to say at the moment. I am concerned because I have worked quite hard to be where I am, and then to lose it all again because of this would be quite devastating really.”

— Participant 7

Other participants reported that having found a particular working pattern that suited them,

and in which they could manage their IBD more efficiently meant they would be reticent to return back to 9-5 employment, especially if there were no reasonable adjustments or poor facilities, as this would limit the amount of control they had over their condition. Some discussed that the fatigue associated with IBD meant that full-time employment was no longer a consideration, as they had found that working reduced hours had been positive for their physical health and mental wellbeing:

“It would take me quite a lot of money to get me out of the house into a Monday-Friday 9-5 job. I can’t see myself going back to one unless it is just around the corner, because I don’t want the anxieties and stresses and pressures...I’ve got the control at the moment.”

— Participant 2

One of the participants had already retired and had explained that their IBD had played a large role in this. Other participants also discussed retirement, and what would affect their retirement decisions. Even those at the younger end of the age spectrum reported that they had to start thinking about future plans more than their peers, especially if their IBD progressed negatively:

“I’m reading a lot more about retirement than other people my age I think, and there was an article that about retirement and the progression of the disease and the control of the disease and stuff does tend to generally go on a downwards slope for more people. I need to be thinking about not being able to work potentially...making provisions for the future.”

— Participant 4

Other participants discussed a wish to retire early, but not as a result of their IBD, but out of personal preference, however, they had to stay at work longer because of the age of that they could begin to receive the state pension. Some voiced concerns about having to work for so long with IBD and the stress that this could add:

“I absolutely would choose to retire early if I thought that I could get my pension. And it means that I can then go out and do things, because 10 years down the line, I don’t know what life is going to be like for me.”

— Participant 12

For some, their future in employment was increasingly optimistic after they had experienced a positive employment relationship with their line manager or senior management, which included having a sympathetic line manager and the provision of reasonable adjustments to help manage the IBD. As a result, participants had a greater understanding and improved confidence about how to approach employers in the future, how and when they should disclose, and an improved awareness of what reasonable adjustments can be made:

“I might have had concerns about the future when I left my last job, but now I’ve got to a place that they’re quite open and flexible then I think that’s really geared me up with my previous thoughts about employers...I feel more optimistic and how to handle it...I know how to handle the situation and how to deal with it and how to work through it...I think it’s only

just going to get better.”

— Participant 15

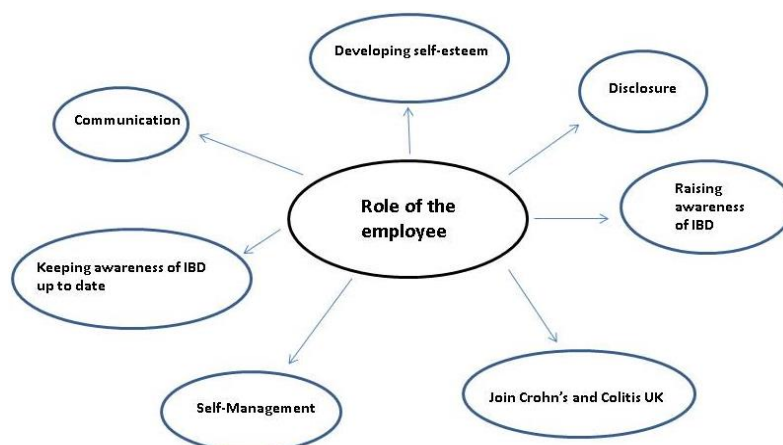
In summary, there were mixed reviews regarding future employment opportunities and IBD. Some participants described optimism about their future, especially if they were in a positive employment relationship and had the adjustments they needed. Those who had their IBD under control or who were in remission were also optimistic about the future, especially if their medication remained stable, or they received appropriate treatment. However, as IBD is a fluctuating condition, the future was unpredictable for many because they were unsure about how their IBD would progress. Participants questioned how much further they could progress up the career ladder, as developing into managerial roles could increase their stress (affecting their IBD), and so in some cases participants had to resign themselves to reducing their career progression. Finally, participants did question their ability to work until retirement age, and admitted to having to keep future plans in mind earlier than their peers, and although some wanted to retire earlier, they would not be able to afford it.

Ideas for improving employment with IBD

Over the course of the interviews, participants suggested ways in which employment could be improved for those experiencing IBD at work. Improvements could be found at a number of stakeholder levels that will now be discussed.

The role of the employee

Participants identified many ways in which an employee with IBD could improve how IBD is managed and experienced at work:



Disclosure: Participants highlighted that they have a proactive role in disclosing their IBD to their employer, as this encourages an open and honest conversation regarding any adjustments that can be made, and may improve the employers understanding of the condition. If an employee began the discussion, it could then be easier to discuss their IBD in the future, and develop the honest and truthful communication required in the employment relationship:

“From my experience I would disclose to future employers, and will make them aware of it. I

don't want it to surprise them...and it will lead to a stronger awareness of the problem of the condition."

— Participant 2

"Be honest about it...I've benefited from raising awareness about it...It is a discussion about how well your IBD is for you, and what this could mean for the role."

— Participant 6

Raise Awareness of IBD: As well disclosing that they have IBD, participants also recognised that they had some responsibility in raising the awareness of the condition, especially as IBD was not as well known as other chronic conditions, and was regularly confused with IBS. The most common way that participants suggested that they could raise awareness of IBD was through using the Crohn's and Colitis UK literature that has been developed for both employees and employers:

"We could provide information, the Crohn's and Colitis leaflets...It's not something you exactly want to discuss as it can be a taboo subject, but they have the detail that is needed."

— Participant 14

"They have some booklets and information that you can pass on to your employers...I've never given them to my employer, but it is something that I probably should do."

— Participant 7

Communication: Participants recognised that they should keep their employer informed about their IBD and how it is affecting them, so that they can jointly plan ahead if necessary, or so that they could be aware if the employee needed to take time off, or if they needed a workplace adjustment:

"They just asked me to keep them informed of what the treatment could be and what decision I make."

— Participant 7

"I believe in being completely upfront about it. I was able to keep them informed and be upfront about what is needed, and say – you need to make a reasonable adjustment for me here."

— Participant 12

Self-Management: Many participants discussed the need to self-manage their IBD, and to learn to understand what they could do to help themselves more (although this can be more difficult with a condition that fluctuates like IBD), both in managing the physicality of their IBD, and also managing their IBD in the workplace. For example, if an individual knew that stress aggravated or triggered their condition, they could learn stress management techniques to cope:

"I've been learning how to manage my stress. It's been difficult to do, but I've had to learn

it...I'd make sure that I know how to handle any stress, that's the most important thing – learning how to handle the stress in a work environment.”

— Participant 3

Others discussed learning how to manage their physical life, and learning to listen to their body so they did not get too tired, and so they could cope with a flare if it occurred:

“There are times that you have to learn about how to be careful about how you manage your life, in terms of trying to get back on track physically.”

— Participant 8

There were examples of self-management techniques to help reduce the anxiety of having an accident at work. For example one participant discussed having an emergency bag in case an accident occurred:

“I carry around an emergency supply bag. So I have a huge handbag that carries wet wipes, changes of clothes, absolutely everything.”

— Participant 9

Some participants also self-managed with regards to when they ate, and had a clear understanding of where the necessary facilities were. Although a method that can be applied in exceptional circumstances, this however, is not an advisable way of managing IBD on a day to day basis:

“I'm very good at managing it now. I make sure that I have emptied my bowels and I haven't eaten anything beforehand and that kind of stuff [if needing to go off site at work]...I have made sure my journey is short and have access to the loos...”

— Participant 8

Others who were concerned that their IBD was affected by their diet highlighted that if this was the case then it was best to eat as healthily as they could to avoid a relapse:

“You should get yourself well and make you as well as you can, and be careful with what you eat.”

— Participant 5

Asking for help was also a self-management technique that was identified in the research. Participants gave examples of when they realised they should have had a greater understanding of the facilities their employer could provide, and to know to ask for it and use it:

“I think that I will take up your advice in seeing if we have an occupational health and going to see them...I should probably ask for more concessions...I've never asked the unions, but I think I will now certainly go to them.”

— Participant 10

“They had different types of support, but I never took advantage of the counselling and that type of thing that they had on offer.”

— Participant 8

Keeping IBD awareness up to date: Participants suggested that keeping up to date with the latest developments surrounding the disorder was important so that individuals with IBD can increase their own awareness and also help others to understand more about IBD. This could involve engaging in discussions around IBD, being aware of developments in medication, and using social media to gain awareness of how others cope with the disorder and what policy makers are deciding with regards to IBD and employment:

“I talk to other people, I keep up to date and get information from Crohn’s and Colitis and through forums and magazines and stuff, and just see what other people’s experiences of it are.”

— Participant 4

Join Crohn’s and Colitis UK: Participants spoke very strongly about the support that Crohn’s and Colitis UK had to offer when diagnosed, and coping with various aspects of IBD as and when they may interact with an individual’s life. Their website was often discussed as a good source of knowledge about guidance (including employee and employer guidance), and that they were a good at providing support if you were an individual struggling with IBD:

“It was mentioned that I should read the CCUK website so I did...and I found out about all the adjustments that I could ask for!”

— Participant 9

Developing self-esteem: Many participants believed that it was very important to have an understanding that the IBD doesn’t control you, and that people with IBD are still very capable and able to work, and that individuals had to recognise what they are capable of achieving. Developing a positive self-esteem had a large role to play in this:

“I’ve got to the place of well, Crohn’s is part of my identity but it doesn’t define me...and it’s employ me, employ my Crohn’s. I don’t need to apologise for it.”

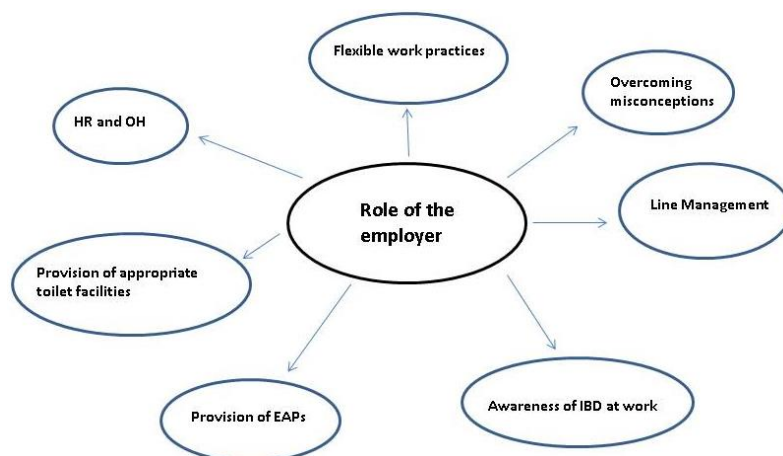
— Participant 6

“People should have the confidence to go out and look for employment even if they have IBD...people with IBD can work, they just need the confidence.”

— Participant 1

The role of the employer

Participants identified many ways in which an employer could improve how IBD is managed and experienced at work for those who experience IBD in the workplace:



Flexible Work Practices: The most common response for how employers can improve the experience of work for those with IBD was to improve or to implement flexibility in working practices, both in terms of when hours are worked (providing flexi-time, reduced hours, time off in lieu, etc.) and in terms of where people can work (most often participants would recommend working from home as an option). This was especially important because of the idiosyncratic and fluctuating nature of IBD:

“It’s about employers being flexible on the face of a highly personalised and idiosyncratic condition that can come and go without any explanation. It’s all about that understanding and the flexibility.”

— Participant 6

“Flexibility could be improved, maybe the chance to do half day working from home, because in some cases it would be easy to do this. Certainly to have the flexibility to work from home would be good.”

— Participant 12

Provision of appropriate toilet facilities: Many participants also discussed the importance of employers providing appropriate toilet facilities at work, to reduce the embarrassment associated with the condition, and to reduce their anxiety about having an accident whilst at work:

“Give us our own private toilet! Because I hate having to use toilet that the staff use, as it is really embarrassing.”

— Participant 1

“It would be helpful; to have access to disabled loos and things like that, rather than communal facilities...This is more comfortable than having someone sat a few inches away from you, with only a thin plywood board to divide you.”

— Participant 2

Awareness of IBD at work: Participants often highlighted that they had trouble discussing

IBD at work because there was little awareness regarding what the nature of the disorder was (sometimes stating that there was confusion with IBS and IBD), and there was little knowledge about how IBD affected individuals at work. Although a number of participants did understand that IBD affects individuals differently, they still believed that an improved awareness of IBD and its typical symptoms would help in workplace situations. However, some participants also mentioned that although awareness raising did need improvement, they found it difficult to say whose responsibility this was, and how this could be achieved:

“I think that they could just make themselves a bit more aware of what the issues are around IBD. It’s not just about running to the toilet all the time, and it’s not just about being stick thin, but there needs to be more awareness of even the medication that people take and how that can affect someone...it’s just an overall improvement in awareness.”

— Participant 12

“It’s difficult to say how this should be done, or in what way this could be improved, but there is something about raising the awareness with employers, but I don’t really know how that can be done.”

— Participant 15

Others noted that they did not expect employers to be experts in IBD, but that they should be aware that something was wrong with their staff, and had the responsibility to be able to help them in some way:

“It’s about being aware...I don’t need them to be experts in IBD, but I do need them to be able to listen, and to respond.”

— Participant 6

Line Management: Continuing from improving the awareness of IBD in the workplace came the recommendation that the line management of those with IBD (or other chronic conditions) needs to be undertaken correctly, including providing the necessary support, engaging effectively with the employee experiencing IBD, and helping to implement the appropriate workplace adjustments that would help the individual remain in employment:

“It is essential that the individual gets the understanding and the support that they require, and if they don’t then this is very often down to the individual line manager...it is important that the individual had the support that is required...you have to be careful as a manager to make sure that the individual that you are dealing with is dealt with sympathetically, that is the main thing.”

— Participant 5

“I think they need to be supportive of people when they need their time off to get well, and to just be accommodating of people when they need their down time to recover and to try not to push you.”

— Participant 4

“It’s about good line management...if there are good policies and procedures and they’ve got competent staff to put these procedures and policies into practice then there is nothing ‘special’ that needs to be done for IBD – it’s all about good employment practices and relationships.”

— Participant 6

Others argued that employers or line managers should be able to provide a culture where individuals with IBD should be able to disclose their condition without having to worry about what effects this will have from those they work alongside. This was not the case for one participant, and thus shows how having the appropriate line managerial support to disclose is important:

“I’m still quite shy about my illness, and I don’t like to shout it around that I have an illness, because even though I am working with other adults there are still people here that would have a good snigger about it, and I don’t want it broadcast around for that reason.”

— Participant 13

Participants also suggested that line managers should be aware of the pressures that they put on employees, especially if stress is a trigger of IBD. Some discussed that it may be beneficial for line managers to have an awareness of the stress that their employees are under, and provide solutions to avoid this:

“...The undue stress from my previous line manager didn’t help my IBD at all, so now that management do actually know what they are doing and my stress has reduced I have no symptoms at all.”

— Participant 15

“My understanding is that stress doesn’t help at all, so ways in which stress can be managed are very useful...there needs to be understanding about managing general stress, mindfulness at work, provide alternative ways to managing workloads.”

— Participant 6

Provision of EAPs: A number of participants referred to the importance of having Employee Assistance Programmes available in the workplace, believing these would be a beneficial source of confidential advice or support for employees with IBD, especially if there are problems in the workplace that need to be discussed and the employee does not think they can approach their employer:

“There is certainly need for an employee advisory service that can run...like a helpline if you were struggling and wanted to speak to somebody about anything really...you can call a number and get through to a person who will be able to point you in the right direction.”

— Participant 5

“The only people that were sympathetic was the counsellor...this is the service that was provided by the [company]. This was great because of the stresses and strains that I was

going through.”

— Participant 2

Role of HR and Occupational Health: Some participants reported that HR and Occupational Health have a role in providing managers with the information that they need to help an employee if they did have somebody disclose their disorder to them. Participants suggested that HR should be able to provide knowledge of the condition, what adjustments could be made, and potentially even have courses for managers to attend regarding how to deal with such conditions in the workplace. There was a call for some joined up practice within organisations so all parties have an understanding regarding the implications of IBD for an individual and what could be done to help them:

“...There should be somebody in the HR department or something to have done a bit of research and found out what the statutory obligations were, and then they can let the employer know...there is a failing by HR, and then this falls on general managers’ shoulders who do not know where to look for, for this kind of information...but in HR there should be someone with their finger on the pulse.”

— Participant 9

“You deal with occupational health and they know what it is. But by the time that’s diluted down to the manager, they just think that you’re standing upright, and you’re fit and ready to get on with your job.”

— Participant 11

Others suggested that in some cases, HR may have to review their sickness absence policies, especially because with IBD, there can be a number of flares, or a need for extended periods of time off work. In these cases, usual sickness absence policies and trajectories may not be helpful:

“The business of sick leave is an important one, because when people have flare ups, then it can be impossible to work, because when you are on your way down, it’s not a quick thing and to get back up to health can take a long time...you’re talking major time off, and if talking to an HR person, then this issue of sick leave could be alleviated or mitigated in some way. There is a bit of a mismatch between IBD and sickness absence policies, as you can be ill for an extended period of time, but then in between flares, you’re perfectly capable of working.”

— Participant 8

Overcoming misconceptions: Many participants were keen for employers to remove the stigma associated with IBD and understand that in the vast majority of cases that individuals with IBD are still able to work, want to work, and could be very productive, especially if they had the necessary support and workplace adjustments:

“I’m hoping that employers will be more ready to hear that people can have IBD and still do their job responsibly and effectively...there are misconceptions that have to be put right

appropriately, but I hope that IBD can just become one of those things that people have and it's ok."

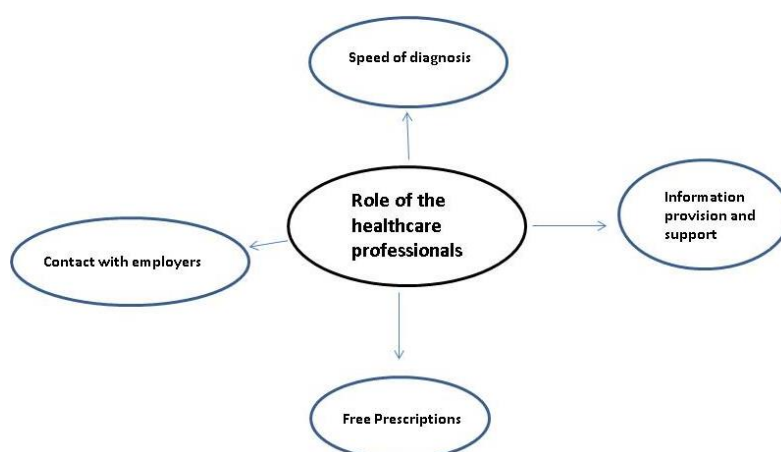
— Participant 6

"Employers need to understand that this is basically something that is manageable, and that most people can manage it."

— Participant 14

The role of healthcare professionals

Participants identified many ways in which healthcare professionals could improve how IBD is experienced and the role they have in helping to improve the understanding of their condition and how it is managed in the workplace:



Speed of diagnosis: Although recognising that IBD can sometimes be difficult to diagnose in its early stages and could be confused with other conditions (those most frequently mentioned were IBS and bowel cancer), a number of participants noted the need to improve the speed in which diagnosis is given, as this not only reduces the anxiety and stress caused as a result of the symptoms experienced, but this could also influence the time it takes for the individual to acknowledge their disorder and implement coping mechanisms. The IBD2020 survey results (2013) found that for 35 per cent of people with Crohn's Disease and 16 per cent of people with Ulcerative Colitis, they had three or more emergency visits before diagnosis. Others also highlighted that the time it took to see an IBD specialist also needs to be improved, as the longer the condition went undiagnosed the greater the impact the condition had on the individual's social and work life:

"Like I say, if I hadn't have had to wait two months for an appointment to see a specialist that would have been very nice. I understand that they're busy and they're always short staffed but I feel for a first appointment that was quite long...maybe they didn't realise that it was so desperate, even though I was stressing the urgency of waiting to see somebody."

— Participant 14

"It was almost a year before I was diagnosed...no-one ever actually did any real tests...there was no consultation...in the end we arranged to go to a different hospital and now I see

someone who is amazing, and things are fine now.”

— Participant 13

Information provision and support: Many participants also discussed the need for more information about IBD at the time of diagnosis, for example, how the condition could manifest itself, how to manage stress with IBD and managing your diet with IBD. However, it was understood that this could be difficult as a result of the unknown cause of IBD and that individual triggers of the condition are different:

“I guess I have learnt stuff in the ten years which it would have been handy for someone to tell me at the beginning I guess is one issue. And there is stuff that I still don’t know but it would be nice to be told. To some extent I do agree that this is difficult as there is no agreed cause of the disease so it can make people cagey about giving advice...but advice from the medical profession could be useful.”

— Participant 4

When participants had been given access to the relevant information sheets and other people (such as an IBD specialist nurse) who could give them information, or guide them to places where information could be sourced, it was seen as very beneficial.

However, having more information provided about employee rights when diagnosed was discussed as an improvement:

“I think it is making sure that all people who are diagnosed do have access to all the information (local team nurses, IBD nurse, Crohn’s and Colitis UK details) because that’s been a real help for me...it is worth pushing for that kind of help and support...but it would be helpful to have more information about how you could work around it and information regarding employee rights and what they’re allowed...I think a bit more information around this would be helpful.”

— Participant 15

“I got no advice about my work or employment, the main focus was to get the symptoms under control.”

— Participant 9

Others suggested that information about how IBD is affecting them medically is important, especially in ways that they would then be able to explain to other people, because it can be a very embarrassing condition to describe:

“I think you could do with more support on the medical side of it...it’s good if you have your IBD nurse and consultant or GP, but you don’t really have anybody who can explain how it is really going to affect you on a daily basis, and how to deal with it, and how to talk to other people about it...because it is actually quite embarrassing.”

— Participant 7

Some participants highlighted that there was also a need for increased information and support at diagnosis to help with the initial shock of receiving the diagnosis, and the mental health implications that this can have for individuals:

“I guess it is about support for people immediately on diagnosis and that may not be the consultant, but it could be the IBD nurse or someone who can hold that space in the face of the uncertainty or shock of the diagnosis. Then there may be need for a more considered follow up conversation...So I guess the more the hospital can provide, the better.”

— Participant 6

“My consultant dealt very much with the medical side, and needing to bring this under control as quickly as we can, so the rest of the stuff, of well, how am I going to deal with this didn't fit in with his attitude...they didn't look at the wider issue.”

— Participant 9

Others mentioned that finding out information about IBD has not always been easy, and they have taken to looking on the internet and discussing the condition in forums, because at times the support they received at the hospitals remained limited. Therefore, improving this support is important when treating somebody with a chronic condition such as IBD:

“It's not all been a bed of roses. There have been times at the hospital where I felt that I've been completely ignored, I've been knocked about, and I've had a dreadful time in some instances. And there have been times when I feel like I've been treated like a lump of meat and not as a human being.”

— Participant 12

Contact with employers: Some participants raised the suggestion that having some medical backing from a healthcare professional about IBD and an individual's ability to work with their condition could help to improve an employer's understanding of both IBD and the adjustments that may be helpful for the individual:

“I don't know whether or not they [healthcare professionals] could provide reports to the employer on the individual's state of health. I'm presuming they could do...to reassure employers basically that this is something generally manageable, an indication of how it could affect somebody in the long-term and short term, and just provide general information really.”

— Participant 14

“Maybe there could be information from the consultant at the hospital to write a letter for your employment or your employer [about the IBD]. It would need to be from a professional within the NHS.”

— Participant 2

Free prescriptions: Some participants were becoming despondent with regards to trying to improve services from various sectors, stating that there was a lot of lip service, but that no

real changes were happening. This included the issue of prescriptions for the medication that those with IBD take, and that they have to pay for them. The Prescription Charges Coalition is calling for an extension of medical exemption to all long-term conditions (<http://www.prescriptionchargescoalition.org.uk/>). Although, calls for free prescriptions have tried and failed, some still argue that free prescriptions would be an improvement:

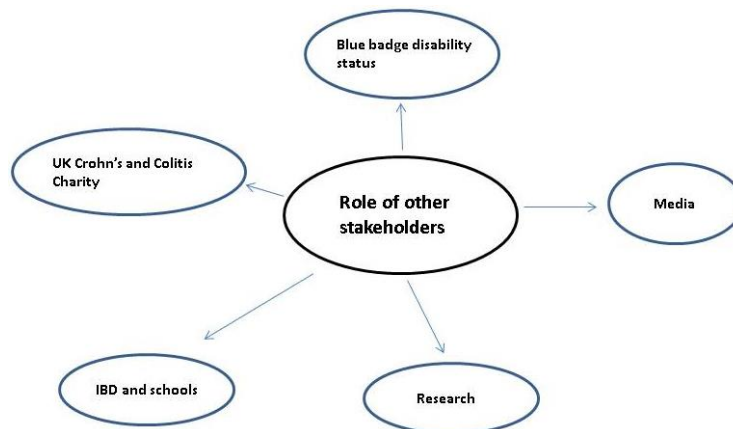
“There’s been big drives for IBD to try and get free prescriptions, but that still hasn’t happened.”

— Participant 11

Research undertaken by the Prescription Charges Coalition (2014) found that nearly 4 in 10 respondents reported that the cost of medication is prohibiting them from taking their medication as prescribed. Of these, three quarters reported that this has impacted on their ability to work in some way. If changes to how prescriptions are charged are made this will however have to pass through government consultation and sign off.

The role of other stakeholders

Participants identified other stakeholders that could improve how IBD is experienced and how it is managed in the workplace.



Media: Throughout the interview period there were a number of media stories regarding IBD, including the idea that eating junk food was a cause of IBD, and also the story of a young woman who was sunbathing with a colostomy bag on show, encouraging others to do the same to reduce the stigma of IBD. A number of participants discussed the role that the media has in promoting IBD:

“It’s terrible unfortunately [the portrayal of junk food and IBD]. There have been publications since that refute it, but unfortunately people tend to remember only the sensational headlines...its just an unfortunate circumstance, and you can’t reverse time, and you can only do what you can to mitigate it...”

— Participant 14

However, there was praise for some aspects of media coverage. For example, in cases

where there had been positive media reports highlighting when celebrities have openly disclosed their IBD, showing that they have been able to manage it and also keep working. This provided individuals with confidence to discuss their IBD, and also helped to raise awareness of the condition and how it can affect individuals. However, there was a concern that IBD should be kept in a positive media spotlight, especially as IBD can often be overshadowed by other health conditions, such as cancer, arthritis and dementia:

“Awareness of the condition has slowly been growing in the last ten years, and I think some of that is the media. There’s a lot more about it in the media now, there’s a few celebrities who have said that they have it and that’s been in the papers. People are less sort of like I’ve never heard of that when you talk to them about it, which helps.”

— Participant 4

“There’s more and more celebrities and normal people as it were coming out and saying I’m still relatively healthy and I’ve got this. There’s more people now showing off pouches and I think that’s absolutely brilliant because it’s nothing to be ashamed of. It’s not your fault.”

— Participant 14

Blue badge disability status: A number of participants discussed the difficulties of defining what IBD is – is it a disability or is it a health diagnosis? Some participants argued for IBD to be given the blue badge disability status, believing that it would make it easier for adjustments to be made, and for greater recognition to be given to those who experience IBD in their employment. Having some clarity about the nature of IBD and its disability clarification was discussed as being helpful. Those who argued towards IBD clearly being given the blue badge disability status often reported that this would help especially as IBD is invisible in nature:

“...Need to try and get blue badge status if we need to use the loo, and that hasn’t happened. It’s not seen by people, and it’s just not seen as a disability. It’s not recognised, and until that changes, until people realise in society, that there are more disabilities that those that affect mobility...we could have a special minister...”

— Participant 11

“I think it should be more recognised within disability policies and procedures. If it was more regularly recognised there and there was more information available on it, then it would be better. Because I think it’s unseen, it’s an unseen disability so it’s quite a difficult one.”

— Participant 7

Others explained that IBD was already seen under the Disability Discrimination Act, now the Equalities Act (2010), and consequently individuals should be able to claim for reasonable adjustments under this act. However, for some, having this description would not have made a difference to them, but recognised that it could help some with HR issues. However, not everyone with IBD has protection under the Act as this depends of impact of IBD rather than the diagnosis:

“I suppose the other legal aspect about employment is IBD and disability and the meaning of

the Disability Discrimination Act. And again that will be dependent on each person's circumstances won't it? So you have IBD therefore you are disabled under the Act. So again that's an HR question. I don't think it would have helped me to call myself disabled, but that's a personal thing."

— Participant 6

Research: For some participants the unknowns about IBD were frustrating. Not knowing what causes IBD, the lack of a cure, and the fact that IBD can be triggered by different factors for different people (i.e. some are affected by stress, some by different food items) highlighted for a few participants that there is need for further research to be conducted into IBD:

"There could definitely be an improvement there [in research], and again, it's a funding element of it. There's got to be funding for the research, it's only ever really charities that are going to fund research and that doesn't have commercial benefit. You're never going to get any big drug companies to fund research for solutions to problems that don't involve selling drugs."

— Participant 4

Crohn's and Colitis UK Charity: All participants were very grateful for the role that Crohn's and Colitis UK has in providing help and information regarding IBD and what can be done in various situations (such as employment). Many had turned to them for support on diagnosis for extra information about the condition, and were grateful that they keep those who experience IBD up to date with current research or changes in laws and policies that affect those with IBD.

"My consultant put me in touch with the national Crohn's and Colitis charity, so I get their monthly newsletter...and this has been very helpful because you just try and research as much information as possible...this is one of the best sources of information, and you can generally trust what you are reading there...but maybe they sometimes have too much information on their site and it could be distilled better."

— Participant 5

Although some participants reported that the information sheets regarding IBD and employment were helpful, others noted that they would appreciate more information on this topic:

"There does need to be more information about IBD and employment and the connection between the two. You don't really hear much about this, and a lot of information is about how you can control this medically...but whether it has an impact on employment is something under researched."

— Participant 3

IBD and schools: One of the participants who took part in this study had undertaken freelance work to understand how younger people who are diagnosed with IBD cope with

the diagnosis and what can be done to improve IBD management at that age. In their opinion, they suggested that schools could have a role in readying school aged people with IBD for employment, and discuss with them what opportunities are realistically available for them:

“I would emphasise the role that schools can play where they have a student who has IBD. There are creative opportunities to work with staff and students around the stuff that IBD throws up....and readying people to be employed, I think there could be some fantastic work done there.”

— Participant 6

In summary, the participants noted many ways through which they believed that the management of IBD, and how IBD is managed at work can be improved, from a variety of perspectives. For example, employers could improve management at work through developing the line manager and employee relationship, providing flexible working practices, improving the facilities that those with IBD have access to, and developing the roles of occupational health and HR. However, the individual with IBD was also seen to have a role in improving how they manage their IBD, including improving their awareness of the condition themselves, learning how to self-manage their condition, and developing the self-perception of their disorder. Healthcare professionals also could help in the earlier provision of information about IBD and offering both medical and psychological support. Participants also recognised the role that media, national charities and schools can have in improving the management of IBD.

Chapter 7 Results: The employer's perspective

The following section presents the results of the thematic analysis of the interview data with employers who have with experiences of working with employees with IBD.

Policies and practices

All employers were able to discuss a number of policies and practices that their organisations had in place for employees with experiences of long-term and chronic conditions, a category into which IBD falls. Sickness absence or attendance policies were the most commonly mentioned, where line management actions were triggered by noticeable trigger points in the pattern of employee absence, e.g. either the number of absences an employee has taken over a period of time, or the length of the period of sickness absence. In these cases, it was then the responsibility of the line manager to recognise these trigger points, and refer individuals to occupational health to understand what could be done to help the individual:

“The key one for us would be our Sickness Absence Policy, and in that we would detail how we would manage people with long-term medical conditions, and also how this policy interacts with occupational health.”

— Employer 3

“We have an attendance procedure, but what happens can depend on the situation. So depending on the pattern of absence, if it's periodic short term absences then we could use the Bradford factor approach, looking at the number of spells and the days. The line manager could consider a trigger for action, but it does depend on a case by case basis.”

— Employer 1

In two of the organisations, line managers were given specific training with regards to how to manage these absence procedures. For example, one organisation provided training for managing long-term health conditions, and how managers could effectively provide support to employees, and the training also provided advice regarding the other services that are available to help line managers and employees manage long-term health conditions in the workplace. Additionally, another organisation trained managers into how to conduct the trigger point interviews effectively:

“The organisation policy basically trains managers to do these trigger point interviews, to be aware of the need to not ask personal details about the actual illness itself...and if the individual said that the absence was caused by a recurrent illness or whatever, then they are to seek occupational health advice as part of that.”

— Employer 2

Other aspects of the training involved respect at work, understanding diversity (which

included disability within it), formal training in terms of how to deal with individuals returning to work after periods of absence, how to conduct a return to work interview, and also training in the role of occupational health and what to expect from occupational health referrals, and how to make best use out of that service.

As can be seen, all organisations also discussed the role of occupational health as part of their policies and practices for employees with long-term health conditions. Referral to occupational health could come from two routes – referral by a line manager, or self-referral (and this was important to highlight, especially if there was a poor employer-employee relationship). It was reiterated that occupational health is a confidential service, where the occupational health clinician would explore the individual's situation, the impact that the condition has on their working life and therefore how the occupational health practitioners can advise both the individual and the business on the best way to manage the condition at work. However, it was highlighted that occupational health was not just there for the employee, but the employer could also use the service if they also needed help. Alongside occupational health, HR was also recognised as a means through which help and advice could be given, who may be able to help with sickness absence policy strategies and policies:

“I would advise them [line managers] to seek occupational health advice, and within that to ask for advice and what help and support they might need in order to do the role that they're employed for.”

— Employer 2

“HR is also available, and HR is more strategic and they're there to advise, but there are various tools that HR can give to help them [line managers] with this.”

— Employer 3

Another policy that one organisation had in place was an organisational passport, which was a form of documentation, either electronic or paper that provided a short summary of an employee's condition, the impact this has on them, and what support they feel they needed to have to help them maximise their effectiveness in the workplace. This was seen as helpful so:

“...The line manager can sit with the individual and their passport so that they can get a greater understanding of the individual's condition, and how it affects them, what various actions have been taken in the past and what management's plans are. This facilitates discussions and plans as to how the individual would be supported in the workplace.”

— Employer 1

In this way, the organisational passport should help the individual when it comes to disclosing their condition, easing any conversations that need to occur around the disorder, and also helps with the ease of the implementation of any reasonable adjustments that are needed.

Finally, organisations had policies to highlight the use of employee assistance programmes – once again a service that was for both the employer and the employee to use. This was a confidential phone service that individuals can access for information and/or advice for any issue that they have, including how employees felt their IBD was being managed, and for employees, how they could deal with the situation most effectively.

In summary, employers were able to explain a number of policies and practices that they have in place to help manage employees with long-term health conditions, an umbrella of conditions they thought IBD sat under. Sickness absence policies were defined by trigger points (either through length of absence or the number of absences a member of staff reported), and the role of the line manager was highlighted as essential in recognising that something was occurring, and referring employees to occupational health. However, employers did note that individuals could also self-refer themselves to occupational health if they wanted information regarding how to manage their condition in the workplace. It was also reported that in some organisations line managers can receive training to conduct trigger point interviews and return to work interviews, and ways to best manage individuals with long-term health conditions. Occupational health and HR were also seen as important tools for practices associated with managing sick leave, as these services can offer advice to both the employee and employer regarding how an employee with IBD can be best managed to ensure that an employee can remain in work. Some organisations developed an employee passport, a way of documenting the employee's conditions and the previous adjustments that have been implemented, to help start conversations with employers regarding the impact of the condition on their work, and what employers can do to help. Employment assistance programmes were also reported as a practice through which individuals could receive confidential help and advice for any issues that were concerning them. This was available for both employers and employees who may require help when managing chronic conditions such as IBD in the workplace.

The role of the line manager

As seen in the description of the sickness absence policies, the role of the line manager was described as key to the implementation of the process and recognising that adjustments needed to be made. It is therefore important that there is a strong, positive employment relationship between the employee and their line manager to allow for honest and open communication, and a need to develop the right culture where employees feel comfortable to disclose and feel supported having done so. The importance of the role of the line manager when considering the management of long-term health conditions was identified by all employers.

Line managers have the responsibility to enforce the sickness absence policies. This does not just involve the referral to occupational health, but the recognition of the trigger points, and developing employee communication to understand when something could be wrong, and identifying a solution:

“The thrust would be for the line manager to keep in regular contact with the individual to know what is going on. That really is paramount. This is the point that I am making, you

cannot really over emphasise the importance of open honest regular dialogue with the employee, whether they are at work or they're off work."

— Employer 1

The employers explained that line managers may have some awareness of how long-term health conditions can affect individuals and discussed the need to train them how in how to handle these situations. In such situations this would help line managers to be supportive and sympathetic, and encourage regular contact with their staff. It is important to highlight that employers were not expecting their staff to be experts in all long-term health conditions, but to use suitable line management practices (or people management) and show an understanding of what their employee may be experiencing:

"In my experience it all depends on the line manager, because some line managers don't have the medical experience or know the medical treatment and so don't know what to do. In some situations they may put their arms out and say, oh I can't handle that. Some of course are brilliant. I think the key and most important tool to helping an individual with IBD is the line manager. And having a good line manager who you can talk to, who can understand you, who knows how to get the information is vital."

— Employer 3

Two of the employers provided line management training, recognising the beneficial role this can have. They discussed how line managers were trained to identify trigger points, conduct return to work interviews with sensitivity, and to know how to handle the support and advice given by occupational health and HR. One employer also described how information provided through internal communication channels could also be used alongside training to provide further information relating to managing health conditions at work:

"We did a lot around health awareness, including some in-house awareness through the internal communication, and so in that way there was some awareness about long-term conditions. And a lot of it is encouraging managers to be supportive, and that comes down to the way in which we trained managers and staff in term of their regular contact."

— Employer 2

However, one organisation did not provide training for long-term health conditions, indicating that it had been raised on the managerial agenda, and they hoped that line managers would receive it as it is beneficial for good practice. However, they also argued that the line manager's role is increasing, in that they have to undertake task related duties as well as people management, and the organisation had to prioritise what training line managers went on, and what training would be more beneficial for the organisation at that moment:

"I have to say that unfortunately line managers have a lot to do, and health is one aspect of that, but I think it would be fair to say that it [long-term health conditions] is not something that they have specific training for at the moment. It is obviously something that I would champion, and I think that training more line managers to assist people with health problems I think is very important...but there's lots of other people and training that line managers

need...the general concept of training for a manager to help them manage a long-term medical condition is definitely more on the agenda than it was a few years ago, but I think there is the realisation that line managers are so important now and we ask so much of them.”

— Employer 3

Another role of the line manager identified by the employers was to create a culture where individual employees felt that they are valued and supported, so employees did not fear disclosing their condition, and know that when they do disclose, they will still be respected in the workplace. Employers discussed the issue of there being a stigma surrounding health conditions, especially something like IBD, as it can be quite embarrassing to describe, and consequently providing the ‘safe space’ to disclose was considered important:

“For some it can be difficult to discuss their symptoms, and so it is recognising when somebody is struggling and offering them support. It’s about creating a culture where employees feel supported and trust their line manager.”

— Employer 2

As line managers are important in referring individuals to occupational health, it is also important that they understand what reasonable adjustments should be made and how to implement them properly. Once again, a line manager is encouraged to have open communication with the employee regarding what would be most helpful for them:

“The line manager and the employee should be able to agree upon appropriate adjustments, so adaptations perhaps to the work, or modifications to the work that will allow the individual to remain at work as effectively and efficiently as possible. It is about adjusting the employee and the condition around the work that they do.”

— Employer 1

In essence, employers were discussing that line managers were to be good managers, to enable honest and open communication, providing a culture where employees could feel safe to disclose their condition without the fear of this having negative implications on their role, and the line manager to refer to, or offer the range of services that an organisation has to support the employee. Employers did mention that it was sometimes difficult to ensure that everyone received good line management as a result of how line managers are traditionally appointed to that role (through completing work tasks and not necessarily by their people skills), but they identified the characteristics they perceived a good line manager should have:

“A good line manager is someone who can hold balances in workloads between their team members. They should have compassion, but equally drive people. Be able to interact. But I have to say in my experience over the years, not all line managers are good at managing people. They’re sometimes technically good at their job, but they often lack, some of them, these basic communication skills. The problem is when you promote some of these people into line management roles....if you’ve got a great people person as a line manager it can be

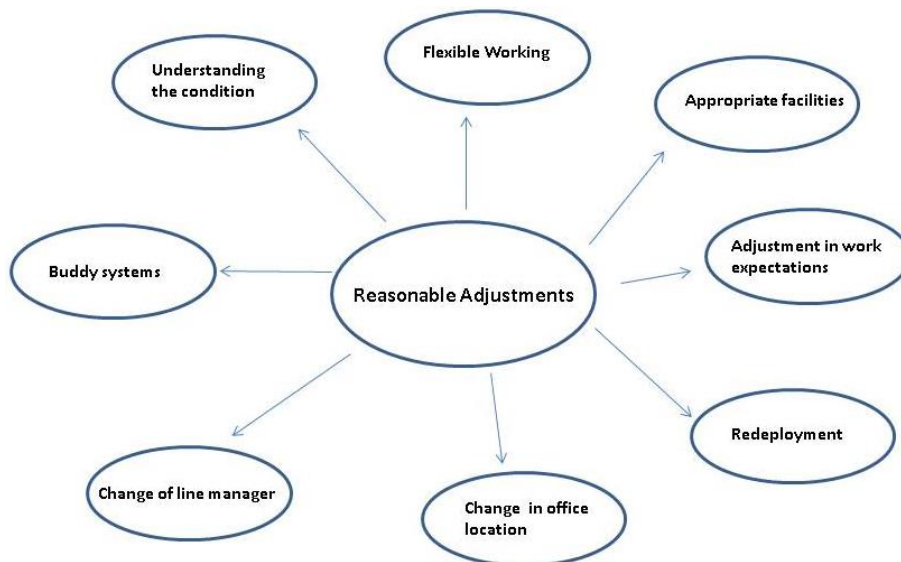
great. Really supportive. The biggest support that you can give people with IBD is a good line manager.”

— Employer 3

In summary, interviews with the employers found that line managers have an important, some would argue critical role in the management of long-term conditions, such as IBD in the workplace. Line managers are to recognise the trigger points in an employee’s pattern of absence and understand that they should refer the employee to occupational health (and even go to Occupational Health themselves if they feel they lack the understanding regarding the condition an employee has). Employers discussed the importance of developing an employment relationship based upon open and honest communication and trust so that the employee could disclose to their line manager directly, enabling further conversations about the need for reasonable adjustments that can be made. Although employers explained that line managers are sometimes chosen as a result of their technical ability instead of their people management training, organisations can provide line management training, where the skills for managing an employee with a long-term health condition are emphasised and taught.

Reasonable adjustments

Throughout the interviews the employers identified a range of reasonable adjustments they have put in place in their personal experiences of managing employees with IBD.



- **Flexible working:** Employers discussed how they had provided flexibility around working hours, where an employee works and their start and finish times:

“We were more flexible around working hours...because the individual found it difficult to attend work early, so we worked on a system where the individual worked on total working hours rather than having to stick to an unpredictable shift pattern.”

— Employer 2

“What I see as reasonable now is flexible working...part-time working is something that we have managed to do, and we’ve managed to cut down hours of work per week...but also flexibility in where they usually work, we have brought in homeworking, flexibility in the start and finish time...these are adjustments that we would bring in for somebody with IBD in particular.”

— Employer 3

Some also discussed flexibility within a role, depending on the type of role that the employee has:

“Giving the individual the flexibility to leave their workstation and to go to the toilet whenever they need to.”

— Employer 1

Others also discussed providing flexibility in allowing people to take time off within the working day to go to hospital appointments:

“I have given employees time off to attend hospital appointments.”

— Employer 3

- **Appropriate facilities:** As a result of the embarrassing nature of IBD, employers were aware that making adjustments to toilet facilities for their employee was important:

“Once they are in the workplace, it is important to ensure that there are appropriately equipped toilet facilities and that they are within easy access to the individual. We have had situations where they have a key and only they use that toilet facility. They are usually disabled toilet facilities, if it is possible to do.”

— Employer 1

“Another adjustment related to the condition would be toilet facilities, I have especially given some people this, and given people private facilities if needed.”

— Employer 3

“I can remember individuals who were changed to the other side of the office because when they needed to go to the toilet they needed to go in a hurry. Quite literally being closer to the toilet made a huge difference to that individual.”

— Employer 2

- **Adjustment in work expectations:** some employees have been able to provide adjustments in the number of cases, or the level of work they are able to complete, especially when they are experiencing symptoms:

“I have given adjustments in terms of their work targets and work expectations. For example if someone had ten cases in a day, and because of their frequent breaks they are only able

to complete five in a day, we had to be able to determine whether an adjustment for that person to do five a day was something that was operationally feasible, and then for how long it should have been made for.”

— Employer 1

- **Redeployment:** On some occasions, employers were able to provide examples of when redeployment was an appropriate course of action, however, this is dependent on the organisation and what roles the individual is able to complete:

“I have changed location. One case that I can think of is in the gas industry, where an employee was out and about on the road, and with IBD this was very difficult as you can imagine. So we managed to redeploy him into an office based role, thus redeployment is certainly an adjustment that I have used.”

— Employer 3

“I have had opportunities to change the work, the type of work that the individual is actually doing. For example, someone was doing a delivery role, and they have been moved to a more office based role.”

— Employer 2

- **Change in office location:** Employers identified that travelling to work may be difficult, especially if the employee could not travel long distances without needing a toilet break. Thus, trying to relocate to an office location closer to home was offered as a reasonable adjustment:

“IBD can have an impact on the individual’s journey to work, so if the individual cannot travel long distances because of the need for a toilet break, then I have considered identifying a work location nearer to the individual’s home. This means that the individual does not have an unduly prolonged journey to work. So we identified work locations nearer to the employee’s home as possible. Sometimes, we have also trained people to become a permanent home worker.”

— Employer 1

- **Change of line manager:** As previously noted, a line manager has a critical role in the employment relationship and providing the employee with support and reasonable adjustments. If the employee reported a poor relationship with line managers, then employers noted a couple of occasions when line managers have been changed:

“If there are issues where there has not been a particularly good relationship with their line manager, they were encouraged to see if the issues could be resolved, but if not, then they can go to a second line manager.”

— Employer 2

“We do try to avoid just changing line management because of the employee’s perception.”

But if the relationship had broken down for whatever reason, then we have looked to see what changes could be put in place and if they were operationally feasible. And something that has been put in place was to support this individual through another line manager.”

— Employer 1

- **“Buddy systems”**: One employer mentioned that as a result of co-location of offices, there are cases where employees may not be in the same location as their line manager. Consequently they have implemented a system where the employee has nominated a ‘buddy’ who is there to support the individual, and to be on the look out in case something goes wrong:

“For example if this individual is going away from their desk and notices that their colleague has been away for some time, this buddy can take the appropriate action necessary. The buddy keeps an eye on the person and asks if they are ok, they can check on them...that sort of help.”

— Employer 1

- **Understanding the condition**: Another employer also reported that they believe a reasonable adjustment is actually trying to understand the condition the employee has, and then they will have a greater understanding of what the employee is going through, and translating the medical terms into practice:

“I think the first adjustment is actually understanding the condition. I see the key area is having the skill to translate a medical condition into practical terms, and that is something that is not easy, but it is something that we try and do.”

— Employer 3

Employers were also asked if they ever had to refuse implementing a reasonable adjustment, and some occasions were identified (albeit rare) when this was the case, for varying reasons. For example, one employer explained that rejecting reasonable adjustments depended on the severity of the employee’s IBD, and the extent of the implications on their work:

“I am struggling to think of examples [where employee requests have been turned down], but I guess the only example that occurs to me is that [company] is a service industry and whilst we do everything we can to accommodate irregular attendance and long periods of absence, if someone was very regularly needing time off unpredictably, then we wouldn’t be able to accommodate that.”

— Employer 2

Another employer described how they had never really had to decline giving any reasonable adjustments and they would always try and find employment that the employee would be able to undertake. However, they did argue that for smaller organisations who may not be able to change roles or provide flexibility, that implementing reasonable adjustments may become more difficult:

“I would recommend other adjustments that the employee might like to look at...generally in my experience we always like to think that we have done something to support the individual. I can see that if you’ve got a small employer and limited jobs that it could be very difficult. And obviously sometimes you cannot create jobs specifically for somebody. It does depend a lot on the size of the organisation.”

— Employer 3

Having to decline reasonable adjustments was described by one employer as being dependent upon the situation, the individual and the impact that their condition has on them, and in the case of IBD if their travel was something that was increasingly difficult to adjust for:

“...It depends on whether the adjustments can be accommodated...for example IBD is to do with travel, and if you have a job that required you to travel extensively, and you cannot travel, then that might be an adjustment that just cannot be accommodated...but we would try and do something...maybe do a job search and find suitable alternative work for that person with their skills and capabilities.”

— Employer 1

In summary, all employers were able to identify a range of reasonable adjustments that they have been able to implement for employees with IBD, including flexibility in the hours worked and place of work, being located close to appropriate toilet facilities, office relocation, redeployment and adjusting work expectations. Some employers had developed a buddy system if a line manager was located in another office, and on occasions when poor line management could not be resolved, employers have provided alternative line managers. However, employers also discussed rare occasions where reasonable adjustments could not be made (or the specific adjustment could not be made), but commented that this was very much situation and severity of the condition based.

Barriers identified by employers

Although employers identified a range of adjustments that they have been able to implement to help employees with IBD remain at work, they did however also discuss a number of barriers and challenges that still exist.

Employers described how the nature of IBD could be perceived as a barrier to employment, in that it is variable and fluctuating condition and as such is unpredictable for both the employer and the employee to manage. However, in the workplace this makes it very difficult for an employer to accommodate a condition that fluctuates:

“The difficulty with IBD is the issue that it’s a variable condition and that it may fluctuate, so they may have long periods where actually they are very well. But then unpredictably they have periods where they get flares or whatever. It’s that ability to accommodate a condition that is unpredictable that is the most difficult barrier I think from my perspective.”

— Employer 2

Others explained how the embarrassing nature of the condition may be a barrier to IBD in the workplace. The physical affects of the condition were especially identified as barriers. Additionally employers recognised that employees may find it very difficult to disclose, especially if there is not an open culture in the organisation towards individuals with chronic conditions. Thus these two factors combined could create barriers to the management of IBD in the workplace. However, one employer argued that it wasn't the IBD itself that could create barriers to employment, but the effects of the condition:

"You do have to accept that with this condition it is rather sensitive, it can be embarrassing to disclose...The other thing is how the IBD has an impact on their day to day lives. Because if you are completely debilitated by the condition, in that, you are permanently having to take toilet breaks, and you are permanently weakened by it, and then don't have the stamina, you're constantly fatigued or constantly in pain or whatever it might be, then obviously that's a barrier to employment and to work."

— Employer 1

"People could still be worried about the stigma and how sympathetic an organisation is going to be in terms of if they disclose. The symptoms are quite often personally embarrassing so it can be difficult to want to discuss, or employees worry about discussing their symptoms with a line manager."

— Employer 2

"I don't think it's so much the condition, I think it's the effects of that. Yes, it is the effects of the disorder that affects the employer."

— Employer 3

As previously discussed, the role of the line managers was viewed as critical when managing an employee with IBD. However, if there was a poor employer-employee relationship this was viewed as creating a barrier to disclosure and a barrier to the implementation of any reasonable adjustments that are helpful for the employee to remain in employment. Additionally, when there was no line manager training to help with the management of long-term conditions in the workplace, this was also identified as a barrier as it meant that employees may not get access to the help and support they need:

"There are benefits for an individual if they feel that they are able to talk to a manager about their condition. If they can talk about their condition then that helps. Some people can feel that they won't tell their manager anything because their manager won't understand and they'll probably put the shutter up...but you have to have the culture to encourage people to be able to talk to their manager about that...training more line managers to assist people with health problems I think is very important."

— Employer 3

"One of the most important things is the manager-employee dialogue and being able to talk openly and honestly about the condition."

— Employer 1

“Some employees may be worried about discussing their symptoms with a line manager...but this is really all about training and being able to deal sensitively with medical conditions.”

— Employer 2

Employers also explained that some barriers may also originate from individual employees, including not being able to take ownership of the condition themselves, employees struggling to come to terms with the initial diagnosis of IBD, and the psychological barriers that may be related to the condition. Employers explained that it is important that employees take the initiative to disclose if they have a long-term condition, as that can help improve the timeliness of reasonable adjustments being implemented. However, they did suggest that this would be easier if there was a culture where they felt able to do that:

“I think the main barrier is psychological...it can depend on the individual’s motivation, determination and enthusiasm...I am just talking from my personal experience here but it can fall into two camps: you have those who adopt illness behaviour and woe is me, I can’t do anything, I need help, and you have those who are really stoical and would say that I am going to live with this condition, I am not going to let it bother me and I am going to overcome it. But, there is still that psychological impact in terms of coming to terms with diagnosis, and coming to terms with the impact that it’s had on their lives.”

— Employer 1

“I feel that probably the employee needs to take ownership of, well all of us need to take ownership of our own issues. Line managers are not telepathic...we do rely upon an individual perhaps starting that process...but within a culture where they feel they can do it.”

— Employer 3

On a more practical note and having experienced how IBD could have direct implications on an individual’s employment, one employer discussed how an employee’s attendance record could be a barrier to employment, especially if there were extended gaps in their work history as a result of IBD. However, the employer did add that understanding this pattern of absence is key, and it is at this stage where employers can begin to look at what potential adjustments can be made, and should seek advice regarding how they could manage the IBD in an attempt to limit the employee’s absence:

“For somebody applying for a job with IBD, I think probably a big barrier would be their attendance record. I can see if an employer is looking at somebody and they’ve had a large amount of absence, and that is going to be, I think, a potential barrier.”

— Employer 3

One factor that can help to improve some of these highlighted barriers was based around the awareness of IBD in the workplace. IBD was not one of the general conditions that organisations discussed in internal communications, and employers observed that, as with other long-term conditions, that even if managers did have information about IBD, if they did not have an employee experiencing the condition, then it is hard to put that awareness into

context. Employers also recognised the recent media exposure that IBD has had and noted that the awareness of the condition is improving:

“You need to put these things in some kind of context. As management are bombarded with information right, left and centre. You can tell them about IBD and they could just as instantly forget about it, especially if it is not relevant and they don’t have anybody on their team with it...But IBD can get confused with other gastro intestinal conditions that have similar symptoms...I do think increasingly that people are becoming more aware, and with the internet and such, people do look things up.”

— Employer 1

In summary, employers highlighted a number of barriers to the management of IBD in the workplace. These included the nature of the disorder, taking into consideration the unpredictable fluctuations in the symptoms experienced, and that it can be embarrassing meaning employees may be reluctant to disclose, especially if there was an organisational culture that led to difficulties or barriers to disclosure. Employers also explained that the employment relationship could be viewed as a barrier; if line managers did not support employees, or did not create an open and honest communication path, then this could lead to employee barriers in disclosure and the implementation of reasonable adjustments. Another barrier focussed on line management training, and if this was not offered by organisations, managers could find it difficult to show the appropriate levels of support. However, employers also emphasised that individual employee barriers may also have a role to play, in relation to how they cope with their diagnosis and how having IBD affects them psychologically. The direct effects of IBD on employment, for example its impact on an employee’s attendance was also raised as a potential barrier. Finally, employers discussed how the awareness (or limited awareness) of IBD could be a barrier, although they also recognise that there are now greater channels to improve one’s understanding of the condition.

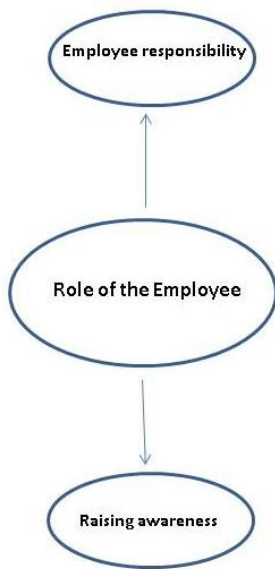
Ideas for improving employment with IBD – the employer’s perspective

Over the course of the interviews, employers suggested ways in which employment can be improved for those experiencing IBD at work. Improvements could be found at a number of stakeholder levels that will now be discussed.

The role of the individual employee

Employers identified many ways in which an employee with IBD could improve how IBD is managed and experienced at work:

Employee responsibility: Employers suggested that employees must take some self-management of their condition, be that understanding the nature of their condition and what can trigger a relapse or flare, dealing with any issues promptly, being compliant with their treatment and also having some awareness of what help is available for them. Employers also suggested that employees have a responsibility for information transfer, to let employers know what is happening, and how they think their IBD can be managed:



“The employee has a significant role in terms of understanding their condition, in recognising how to maximise their wellbeing if you like, of dealing promptly with any issues. I would also say being compliant with treatment, and then being aware of the help that’s available both within organisations and outside of organisations...things like specialist charities.”

— Employer 2

“Employees have a role. I think employees do need to take responsibility for themselves. People do, we all do. But they need not think of their IBD as leprosy. I have seen that, where people have said my manager now knows that I’ve got IBD and so they must know what that means for me, and what they need to do for me. Managers don’t and they won’t. So they’ve got to get the information across.”

— Employer 3

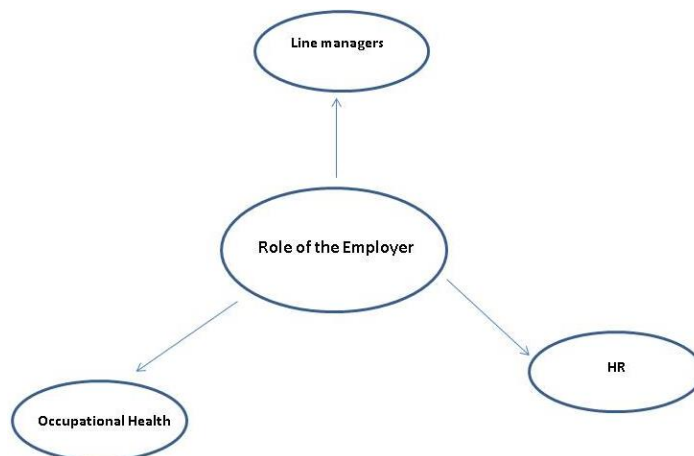
Raising awareness: An employer suggested how employees with IBD can get involved in raising awareness of IBD especially within organisational health promotion days. This went along the ‘intelligent patient’ model. The employer suggested that individuals with IBD could be on hand to raise awareness of the condition themselves, to put the condition in context in a way that other employees could understand:

“You can have these stations in the workplace, and employees often want to participate in these health promotion and awareness activities about their condition. Then friends and colleagues can relate to the person who is getting involved in the awareness programmes and that helps. And that is how you get people to take an interest...it has some relevance, it’s been put in context.”

— Employer 1

The role of the employer

Employers identified many ways in which employers (including line managers, occupational health and HR) can improve how IBD is managed and experienced at work:



Line managers: As has been previously highlighted the line manager and employee relationship was described as vital when managing a condition such as IBD in the workplace. Thus, employers discussed ways in which the employer-employee relationship could be improved, and what line managers in particular could do:

“For line managers, I am a great believer that it’s actually not about waiting until issues arise, but it’s about knowing your staff. Having regular contact with them, recognising when somebody is actually struggling for one reason or another, and offering support and help. So it is about creating that culture where employees feel supported and that they can trust their line manager.”

— Employer 2

“I still think the key here is line managers. A good line manager is a particular type of person. It’s somebody who again is not just terribly good at their job, but they have these other skills, and that is to really support people in the workplace.”

— Employer 3

“Line managers need be aware of what adjustments need to be made, and whether the adjustment is feasible.”

— Employer 1

One employer discussed how co-workers may also be affected if a team member has IBD, especially if the employee needs more time off work, and co-workers may experience an increase in workload, and in some cases co-workers felt under excess pressure and stress. Thus, they believed that the line manager had responsibility to not just focus on the employee with IBD, but to look at the team as a whole, and how to support everybody, and this could be achieved through developing line management training:

“I think the important thing, and again, this is down to manager training, is that you have to look at the whole team. That is quite difficult, but you have to consider the effects of that individual with IBD on everybody and how you’re all going to support that...a good team manager will try and create an environment where everybody understands and that you all work together...but that doesn’t always occur and it could be a real problem.”

— Employer 3

HR: Employers also noted that HR had an important role in improving the management of IBD in the workplace. For example employers suggested that HR need to look at the bigger picture of managing long-term chronic conditions in the workforce, breaking down the barriers and stigma associated with IBD, they had to embrace their role in accommodating appropriate adjustments and training, and ensure that the right policies and practices for managing long-term conditions are in place:

“In terms of HR, it’s having the right policies and approaches in place, for example designing the line manager training and the processes involved so that line managers can both recognise a condition and then make an appropriate referral as necessary.”

— Employer 2

“HR needs to ensure or identify that the appropriate roles of individuals are done correctly, and to assist with the accommodating of adjustments and so on.”

— Employer 1

“HR, I suppose then again, the role of HR is part of the bigger agenda, again thinking about discrimination, breaking down barriers, and acknowledging that people with long-term conditions and disabilities can work and want to work.”

— Employer 3

Occupational health: The employers also reported the role that occupational health had in the management of IBD in the workplace and how this could be improved. Suggestions included helping managers with their understanding of the condition and ensuring everyone gets an occupational health referral:

“Occupational health advice should be given to management as to the things that are likely to lead to exacerbation and stressful situation. The occupational health service needs to give advice as to what could be done to assist the individual to better manage their condition and try to maintain their stability in the workplace. They need to advise on the services that are available to support the individual in the workplace, everything from the employee passport to the mental health services, even around specialist disability services and work station assessments.”

— Employer 1

“I think that OH has a role in encouraging people to have the opportunity to disclose in the process of selection that they have a medical issue...and this can be done and looked at by the OH team. So it could be OH providing a very confidential pre-employment process...I think that a very good selection process that gives people an opportunity to get any support that they need to, and so anything very impartial and independent will help...If managers need more information then they need to go to OH, but we need to suggest that everybody with IBD must go to the OH service.”

— Employer 3

The role of other stakeholders

Employers identified some ways in which other sectors, working alongside organisations can improve how IBD is managed and experienced at work:

Healthcare professionals: Employers often spoke of the need for joined up thinking between a variety of stakeholders, which included healthcare professionals. Although it was recognised that healthcare professionals are invaluable in the help that they can provide an individual with IBD, it was noted that an improvement was needed with how they interact



with organisations, and that closer work with health specialists is needed:

“Many healthcare workers have never actually worked in an environment other than the NHS, and so often the knowledge of how work operates is very limited. Say an individual with IBD produces a letter written by a specialist consultant, which has a very good meaning, it can sometimes put the employer in a very difficult position, and they may not understand the difficulties that employers have. I think that closer working between specialist nurses and consultants with the OH team is needed.”

— Employer 3

“Letters from consultants may not be necessary in all conditions, but there can be some instances where an individual may have particular complications where it could be helpful for OH to have a consultant’s report.”

— Employer 2

Crohn’s and Colitis UK: Once again, employers reported that the role of Crohn’s and Colitis UK was very important in the information that they produced regarding IBD and employment. However, it was suggested that some specific roadshows or management awareness could be beneficial:

“We do work with external organisations and charities, but it is important to get the up to date advice, and they can come in to do roadshows, and raise awareness with managers and that type of thing.”

— Employer 2

In summary, employers found, similarly to employees, that improvements could be made from a range of stakeholders, but clearly highlighted that joined up practice is needed, and is the most preferred option for improving the management of IBD at work and reducing the stigma associated with this. However, individual employees did have a role in disclosing their condition (especially if they felt that the culture was suitable to do so), for understanding their condition, and raising awareness to employees about what can be best done for them. The employer’s main role was to improve the line management relationship, but also to ensure that HR and occupational health had their policies and practices in place to support both the employer and the employee. Finally, employers also found that the communication between external stakeholders such as healthcare professionals and specialist charities could be improved to raise awareness of the condition and support management.

Chapter 8 Discussion

This study has made a number of contributions to the literature discussing the employment decisions of those who experience IBD and what they perceive the barriers to employment are. The research also provides an in depth understanding regarding how IBD is managed in the workplace, adding the much under-researched employer's perspective. Additionally, how the management of IBD can be improved in the workplace from a number of stakeholder perspectives was also discussed.

The findings demonstrated that there were a number of inter-connecting factors that had a role in why employees chose their employment and employment pattern. For example, the nature of IBD, in that it is a fluctuating condition, can have a variety of physical symptoms, and often results in fatigue meant that some participants decided to choose more flexible styles of working (for example working for an agency, self-employment, contract work), or had negotiated flexible working practices with their employer (so worked full-time but had reduced/compressed hours, could work from home, had flexi-time and had time off for hospital appointments). How IBD affected an individual psychosocially was also an important consideration. Participants when symptomatic described having reduced self-esteem, a loss of confidence and limiting their social activities for fear of having an accident in public. This also had employment implications as participants had reduced wellbeing and found coping strategies harder. However, for those who had found medical treatment to stabilise their IBD, or who had undergone surgery which had effectively placed them in remission, their attitude towards their wellbeing and job opportunities were increasingly positive.

However, the research clearly highlighted that other factors played a large role when individuals with IBD make employment decisions, especially job satisfaction. Many participants were determined to remain positive and resolute, and were keen for their IBD not to rule their life, including their employment, and so were keen to pursue roles that they were interested to undertake, even if the conditions of their employment were not always conducive to working with IBD. Financial considerations were also an important factor, with participants choosing to return to work, or remain in work, or staying in a role even though they were not using all their skills (but the role provided appropriate flexibility to help manage their IBD at work) so they had their required income.

Other stakeholders also had some input when considering employment decisions. The role of healthcare professionals was often reported, especially when discussing employment options and how IBD can be managed in the workplace. Age was important here, for example those diagnosed with IBD before entering employment often stated that they would have appreciated more information about IBD and employment. However, those who were diagnosed throughout their employment, although some would have appreciated employment information, were usually already settled in a career choice.

When discussing barriers to employment with IBD the employment relationship with the line manager came under scrutiny. Participants described a positive line management relationship as having a manager who was supportive and sympathetic, who had some understanding of how IBD can affect them at work, and provided flexibility to the participant so that they could best manage their IBD. In essence, participants were describing the characteristics of 'good people managers'. In many cases, a positive employment relationship was described when individuals had been employed with their line manager for a long period of time, which provided the opportunity for a social exchange relationship to develop, not only important for improving employee productivity and reducing organisational turnover, but also for maintaining positive employee wellbeing and satisfaction. The line manager was also important for developing a culture where individuals felt safe to discuss their IBD (or any other chronic condition), and not feel discriminated against as a result of doing so.

The importance of the line manager was also highlighted by employers who had experience of managing individuals with IBD in the workplace. They also discussed the importance of the line manager-employer relationship, defined by open and honest communication, trust and an awareness or understanding about how experiencing IBD can affect employment. However, they also discussed the importance of line managers having an awareness of the sickness management policies, recognising the absence trigger points, understanding the role that occupational health can have in supporting both the individual and the employer, and having the ability to conduct return to work interviews sensitively. Employers mentioned that line manager training for managing chronic conditions in the workplace was beneficial and would help to improve the employment relationship in many cases however, whether this occurred in employment settings was dependent on how far up the scale organisations considered long-term conditions to be of importance.

The employee-employer relationship was reported as being of particular importance when discussing disclosure. Both employees and employers described how they understood that disclosing a condition such as IBD was difficult, due to its embarrassing nature, but disclosure would lead to a greater understanding of what the individual was facing at work, and could allow for the discussion of what reasonable adjustments could be implemented to help the individual. Many participants believed that disclosure was important, so that they could receive employer support and so they could begin an 'honesty is the best policy' relationship with their employer. Although for many, it required a lot of confidence to disclose, they did recognise that once they had done it opened up the necessary discussions around employer support. Employers were usually thankful when employees disclosed as it ensured that they were aware of symptoms to look out for, especially as in many cases line managers had both people management and task management responsibilities and may not have otherwise been aware of the support they needed to provide.

Even though the line management and employer relationship was at times discussed negatively, participants who have experienced IBD in the workplace also provided evidence of reasonable adjustments that line managers had put into place. These included the provision of flexible working (both in terms of working hours and place of work), flexible start

times, phased return to work after an extended period of sickness absence, greater provision and accessibility to facilities and time off for hospital appointments. Employers also reported a number of additional adjustments that they have had first-hand experience of implementing reasonable adjustments for employees with IBD. These included providing an adjustment in work expectations (reducing the level of work they are asked to complete especially when symptomatic), redeployment (especially if the organisation has other roles available that the employee is able to undertake), changing office location, appointing a new line manager (especially if there was a particularly poor employer-employee relationship), developing a buddy system (where specific individuals were designated to monitor an individual with IBD especially if the line manager was absent), and employers also thought it was of particular importance to develop an understanding of the condition, to be able to empathise with the employee and translate the medical terms into practical improvements.

It is also important to highlight the role of co-workers in the workplace, as they also had a role in developing an open culture or work environment. For example, participants acknowledged attending work when symptomatic on many occasions, for fear of letting other employees down. Some reported that they had perceived negativity from colleagues who had made comments regarding their extended periods of absence, time off or mentioning that their workload had increased. However, in some cases such comments resulted from a lack of awareness of the disorder (and the fact that IBD can be invisible, so outwardly an individual may not appear unwell) and an individual with IBD did not feel comfortable enough to disclose. Thus, where there was a culture where support was perceived disclosure to co-workers was easier, but this was usually related to the size of the organisation, the length of time the team had worked together, and how confident the individual was in mentioning their IBD and providing the associated information that could help others.

Both employees and employers discussed number of ways in which the management of IBD in the workplace could be improved, importantly recognising that this would require joined-up working from a number of stakeholders. An individual with IBD could help themselves by raising awareness of the condition, understanding the implications of the condition in the workplace, disclosing to their line manager and learning how to self-manage their IBD. To improve employer management of IBD at work, improving line management was seen as key, which would then help with the provision of reasonable adjustments such as flexible work practices, appropriate toilet facilities and improving the awareness of IBD in the workplace. The roles of occupational health and HR were also discussed, with reference to understanding the policies and practices related to managing long-term conditions in the workplace, and providing the necessary training to line managers.

Employees with IBD reported how healthcare professionals could help them manage their IBD in employment situations, for example providing information and support about employment at the point of diagnosis, guiding them to other sources of support (for example Crohn's and Colitis UK, who have a number of resources available helping individuals medically, psychologically, socially and with employment) and discussing treatment options. Specialist nurses were seen as a great source of support, and thus improving access to these as soon as possible was considered very important in the management of IBD from

healthcare specialists. Both employees and employers suggested that greater contact between organisations and healthcare specialists could be beneficial to improve the understanding of the condition and what reasonable adjustments would be most helpful.

Finally, a range of other stakeholder groups were considered to be important, especially by employees when considering the improved management of IBD for employment. Crohn's and Colitis UK were seen as a very positive source of support (from both employers and employees), however, participants expressed that more information regarding employment and IBD would prove useful, and employers suggested that more organisational engagement (e.g. roadshows or management awareness) would be beneficial. The media was seen as a factor that could help to promote positive images surrounding IBD and employment, and IBD should not be overshadowed by other conditions such as cancer and arthritis.

The research highlighted that individuals with IBD want to work (and will do anything they can to work in their chosen career), and in many cases have the health to work, however a range of inter-related factors, including individual constraints, healthcare related support and organisational management structures still provide a number of barriers to managing employment with IBD. However, with joined-up working from relevant stakeholders ensuring positive employment relationships, supportive organisational cultures, improved diagnosis and awareness of IBD and the appropriate information provided to employees and employers, how IBD is managed in the workplace can be easily improved so that individuals with IBD can enter, remain and ensure productivity in the workplace.

Chapter 9 Recommendations

The following recommendations are organised by stakeholder group, offering targeted suggestions for improving the experiences of those with IBD at work.

The Individual:

- **Seek help and equip yourself with information:** doing this will help you to understand and manage your condition both socially and in the workplace. By increasing your understanding of IBD you will be able to help yourself and raise the awareness of IBD for others by passing on information. Crohn's and Colitis UK (<http://www.crohnsandcolitis.org.uk/>) provide a comprehensive website and information sheets about the nature of IBD, medications, support groups and information for both employees and employers on managing IBD at work.
- **Understand how the condition affects you and your work:** as a result of the individual nature of IBD with a greater understanding of what can trigger your IBD, you will become more aware of what foods or stressful situations to avoid. Additionally, becoming more aware of the symptoms that signify a relapse will help you to plan ahead and to seek help from healthcare professionals.
- **Having the confidence to disclose:** being confident enough to disclose to your line manager/employers/co-workers about your IBD means that adjustments can be made in the workplace that will enable you to stay in employment in a way that is suitable for both you and your employer. This can also reduce any stress or anxieties that you have about how you will cope in the workplace.
- **Learn self-management techniques:** by finding ways that you can self-manage your IBD, you can improve your confidence in managing the disorder and how it will affect your employment.

The Employer:

- **Improve line management:** employers have a responsibility to ensure that appropriate line management is undertaken in the workplace. This involves ensuring that line managers are good at people management instead of focussing solely on task management, and develop a positive employment relationship involving honest, open and trustworthy communication between the employer and employee, where the employee feels they are able to disclose to their line manager and ask for any reasonable adjustments that are needed.
- **Line manager training:** in addition to ensuring a positive employer-employee relationship, line managers should receive training in people management, how to manage long-term health conditions in the workplace and how to conduct return to

work and sickness absence interviews. Line managers should also be trained to understand and highlight to their employees the role that occupational health can have in aiding both the employee and employer manage the condition and the role of implementing the recommended reasonable adjustments.

- **Provision of functional adjustments:** employees should be able to provide adequate access to separate toilet facilities for those with IBD so that they have the privacy they need when at work. This is especially important as whether there are suitable toilet facilities is a major source of stress for individuals with experience of IBD.
- **Provision of flexible working:** as IBD is a fluctuating condition having flexibility in both working hours and work location can help individuals maintain employment even if they are symptomatic. Flexible working may include flexible start and end times, shorter working hours, working from home (especially when experiencing a flare). Allowing flexi-time for hospital appointments (which are frequent and regular) is also recommended.
- **Develop a supportive culture:** this is important so employees feel that they are able to disclose their IBD to both their line manager and co-workers without the fear of discrimination. Organisations need to develop a culture where there is no stigma in disclosing long-term chronic conditions, such as IBD.
- **Increased awareness and availability of Occupational Health:** this is a service that is useful for both the employee and the employer. The occupational health service should be advertised so that employees know that they may self-refer to ask for help/advice, discuss reasonable adjustments that will help the employee maintain in employment. However, the role of occupational health for helping the employer must also be highlighted so they are aware of extra help and advice they can receive about helping an employee with IBD.
- **HR to understand their role in implementing policies and practices effectively:** as an employer it is important to understand your responsibility to people with long-term conditions. This includes the provision of reasonable adjustments to allow individuals with IBD to do their role. Government guidelines can be found here: <https://www.gov.uk/government/publications/employing-disabled-people-and-people-with-health-conditions/employing-disabled-people-and-people-with-health-conditions>
- **Introduce Employee Assistance Programmes:** these will provide employees with another source of support and confidential advice, and help with both the physical and mental health wellbeing of the employee. Employers can also ring EAPs for any help/support they may need.
- **Understanding physical and mental health effects:** this is important as employees with IBD may suffer from other side effects, such as anxiety, depression

and fatigue. It is important that these are recognised and adjusted for also.

Healthcare Professionals:

- **Information provision at diagnosis:** as well as focussing on medical information when an individual is diagnosed, it is important to provide any other information regarding IBD, such as how to cope with physical and mental health side effects, coping with stress and adapting to the diagnosis.
- **Discussing an individual's work life:** many people with IBD will want to work and the benefits of work (social, psychological and financial) should not be underestimated. Managing the symptoms of IBD at work should be considered. Returning to work or job retention should be seen as a clinical outcome of the care provided to patients.
- **Improving the speed to receiving specialist support:** this would help with the speed of diagnosis for individuals, reducing any anxiety that individuals may have and speeding up the use of medication to aid IBD symptoms.
- **Provision of more specialist nurses:** specialist nurses were seen as crucial in supporting individuals with IBD when they were experiencing a flare, had problems with medication, when they had any questions or anxieties that needed answering, or when they were unable to contact their consultant. Ensuring that all IBD patients have an allocated specialist nurse is seen as very beneficial to improving the management of IBD. Additionally, ensuring that this care is as close to the patient's home as possible is also important in the provision of care.
- **Consideration of other symptoms:** such as pain, fatigue and stress etc. which could affect an individual's quality of life and employment status should also be reviewed and actively treated.
- **GPs:** should make quicker referrals to specialists for possible IBD patients.
- **IBD Standards:** the national standards for the care of IBD patients should be used and implemented effectively (www.ibdstandards.org).
- **Co-ordinated access to key professionals:** this should occur so that important issues regarding treatment decisions without having any system-impact delays (for example discussing surgery meetings with both a surgeon and gastroenterologist present) to reduce the occasions where treatment decisions are not made by specialists in isolation.
- **Early identification of most challenging patients:** and early steering to specialist IBD centres where the chances of achieving long-term remission are higher. This will also reduce costs of hospitalisation and expensive drug treatments.

- **Shared decision-making:** clinicians should be encouraged to work together with patients to select test, treatments, management or support packages that are based on clinical evidence and the patient's informed preferences. Shared decision-making could help to provide support to and enable effective discussions with employers about the treatment of the sometimes embarrassing nature of IBD and how this could affect their employment as through the process obstacles or enablers to remaining at work can be sensitively explored.

Patient Charities:

- **Increase the dissemination of information to raise awareness among employers and other employees:** distributing information about IBD, and the impact that it can have for individuals, to raise its awareness in the workplace can help reduce any stigma related to IBD, and provide methods by which employers and co-workers can help an individual with IBD at work. Charities can also find new ways to disseminate such information, including sending resources directly to employers, provide roadshows and engage with the media so that they report correct facts.
- **Continue raising the awareness of IBD:** alongside clinicians, academics, patient group representatives and wider stakeholders, patient charities should continue to hold debated on issues that matter.

Policy Makers:

- **Access to Work:** increased awareness of Access to Work programme, created to support employers who need to make adjustments for individuals with IBD in the workplace, is necessary. Access to Work is a government funded scheme to help people with a disability overcome practical difficulties that may stop them from working. It is available for part-time or full-time workers and for those who are self-employed or unemployed and looking for work. It also applies whether you are on a permanent or a temporary contract but does not cover voluntary work. Besides possible help towards installation of toilet facilities, Access to Work can help in a number of ways such as with the additional costs of travel to work if you are unable to use public transport. This is especially important for SMEs.
(https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/307036/employer-guide-atw-dwpf03a.pdf).
- **Fit for Work Service:** should address the specific needs of people with IBD (i.e. fatigue, affect of stress, etc.) in the return to work plans. This also argued that GPs should enforce the fit note (see below) with an understanding of the fluctuating nature of symptoms, including making full use of the narrative section of the form which allows recommendations for reasonable adjustments in the workplace.
- **Fit note:** ensuring that the guidance regarding the adjustments that GPs provide on fit notes is more detailed and specific so that employers have a clearer message about the adjustments they need to implement in the workplace.

- **Increase the number of specialist IBD centres:** for biological treatment to be most effective and to reduce costs of IBD treatment, IBD patients have to be caught at the right time. Thus by speeding up the process of specialist treatment, costs will be reduced and the chances of long-term remission are improved.
- **Eligibility criteria for state benefits:** individuals with IBD can struggle to meet the criteria for state benefits as IBD is a fluctuating condition, and consequently does not fit the customary model of a deteriorating long-term condition, or a steady state condition. Thus the criteria could be amended to include fluctuating conditions.
- **Further investment in IBD specialist nurse posts:** as specialist nurses were identified as being vital to patients with IBD, this is especially important as specialist nurses are under threat in some areas of the country.
- **Cross departmental strategy:** for tackling chronic diseases such as IBD should be created.
- **Better understanding and recognition of urgency as a symptom and the nature of fatigue:** the assessment of continence in state benefits often does not recognise the impact of urgency of needing the facilities and the limitations that this can impose on daily life (travel restrictions, fear of public transport, planning a day/work around the availability of public toilets). There is a need for some system to increase their recognition of the nature of fluctuating conditions and to allow patients to park urgently at crucial moments (blue badge or equivalent) and the need for improved provision of public toilets, or toilets that are accessible to the public (perhaps through an extensive community toilets scheme). There is also a need to recognise that fatigue is associated with IBD, and that systems need to be in place to accommodate this.

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Appendix 1 Recruitment advert

Research participants wanted

The Centre for Workforce Effectiveness at The Work Foundation is conducting a new piece of research building on the previous survey conducted by Crohn's and Colitis UK looking at the effects of Crohn's and Ulcerative Colitis on employment. The aim of the research is to discuss enablers and barriers to employment as a result of Crohn's and Colitis from the employee and employer perspective. Researchers at The Work Foundation would like to conduct telephone interviews with individuals with a diagnosis of Crohn's or Colitis about their experiences of work. We would also like to hear from any employers who have any experience of working alongside individuals with Crohn's and Ulcerative Colitis to discuss the issues from your perspective. The research will be used to develop recommendations for a range of stakeholders to enable increased opportunities for those with Crohn's and Colitis to access and remain in employment. The work will also be used to influence policy to tackle the barriers to work that people with Crohn's and Colitis face.

We would like to interview anyone with a diagnosis of Crohn's Disease or Ulcerative Colitis, who is currently in work, or who has worked previously. We would also like to hear from any employers wishing to offer their perspective.

If you would like more information about the research, or would like to register your interest for an interview, please contact The Work Foundation at...

Appendix 2 Information sheet

IBD and Employment

We would like to invite you to participate in this research project conducted by the Centre for Workforce Effectiveness at The Work Foundation. Before you decide whether you would like to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully.

What is the purpose of this study?

The current study is being undertaken to identify the main barriers to employment for people with IBD, and to explore why IBD sufferers have made certain life decisions in relation to employment and the implications of these decisions for both their wellbeing and employment outcomes. The research also aims to explore examples of interventions which have aided employment and employee wellbeing. The research also explores the management of IBD and employment from the employer's perspective, with the aim of developing recommendations to improve the management of IBD and employment.

Why have I been chosen to participate?

You have been invited to participate after having responded to an advert in the National Crohn's and Colitis UK newsletter, requesting individuals who are currently in employment or who have been employed and have IBD, or are employers who employ somebody with IBD.

What will happen if I take part?

If you choose to take part, you will be asked to complete an interview that should take around 30 – 40 minutes, and may be recorded subject to your permission. Questions asked will relate to your experiences of employment with IBD and how this affected your work decisions and wellbeing. Interviews will take place over the telephone at a time that is most convenient for you.

You should only participate if you want to. Choosing not to take part will not disadvantage you in anyway, and you are free to withdraw from the study at any time, without giving any reasons.

What are the benefits of taking part?

The aim of the research is to gain a greater understanding of the experiences of employment when suffering from IBD, what interventions were put in place, and what the implications of

these experiences were for your employment outcomes and wellbeing. The research also aims to develop how the management of IBD in the workplace can be improved. By participating in the research you will be contributing to research to develop recommendations for improving the wellbeing and employment outcomes of individuals who suffer with IBD.

What are the risks of taking part?

Participating in the research will take up to 40 minutes of your time, but we will do our best to minimise any inconvenience to you. You are free to terminate participation at any time. If you have any concerns regarding the research, you can contact the project lead to discuss any questions you may have.

What are the arrangements for ensuring anonymity and confidentiality?

All the research data collected will be anonymous, and completed interview data will not be shown to any other participant in the research. The data will be stored securely without any information that could identify an individual participant, and will only be accessed by researchers involved in the study. Any information which could personally identify an individual will not be used in any reports or sample analyses based on this study, and you will not be referred to by name in the reporting of the results. Participants have the right to withdraw their data anytime before publication. If you withdraw two weeks after your participation your data will be destroyed, however, if you withdraw after this time, your data will still be used.

Contact for further information:

The project manager of this research is Dr Zofia Bajorek, a researcher at the Centre for Workforce Effectiveness at The Work Foundation. The research will also be conducted by Kate Summers, Research Assistant at the Centre for Workforce Effectiveness, The Work Foundation. Should you have any concerns resulting from your participation in the study, please contact Zofia by e-mail ...

If you have any concerns or complaints you can contact Geraint Johnes (Director of the Work Foundation) at ...

Appendix 3 Employee interview schedule

General Introduction:

- What age were you when you were diagnosed with IBD and how did the diagnosis have an impact on any education or employment decisions you made?
- What was the gap between the onset of symptoms and diagnosis? Who did you ask for help?
- Did medics ask about your education/employment status or aspirations at the time of diagnosis? In what way was help provided? (If not, did you ask about employment, or consider that your employment outcomes at this stage?)
- What IBD symptoms do you have now? How have they changed since diagnosis?
- How did the diagnosis affect your general health and happiness and your attitude towards future plans? Life opportunities?
- What specialist help did you receive at diagnosis in terms of managing your condition? Did this help relate to education and employment decisions at all and if so how?
- In what ways do you think information services could be improved?

Current Employment:

- Can you describe to me why you chose your current employment?
- How much of an impact was your IBD in making this decision? What other factors also affected this decision?
- What is your current working pattern and is this suitable for you? Why(not)? (full-time, part-time, flexible)
- How do you manage your IBD in your current employment?
- Have you disclosed your IBD and why (not)?
- How much say do you have in the adjustments/flexibility your organisation offers?
- What has your line manager and other co-workers done to help you?

- How well does your role match the skills that you can offer your organisation? Do you feel valued?
- Are you aware of any other services that your organisation could provide to help you remain at work with IBD?
- From your experiences in your current job, how do you think the management of IBD in employment can be improved?

Previous Employment:

- In what ways has your experience with your current employer differed to previous employers?
- In what way do you think employer or organisational awareness of IBD has changed, and how has that affected your employment decisions and wellbeing?
- How has your own awareness of IBD and symptom management affected your employment decisions?
- What specialist help/advice have you received in relation to IBD and employment, and in your opinion how can this be improved?

Future Plans:

- In what ways do you think your IBD will affect your future plans? What other factors will affect employment decisions, and how important are these in relation to IBD?
- What concerns, if any, do you have about future employment plans and your IBD? How do you think employers or other organisations can help with this?
- How optimistic do you feel about remaining in employment in the future?
- What do you think the long-term impact of your current past and current experiences will be?

Conclusions:

- Have you any other comments regarding IBD and employment and wellbeing that you would like to discuss that you feel we have not covered?

Appendix 4 Employer interview schedule

- Can you describe to me the organisational policies that you have in place for individuals with Long-term Conditions and sickness absence?
- What are the organisations practices for encouraging disclosure, and how does an employees disclosure affect management and employment decisions, if at all.
- How have you managed, or how are you managing those with IBD in your workplace?
- What adjustments/interventions have been made and how did these changes come about?
- Have you ever had to decline implementing an adjustment and why?
- What do you think the main barriers to employment for people with IBD are, and how do you think that organisational/employer support given to those with IBD at work can be improved?
- What is the role of HR/OH/the employer and the employee in achieving changes to the management of IBD in the workplace?

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The Work Foundation transforms people's experience of work and the labour market through high quality applied research that empowers individuals and influences public policies and organisational practices. Through its rigorous research programmes targeting organisations, cities, regions and economies, The Work Foundation is a leading provider of research-based analysis, knowledge exchange and policy advice in the UK and beyond. The Work Foundation is part of Lancaster University – an alliance that enables both organisations to further enhance their impact.

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