The role of prospection as a function of subjective wellbeing in people diagnosed with Inflammatory Bowel Disease.

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Lay Summary

Background

Even though we all know that things have a way of not always turning out as we imagined, we continue to look ahead and picture future possibilities. This uniquely human ability is important to our psychological health. However, like with most things, it is not immune to glitches and malfunctions. These can put our emotional wellbeing at risk. Studies have shown that negative emotional states, such as anxiety, depression or even suicidality, are related to a disruption to one's ability to look ahead. For example, becoming preoccupied with unpleasant events that might happen in the future and/or struggling to think about the positive ones. This pattern of disruption has been repeatedly shown across many different groups of people. However, some groups have been neglected from such investigations, creating a gap in our knowledge, and understanding.

Onset of a chronic illness is a good example of how our ability to picture future possibilities may be challenged. It seems probable that no one anticipates a physical illness becoming part of their 'idealised' personal future, but many of us will face exactly this scenario, if are not already, especially considering that the number of people with long- term physical health conditions (LTCs) is predicted to grow exponentially (DOH, 2012). In such circumstances, a person's ability to think about their future may be challenged not once, but continually throughout the disease course, especially if that course is unpredictable and largely unknown. However, despite undeniable challenges that a chronic illness brings to one's life, many manage to maintain their psychological health or even find happiness and growth in the most trying of times. This laid the foundations for the development of this thesis, of which the central focus became understanding the role of future-directed thinking in illness and seeing if the way in which people diagnosed with chronic physical health condition think about their future is linked to their wellbeing.

In short, the present thesis builds upon what is already known in relation to future-directed thinking and psychological wellbeing and considers this in a novel context. The work was constructed around Inflammatory Bowel Disease (IBD), a chronic condition of the gut which presents a unique challenge to the imagined life trajectory. The disease is most diagnosed in young adulthood, varies in severity and often has an unpredictable course. Currently, there is no cure and various medical treatments aim to reduce burdensome symptoms. However, relatively high treatment failure rates mean that many patients will undergo surgical interventions with potentially permanent consequences, sometimes even without a promise of escaping the disease 'flaring-up' again. Therefore, a comprehensive review of existing studies was conducted focusing on the postoperative levels of psychological wellbeing in people diagnosed with IBD. Then, I conducted a new study to examine the impact of future-directed thinking on individual levels of wellbeing in people who are diagnosed with IBD.

Taken together, I hoped that the findings would further our understanding of psychological wellbeing and future-directed thinking in people diagnosed with long-term physical health conditions. I also anticipated that this would create new opportunities for prevention and treatment strategies, and would offer suggestions for future studies.

Comprehensive Review of Existing Studies

This review focused on levels of psychological wellbeing following surgical interventions for IBD. These interventions are common despite often being considered a last resort. They can lead to irreversible changes and are associated with risks. Despite the fact that the prospect of surgery is the most prevalent concern amongst people diagnosed with IBD, there is currently no clear understanding regarding how these procedures impact wellbeing of people who undergo them.

Using a comprehensive search strategy this review was able to identify nine published papers to answer our question. The findings were taken together, and each study was also assessed individually in relation to the quality of its methods. We provided detailed description of patterns found across the studies.

Overall, findings were mixed as it was not clear whether surgical interventions are related to an improvement or deterioration in psychological health nor if these effects are short-lived. Therefore, we still do not know for sure if surgical interventions for IBD impact people's wellbeing. The quality of the studies was modest therefore we propose that future studies need to use higher-quality designs with consistent incorporation of better psychological measures to enable future reviews to build on our findings.

My own Study

This study aimed to investigate how adults of working-age who are diagnosed with IBD think about their future whilst examining its connection with psychological health.

Eighty-eight adults diagnosed with IBD who took part in the study, were asked to complete various questionnaires related to their psychological health and to think aloud about what they *do* and *do not* look forward to at three different future time periods.

In terms of our analytical strategy, we examined the relationship between levels of positive and negative future expectancies and psychological wellbeing, as well as developed a novel methodology to investigate the content of future-directed thoughts.

Broadly speaking, people had more positive than negative thoughts about the future. Well-being was not linked to having more positive thoughts or fewer negative thoughts. It was, however, related to having fewer thoughts (either positive or negative) that were related to IBD and having more thoughts about other things in life. Therefore, people with higher well-being tend to think about good and bad things in the future more in terms of a variety of things in life whereas those with lower well-being were more focused on how their future would relate to IBD (again this was true for positive and negative things in the future).

Integration, impact and dissemination

In summary, both the comprehensive review of existing studies and my own study aimed to examine psychological wellbeing in people who are chronically ill. Firstly, the review showed that we are currently unable to confidently describe the impact surgical interventions for IBD have on people. As such, it identified an important area for future investigations. Secondly, the empirical study showed that wellbeing was not linked to the number of future-directed thoughts but instead was related to having fewer thoughts that were related to IBD and more thoughts about other things in life. Therefore, the study suggested that individuals who are ‘absorbed’ with their IBD are at risk of psychological distress which offers new therapeutic avenues. It may prove possible to mitigate such risk by tailoring assessment/consultation appointments as well as investing in therapeutic strategies that aim to encourage people to think about their futures more broadly and detach from the disease more easily.

The current thesis raises awareness of mental health and wellbeing within the IBD community, an area that some argue has been largely neglected. We hope it opens a conversation highlighting to both clinical and scientific communities, exciting new opportunities. The current research advocates for closer collaboration between physical and psychological care professionals, which might enable the development of more consistent methods of assessing the broad needs of people diagnosed with IBD and the development of bespoke therapeutic spaces.

Lastly, it is planned that the results will be disseminated to all relevant stakeholders using various methods to maximise engagement with an audience and increase our reach. This might include attendance and/or poster presentations at the IBD UK Congress, publications in relevant journals and making results alongside key discussions points available through social media accounts of two organisations we have closely collaborated with, namely, ‘Crohn’s & Colitis UK’ and ‘GetYourBellyOut’.

Psychological functioning in working-age adults, post-surgical interventions for Inflammatory Bowel Disease: A systematic review

Abstract

The prospect of surgery is the most prevalent concern amongst people diagnosed with Inflammatory Bowel Disease (IBD). The surgical interventions are usually considered a final option to alleviate burdensome symptoms as they can lead to irreversible changes and are associated with risks. Yet, it is estimated that a significant proportion of people diagnosed with IBD will undergo surgery over the course of their disease possibly increasing risk of psychological distress. However, the exact impact of surgical interventions for IBD on psychological functioning is largely unknown as extensive reviews have not been conducted.

This systematic review aims to consolidate current evidence relating to the impact of surgical interventions on subjective levels of wellbeing in adults diagnosed with IBD. Using a pre-determined searched strategy, nine studies met eligibility criteria. Relevant data were extracted from each paper, a quality assessment was carried out and narrative synthesis used to present findings.

Overall, evidence presented in this review has been mixed and failed to offer convincing narrative relating to the impact of IBD-related surgical interventions on psychological wellbeing. The review identified significant gap in the evidence-base and turned attention to new research opportunities.

Keywords: *Review, Inflammatory Bowel Disease, Crohn's Disease, Colitis, psychological wellbeing, surgery, ostomy, IPAA, outcome*

Introduction

Inflammatory Bowel Disease (IBD) is a chronic disease of the gut of varying severity and somewhat unpredictable pattern (Farmer et al., 1975; Louis et al, 2001). It comprises three main conditions, namely, Crohn's Disease (CD), Ulcerative Colitis (UC) and Indeterminate Colitis (IC) (Flynn & Eisenstein, 2019). Its frequently associated symptoms include persistent abdominal pain, diarrhoea, bleeding, nausea, and fatigue (Yangyang & Rodrigez, 2017) with differential diagnosis often presenting a challenge (Gecse & Vermeire, 2018). Additionally, symptoms associated with IBD are not always confined to the gut only. For example, extraintestinal symptoms such as inflammation of the skin and/or joints can intensify IBD-related burden (Vavricka et al., 2015). IBD is most diagnosed between age of 15 and 40 (Mikocka-Walus, 20018), and it is estimated that there are over five million people currently living with IBD around the world (Mikocka-Walus, 2018). Overall, crude point prevalence estimates for the UK in 2018 were 725 per 100 000 people (Pasvol et al., 2020).

The ultimate cause of IBD remains largely unknown (De Souza et al., 2017) but several risk factors have been identified, namely, genetics (Katakure et al., 2013) and environmental factors, such as frequent use of antibiotics (Koloski, et al., 2008), diet changes (Amre et al., 2007; Sakamoto et al., 2005), smoking and oral contraceptives (Bernstein, 2017; Koloski et al., 2008). IBD remains incurable and the goal of existing treatment efforts is an 'optimal' symptom management (Abraham, 2015). However, treatment failure, unacceptable side effects and the possibility of an ongoing disease activity, despite medical interventions, are common (Peyrin-Biroulet et al., 2016). Furthermore, IBD is associated with relatively high rates of hospitalisation and/or surgeries, as well as disability amongst sufferers (Bernstein et al., 2012; Cosnes et al., 2022; Fiorino et al., 2017; Peyrin et al., 2010), which contribute to substantial direct and indirect costs (Bassi et al., 2004; Beard et al., 2020).

However, to fully appreciate and understand the impact IBD has on patients we cannot be restricted to the realm of physical health only. It is well-documented that living with IBD and adhering to medical regimes can be burdensome (Banez & Cunningham, 2003). Aspects of IBD symptomology can be considered embarrassing and are stigmatised across many societies (Lenti et al., 2002; Polak et al., 2019). The symptoms alongside surgical interventions can negatively impact people's sexual functioning and satisfaction with sex (Mantzouranis et al., 2015). Additionally, diet restrictions and the unpredictability of symptoms often limits social and employment participation (Kaplan, 2015), consequently contributing to systematically reported lower quality of life amongst people diagnosed with IBD (Bernklev et al., 2005). The psychiatric co-morbidity, namely, prevalence of anxiety and depression, is significantly higher in people with IBD compared to the non-clinical samples (Mikocka-Walus et al., 2016; Neuendorf et al., 2016). Yet, the extent to which this increase is driven by disease activity remains unclear. On the other hand, higher levels of depression and anxiety are associated with more aggressive disease course (Gao et al., 2021; Kochar et al., 2018) as well as decreased effectiveness of some medical treatments (Graff et al., 2009), highlighting the importance of addressing the psychological needs within physical health context.

Amongst people diagnosed with IBD, surgical interventions are the most prevalent concern and are often considered a final option (Dibley et al., 2018; Stjernman et al., 2010). Broadly speaking, surgery may be recommended in relation to medication failure (NICE, 2019). It can occur under an array of circumstances, stretching from an elective and planned procedure to a life-threatening emergency. In

Europe, cumulative surgery rates in CD are estimated between 30 – 50% after 5 – 10 years from diagnosis and risk of surgery in UC is around 10% (Burisch et al., 2013). Most common surgical interventions for UC include proctocolectomy (i.e., removal of both colon and rectum), which is accompanied by curative narrative (Hwang & Yu, 2019), whereas for CD surgical options such as strictureplasty and/or (procto)colectomy are considered elective (Bemelman et al., 2018). For supplementary overview of these procedures, please refer to Table 1. Of note, additional procedures may be required to attend to fistulas, abscesses, intestinal obstructions, perforations of intestinal wall and/or a life-threatening emergency such as a toxic megacolon (M'Koma, 2022).

Table 1.

A Simplified Overview of Common Surgical Procedures in IBD.

Type of IBD	Surgical Intervention(s)[1]
Ulcerative Colitis	- **A Proctocolectomy**: removal of large intestine o Proctocolectomy with ileal pouch-anal anastomosis (IPAA): removal of large intestine with an internal pouch o Proctocolectomy with end ileostomy: removal of large intestine and anus with creation of an external ostomy
Crohn's Disease	- **A Strictureplasty:** a procedure fixing narrowing of a section of intestine - **A Proctocolectomy:** removal of the colon and rectum (see above) - **A Colectomy:** removal of the colon

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[1] Information collated from information published on Crohn's & Colitis Foundation (2022) website: https://www.crohnscolitisfoundation.org/; Accessed 11th of May, 2022

Indeterminate Colitis	People with IC are often treated in similar fashion to those who have been diagnosed with UC (Tremaine, 2011).

In relation to evaluating surgical interventions for IBD, studies have considered various avenues for example, factors reducing the actual need for surgery (Chatu et al., 2014), preoperative optimisation (Zangenberg et al., 2017), surgical challenges and optimal technique management (Wu et al., 2010), mortality risks and postoperative complications (Law et al., 2018; Singh et al., 2015; Subramanian et al., 2006) as well as recovery time and cost-effectiveness (Buskens et al., 2014; Pillai et al., 2017). Furthermore, qualitative studies have offered some insight into both expected and perhaps somewhat unexpected experiences of surgery. For example, a study by Petersen and Carlsson (2021) discussed pragmatic and emotional challenges faced by people living with stoma, including a negative relationship with one's own body, whereas a study by Rapport et al., (2019) offered a wider narrative around sense of 'surprise' and 'relief' experienced by patients following IBD surgery and associated decrease in symptoms. However, systematic reviews concerning wider postoperative outcomes in IBD, have been somewhat fixated with the concept of health- related quality of life and functional outcomes (Baczyk et al., 2017; Baker et al., 2020, Umanskiy & Fichera, 2010). Omission of standardised and more comprehensive psychological outcome metrics seems surprising, if not shocking, given the body of evidence tentatively linking IBD to body image dissatisfaction (Beese et al., 2019) and/or decreased confidence and self-esteem (Taft et al., 2009) alongside a body of evidence suggesting that psychological distress is associated with delayed wound healing and an increased risk of postoperative infections in abdominal surgeries (Akortiakuma et al, 2022).

The concept of ‘psychological wellbeing’ is complex and multifaceted (MacLeod 2017). It represents a careful balance between the absence of debilitating states like depression, anxiety or suffering and the presence of ‘positive’ ones such as purpose, flourishing, joy (Adler er al., 2017). Broadly speaking, it encapsulates three different aspects such as: life evaluation (i.e., cognitive judgement about ‘goodness’ of one’s life) as well as hedonistic (i.e., feelings or moods) and eudemonic wellbeing (i.e., meaning and purpose of one’s life) (Adler er al., 2017; Diner et al., 1985; 1999; Kahneman et al., 1999). Therefore, psychological wellbeing is a core feature of mental health which can be measured using various tools, stretching from a single item measure to more complex multidimensional scales and indexes (Adler er al., 2017; Ryff et al., 2004; Watson et al., 1985). Of note, some dimensions of psychological wellbeing such as ‘life satisfaction’ are often incorporated within quality-of-life measures, consequently broadening the construct further by including additional aspects like physical symptoms, interference with daily activities and perceived disability (Salvador-Carulla et al., 2014). Therefore, the fact that ‘psychological wellbeing’ comprises of numerous constructs which to a degree are interrelated, presents a challenge for researchers (Trudel-Fitzgerald et al., 2019).

Additionally, psychological wellbeing and physical health are closely related (Steptoe et al., 2015; Trudel-Fitzgerald et al., 2019). For example, studies have shown that rates of depression increase in a significant proportion of people following diagnosis of various health conditions such as, coronary heart disease, stroke and/or diabetes (Hedayati et al., 2010; Meijer at al., 2011). Whereas higher levels of stress and/or depression have been linked to much reduced life expectancy, for example in people with coronary heart disease (Steptoe et al., 2015). On the other hand, individuals with higher levels of psychological wellbeing are more likely to enjoy better general physical health and stronger immune systems, tend to make healthier life- style choices, are predicted to live longer, recover more quickly from surgery and are less likely to report somatic symptoms (Adler at al., 2017; Dillon et al.,1985; Froh et al., 2009; Lyubomirsky et al., 2005; Segestrom, 2007). This highlights the interlinked nature of both physical and psychological health and importance of investigative efforts to consider both in equal measure.

Furthermore, supporters of ‘positive psychology’ argue that the secret to psychological wellbeing is rooted in one’s ability to imagine future possibilities (Roepke & Seligman, 2016; Seligman, 2011; 2002; Seligman & Csikszentmihalyi, 2014). In this orientation, depression is not considered to be a reaction to past/present ‘stressors’ (Beck, 1964) but rather a result of a distorted projection of what lies ahead (Seligman, 2011). Research has shown that different facets of psychological wellbeing may be related to aspects of future-directed thinking (Bronk & Mitchell, 2022; MacLeod 2017). For example, studies have shown that prospection can promote hope, resilience, and grit (MacLeod 2017). Prospective cognitions are also likely to encourage prosocial behaviour and/or goal driven behaviours as well as play a role in facilitation of ‘sense of purpose’ (Bronk et al., 2019; Bryant & Ellard, 2015; Damon et al., 2003; Osman 2014). This may be considered a helpful lens, especially when considering psychological wellbeing in illness.

Finally, at present, limited guidance in relation to pre-/post- operative psychological care in IBD exists which is somewhat ‘behind’ such guidance being already in place for other physical health conditions (IBD UK 2019; NICE 2019; 2021). Therefore, the aim of this systematic review was to determine the impact of surgical interventions on levels of broadly understood psychological functioning in adults diagnosed with IBD. To the best of our knowledge this is the first review of this kind.

Method

This systematic review was registered in the International Prospective Register of Systematic Reviews (PROSPERO; CRD42022315876) and followed guidance outlined in the Preferred Reporting Items for Systematic Review and Meta-analysis Protocols (PRISMA – P) and the PRISMA statement (Moher et al., 2009; 2016).

To identify relevant studies, four main categories were developed within the review search strategy (Munn et al., 2008; Schardt e al., 2007). Within each category, the wildcard asterisks and the Boolean operator ‘OR’ were used whereas the Boolean operator ‘AND’ was used to join categories together. The operator ‘NOT’ was used to limit number of irrelevant studies being identified. The final search strategy was achieved after consultations with the relevant Information Services Consultant and thesis supervisor (See Table 2). Of note, the current research takes an inclusive approach in relation to the construct of ‘psychological wellbeing’ ensuring that all facets are being considered.

Table 2.

Formulation of the Review Search Strategy.

1. Terms relating to Inflammatory Bowel Disease (IBD)	"Ibd" OR "inflammatory bowel disease" OR "CD" OR crohn* OR "UC" OR "ulcerative colitis" OR colitis OR "IC"
2. Terms linked to surgical interventions	stoma OR ostomy OR colostomy OR ileostomy OR proctocolectomy OR pouch OR strictureplasty OR stricturoplasty OR colectomy OR "IPAA" OR resection OR “postoperative”
3. Terms to capture various aspects of psychological functioning	depress* OR anxiety OR "psychiatric condition" OR "psychiatric conditions" OR "mental illness" OR "mental distress" OR "mental disorder" OR "mental health" OR "mental ill-health" OR "emotion*" OR wellbeing OR "well-being" OR "psychological impact" OR "psychological outcome" OR flourishing OR happiness OR "stress" OR "distress" OR acceptance OR confidence OR "self-esteem" OR "self-image" OR "self" OR "identity" OR satisfaction OR "body image" OR coping OR adjustment OR readjustment OR "psychological functioning" OR trauma OR PTSD OR "sexual satisfaction" OR "sex life" OR "sexual health" OR "quality of life" OR "QOL" OR "life satisfaction"
4. Terms to restrict number of irrelevant publications	‘complications" OR "indications" OR "recurrence" OR "relapse"

Subsequently, the Boolean phrase combining all search terms was used to systematically search the PsychArticles, PsychTests, Psychinfo, PubMed databases.

The search was carried out on the 14th of March 2022. Additionally, the primary reviewer conducted supplementary search on three recent reviews conducted in related areas (Baczyk et al., 2017; Baker et al., 2020, Umanskiy & Fichera, 2010) as well as publications published by the prominent researchers in the field to identify further articles for inclusion.

The search was limited to the English-language and peer-reviewed publications for pragmatic reasons. We restricted our search to publications examining the 'working-age' adult population for several reasons. Firstly, guided by a lifespan perspective pertaining to the unique relationship between levels of physical activity and mental health across different life-stages, it seems possible that differential temporal effects exist (Hyde et al., 2013). Secondly, adulthood introduces several unique areas which cannot be generalised across to other life-stages. For example, areas such as, employment and earnings potential, long-term relationships, intimacy, family planning and/or childbearing might not only be linked to levels of subjective wellbeing in adulthood, but more importantly could be intimately connected and affected by the experience of IBD (Malmborg et al., 2022). Thirdly, holding in mind feasibility argument and aspiration to strengthen the connection between this review and the empirical study the restriction was deemed necessary. We also excluded publications related to the instrument validation, articles not exclusively focusing on IBD as the primary health condition and those that lacked surgical focus or used indirect measures to ascertain levels of psychological wellbeing. For example, studies that used antidepressant use as a measure of levels of anxiety and/or depression or presence/absence of diagnostic label identified through medical records given possible inaccuracies and misrepresentations. Finally, publications that focused explicitly on functional status and/or quality of life were excluded as this has already been extensively reviewed. For a comprehensive list of eligibility criteria see Table 3.

Table 3.

The Systematic Review Eligibility Criteria.

Inclusion Criteria	**Exclusion Criteria**
• Peer-reviewed papers written fully in English • Studies exclusively concerning established IBD (i.e. CD, UC, IC) • Studies examining any of the following surgical interventions: resection, stoma, ostomy, colostomy, ileostomy, proctocolectomy, pouch, strictureplasty, stricturoplasty, colectomy and "IPAA" • Studies examining any aspect of psychological functioning using validated measures	• Studies in languages other than English • Conference abstracts or any short papers with incomplete data presented • Case reports, case series, or qualitative research • Studies with no original data (i.e. reviews, editorials, opinion papers) • Non-human studies • Studies focusing on populations outside of 'working age' group (i.e. 18 – 64) or studies which samples do not fall within this range • Interventional studies where psychological outcome is not included • Studies using non-validated measures of psychological wellbeing

The search strategy returned 2 148 papers. Initially, the primary reviewer screened all titles and abstracts with a second reviewer independently screening 15% of all returned articles (n = 322) to check the process. The alignment between raters was kappa = 0.61 indicating good agreement between the raters (Landis & Koch, 1977). Disagreements and uncertainties regarding inclusion and exclusion criteria were discussed and negotiated amongst reviewers. Remaining questions were escalated to the thesis supervisor when necessary. If doubts remained, studies were retained until next stage.

Full-text screen for eligibility was also conducted by the primary researcher on 117 papers, with a second reviewer independently screening 10% of these articles (n = 12) to check the process. There were no disagreements about inclusion, but two separate enquires were made in relation to the exact age-ranges of the participants recruited in considered publications (D'ugo et al., 2020; Knowles & Jarrad, 2013). However, these were subsequently excluded from the review as did satisfy eligibility criteria. Finally, mindful of the relatively small number of studies found, further backwards and forwards citation searches were performed to increase inclusivity (O’Mara-Eves et al., 2015), but none did not satisfy eligibility criteria.

Data Extraction

All relevant data were extracted from nine eligible papers independently by the first reviewer with second reviewer extracting data for only a subset of eligible papers for process check (n = 2). The data items followed the outline of the key components defined by PICO - population characteristics, intervention type, comparison (if any) and psychological outcome (Boudin et al., 2010). Other data items included authors, years of publication, country of origin, study design, setting, type of analysis and information required to assess the risk of bias.

The categories were initially piloted with the first two eligible studies independently by the first and second reviewers, and then reviewed by the research supervisor to ensure that no relevant data were missed**.**

Quality and Risk of Bias Assessment

The quality assessment was conducted by the primary researcher with 20% of papers' data being blindly extracted and evaluated by an independent rater, as a quality check of the process. 'QualSyst' tool was utilised for quality assessment of identified papers given its pragmatic focus as well as transparent and easily reproducible methods sensitive to studies of varied designs (Kmet et al., 2004). The quality assessment checklist for quantitative studies consists of 14 items, which are phrased as questions. For example, *'Objective sufficiently described?' or 'Study design evident and appropriate?'*. Each item is scored on a short scale which consists of the following options: 'yes' (i.e., worth 2 points), 'partial' (i.e., worth 1 point), 'no' (i.e., worth 0 points) with scoring manual providing clear instructions. Furthermore, for specific five items included in this tool 'N/A' can be selected, which results in the removal of said item from summary score calculation. The summary score is a function of simple division between total sum and total possible sum adjusted for number of N/As selected multiplied by two. Therefore, all items are equally weighted.

The inter-rater agreement for 'Paper 1' was kappa = 0.76, and for 'Paper 2' was kappa = .66 indicating good agreement between the raters (Landis & Koch, 1977). Disagreements between the review authors over the quality assessment in particular studies were resolved by discussion. Involvement of a third reviewer was not necessary. Studies were not excluded due to methodological flaws but reported in the context of overall study quality.

Data Synthesis

Mindful of the guidance (Centre for Reviews and Dissemination [CRD], 2009; Popay et al., 2006), methodological consideration and challenges (Lisy & Porritt, 2016), as well as existing inadequacies relating to the quality of reporting (Campbell et al., 2016, 2019), a narrative synthesis of the findings was provided. A narrative synthesis, rather than a meta-analysis, was appropriate due to variation in study designs and outcomes of included studies.

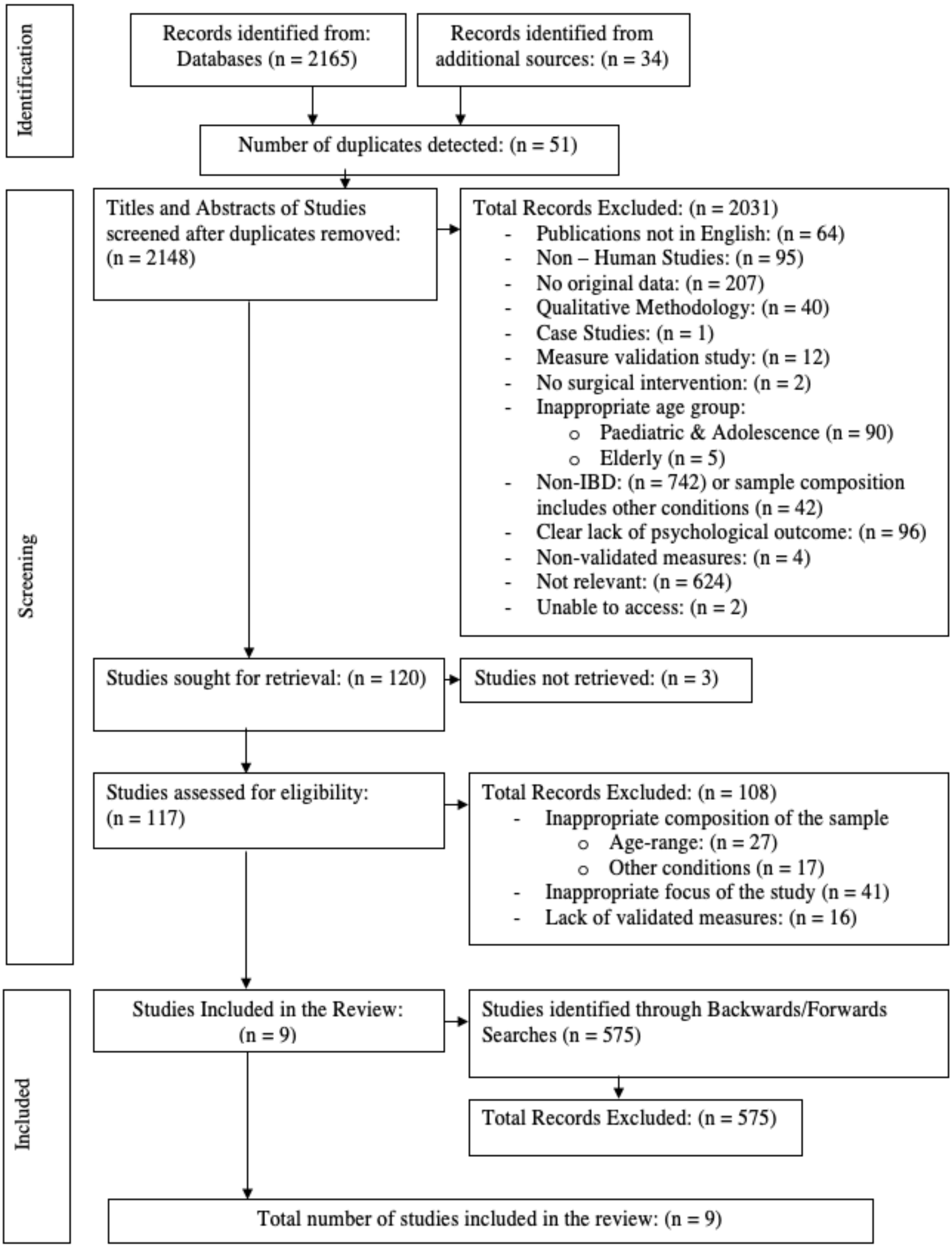
The narrative synthesis followed four elements: theory development, preliminary synthesis of included studies, exploration of relationships between studies and assessment of the robustness of the synthesis (CRD, 2009). The narrative focused on the impact of surgical interventions on psychological functioning of adults diagnosed with Inflammatory Bowel Disease (IBD) and attempted to describe patterns across the results.

Results

In line with PRISMA guidelines (Page et al., 2021), the selection process is detailed in a flowchart (See Figure 1) and the characteristics of selected studies are shown in Table 4. Of note, a high number of papers were excluded owing to the inappropriate sample composition and/or use of non-validated measures to ascertain psychological outcomes.

Figure 1.

PRISMA flowchart Outlining Study Selection Process.



This review consists of nine relevant studies, published between 1999 and 2022 with the majority being conducted in Europe. Two were carried with an English-speaking population, one was carried out with Spanish, Swedish, German, Dutch, Korean and Chinese speakers, respectively, and one study failed to clarify this (Ref. no. 1). All studies resorted to the observational methodology with six studies utilising a cross-sectional strategy and the remaining three a cohort strategy. Sample sizes ranged from 16 to 4 733, median 99, IQR 55 - 182, with eight out of nine studies recruited participants through methods of convenience. Two studies recruited participants who were scheduled to have a surgery, one study invited participants who were seen for a planned medical review, three studies identified eligible participants through hospital databases/medical records, two studies utilised mixed- methods benefiting from an access to hospital database and making connections with the German and the Chinese Crohn's and Colitis Foundations, respectively, with the final one extracting data of subset of patients already engaged with a longitudinal study. None of the studies included in this review considered impact of surgical interventions through wider lens, for example by investigating experience of partners, siblings, parents and/or within context of intimate relationships. The conversion rate, expressed as a percentage of people who were included in the final analysis compared to the total number of people contacted about the study, stretched between 28.2% to 100%.

Of the participant samples, 3,967 were females and 1,716 males, four studies were predominantly female with overall percentage of female participants ranging from 36 to 73. Ages of participants ranged from 18 – 64 years. Other demographic information such as ethnicity, marital status, highest level of educational attainment and/or employment status were inconsistency reported and/or missing preventing meaningful summary.

The total number of adults diagnosed with IBD recruited in the selected studies was 5,683, the majority diagnosed with CD (90.53%) and the rest with UC. Seven studies were able to verify participants' IBD diagnosis through access to their clinical records, one study relied on self-report and one study did not specify this aspect. Disease severity, expressed as a function of disease activity using standardised tools was reported in five studies whereas an estimate of numbers of years participants lived with the condition was reported in eight studies. However, inconsistent use of reporting methods prevented further summary. Other physical health related factors, such as the Body- Mass Index, a smoking status, number of previous surgeries and presence of any physical health co-morbidities, seemed sparse.

In total, six studies focused on the impact of bowel resection surgeries, whereas the remaining three investigated implications of a stoma/ostomy specifically. Of note, six studies clearly specified type of surgical intervention of which three investigated planned interventions with the remaining studies failing to comment about this characteristic. Out of nine studies, seven reported time since IBD-related surgery took place and this ranged from 3 months to over 10 years. Related to this, out of three studies concerning 'stoma/ostomy' specifically, only one (Ref. no. 9) provided further details regarding the type of surgical procedure participants had undergone as well as whether the opening was temporary or permanent. Unfortunately, inconsistent reporting was also noted in relation to within surgery characteristics (i.e., anatomical location and technique used) and/or related factors, for example, surgical skill assessment, number of previous surgeries, contextual factors leading to surgical procedures, length of bowel resection, possible changes to the surgical plans during the procedure and/or post-operative care and physical outcomes/complications, which made it difficult to comment on any possible patterns.

All nine studies used self-reported measures to ascertain psychological outcome. Most studies used between 1 to 2 brief measures to capture postoperative levels of subjective wellbeing. Psychological constructs that were identified included: depression (n = 4), anxiety (n = 2), body image (n = 2), adjustment (n = 1), general wellbeing (n = 1), resilience (n = 1), perceived stigma (n = 1) and self-efficacy (n = 1). Together, nine validated measures were identified and included the Beck Inventory II (BDI-II, Beck et al., 1996), the Psychological General Wellbeing-Index (PGWBI, Spanish Version) (Badia et al., 1996; Dupuy, 1984); the Ostomy Adjustment Scale (OAS, Olbrisch, 1983), the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983), the Body Image Questionnaire (BIQ, Burchon-Schweitzer, 1987); the Resilience Scale (Wangnild & Young, 1983), the Self-Efficacy Scale (Sherer et al., 1982) and the Social Impact Scale (Fife & Wright, 2000). Furthermore, four studies considered the psychological variable as their primary outcome of interest and three studies did not specify this clearly. The remaining two studies explored psychological outcome as a secondary outcome. Finally, four research groups failed to disclose their source(s) of funding but declared no conflicts of interest (Ref. no. 1, 5, 8, 9).

Table 4.

Study Characteristics.

Ref. No.	Author(s) & Date of Publication	Country of Origin	Participants & Sample Size	Age (years)	Disease Duration (years) & Severity	Study Design	Intervention and/or Comparators	Statistical Analysis	Outcome Variable	Findings
1	Tillinger et al., (1999)	Austria, EU	N = 16 (CD), 38% Female	IQR: 21 – 41 Median: 31.5	IQR .07 – 9.57 Median: 3 Severity: CDAI	Pre vs post vs follow-up1 (6 months) vs follow-up2 (24 months	Elective bowel resection	Wilcoxon's signed rank test	BDI-II, unclear cut-off points	BDI: Significantly lower 3 (p < .01), 6 (p < .001) months post-surgery and 24 months (p < .01) but for those in remission only CDAI Significantly lowered post (p <.001), 3 months (p < .001), 6 months (p <.001) and 24 months (p < .02)
2	Casellas et al., (2000)	Spain, EU	N = 119 (CD) 67% Female	Operated CI 32 – 40 Median: 33 Non-operated CI 28 – 35	CI 31 - 55 Median: 34.5 Severity: HBI	A cross-sectional, Operated vs non-operated CD in remission vs Active CD No baseline data.	Segmentary intestinal or colonic resection (N = 26 / 93%) Total proctocolectomy (N = 3 / 7%)	The Mann-Whitney test	PGWBI	PGWBI No difference between operated vs non-operated (remission) (p > .05) Both higher than active CD (P < .001) HBI: Lowered in operated vs non-operated (p < .001)

				Median : 29.5 Active CI 29 - 38 Median : 29			Control group (N = 63, Healthy Individuals)			
3	Berndtsson & Oresland (2003)	Sweden, EU	N = 43 (UC) 37% Female	Female: Range 22-53 Median : 35 Male: Range 22-58 Median 34	G1: Range 3 – 38 Median:19 G2: Unclear Severity: Unclear	Pre vs post (at least 1 year)	IPAA (N = 48 / 100%) G1: medically treated (N = 11) G2: well-established ileostomy (N = 32) No control group	The Wilcoxon's rank sum test	OAS	OAS improved postoperatively (p < .001) for G1 and G2 combined. G1: significant decrease in factor 4 (p < .02) G2: significant improvement in factor 4 (positive or negative role function – enjoyment of sexual activities) (p < .001)
4	Hauser, Janke & Stallmach, (2005)	Germany, EU	N = 99 (UC) 36% Female	G1: IQR 27 - 57 Median 45	G1: IQR 10.3 – 23.0 Median 17.4	A cross-sectional study, G1 vs G2 vs national database	Ileal pouch-anal anastomosis G1: with IPAA (N = 37)	Wilcoxon Mann-Whitney test (G1 versus G2).	HADS-D cut off: >11	No differences in the frequency of a probable mental disorder between G1 and G2 (p > .05) and the general German population (p >.05).

				G2: IQR 34.2 – 53.5 Median 44.4	G2: IQR 5.1 – 20.1 Median 11.1 Severity: GIBDI Pouchitis: PDAI	No baseline data.	G2: without (N = 62)	Student T-test (G1 & G2 versus control)		
5	Eshuis et al., (2010)	Netherlands, EU	N = 55 (CD) 61% Female	G1: IQR 29 – 41.2 Median: 34.8 G2: IQR 29.4 – 46.6 Median: 38.9	G1: Unclear G2: Unclear Severity: Pathological Examination	A cohort study; Laparoscopic vs Open (median follow-up 6.7 years);	Ileocolic resection G1: laparoscopic (N = 29) G2: Open (N = 26)	Unclear if parametric or non-parametric test used.	BIQ	BIQ scores were significantly higher in the laparoscopic group ($p < .01$).

6	Brown et al., (2015)	Canada[2], NA	N = 351 (UC) 51% Female	IQR 30 – 52 Median: 40	IQR 5.7 – 15.1 Median: 9.2 Severity: Self-reported	A cross-sectional (post surgery median: 7 years) No baseline data	A colectomy & proctocolectomy No control group	Wilcoxon–Mann–Whitney test or Chi square, as applicable.	HADS: 7/8 mild intensity; 10/11 severe intensity – unclear usage BIQ	Depression: No gender differences observed ($p = .3$) Anxiety: Women were nearly twice as likely to have clinically meaningful anxiety as men ($p < 0.001$). Anxiety & Depression: Lack of full-time employment associated with higher scores ($p < .001$) BIQ: Scores were worse among women than men ($p < 0.001$) and worse among those <50 years of age ($p < 0.05$).
7	Abdalla et al., (2016)	USA, NA	N = 4733 (CD) 73% Female	With ostomy Mean: 49.2 Without: 43.7	With ostomy Mean:26.2 months Without Mean: 15.1 months Severity: MIBDI	A cross-sectional Min six months post-surgery	Ostomy G1: without Ostomy (Active Disease) G2: with Ostomy (Active Disease)	Pearson's chi-square test; Student's t-tests and within strata[3], multivariable logistic regression models to investigate association	PROMIS	Ostomy associated with clinical remission ($p < .001$) Anxiety: non-significant effects between all groups ($p > .05$) Depression: non-significant effects between all groups ($p > .05$) Active Disease:

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[2] Sample recruited from Canada (NA), United Kingdom (UK) and Australia (AUS).

[3] Defined by disease activity

							G3: without Ostomy (Remission) G4: with Ostomy (Remission)	s between ostomy status and PROMIS domains.		ostomy found as an independent predictor for fatigue (OR, 1.66; 95% CI, 1.15–2.39), pain interference (OR, 1.63; 95% CI, 1.12–2.35), and reduced social satisfaction (OR, 1.42; 95% CI, 1.03–1.95) Remission: Ostomy was only associated with reduced social satisfaction (OR, 1.68; 95% CI, 1.19–2.38)
8	Hwang & Yu, (2019)	S. Korea, AS	N = 90 (UC & CD) 41% Female	G1: 20-29 4.2% 30-39 20.8% 40-49 16.7% 50-64 58.3% G2: 20-29 36.4% 30-39 36.4% 40-49 25.8% 50-64 1.5%	G1: <5 y: 25% 5-9y: 25% >10: 50% G2: <5 y: 8% 5-9y: 28% >10: 30% Severity: Unclear	A cross-sectional study (median follow-up 6.7 years); No baseline data	Ostomy G1: UC with ostomy G2: CD with ostomy	The χ2 test; The Mann-Whitney U test, Kruskal-Wallis test, independent t test, and ANOVA, the Spearman's and Pearson's	BDI-II; RS	Non-significant findings (p > .05) found between: a) depression scores and general characteristics G1 b) depression scores related to clinical characteristics of G1 and G2 c) the degree of resilience related to general characteristics of G1 Negative correlation found between depression and resilience in G1 (r = –0.668, P < 0.001) and G2 (r = –0.604, P < 0.001).
9	Wang et al., (2022)	China, AS	N = 176 (UC & CD)	Range 18-64 Mean: 37.1	>10 years (39.2%)	A cross-sectional study; time	Stoma Temporary: 55.11%	Multivariate linear regressions (with	SES; SIS	Factors associated with self-efficacy: - age (β = –0.211, P < 0.001),

	49% Female	Severity: Unclear	since surgery unclear No baseline data	Permanent: 39.77% Result of: ileostomy (72%), colostomy (20%), jejunostomy (3%)	stepwise variable selection)	- stigma ($\beta = -0.555$, $P < 0.001$) - educational level (college or above vs. primary school) ($\beta = 3.388$, $P = 0.007$) Factors associated with stigma: - self-efficacy ($\beta = -0.524$, $P < 0.001$) - nursing privacy ($\beta = 0.146$, $P < 0.001$), - acceptance of the stoma by the closest person ($\beta = -0.178$, $P = 0.005$), - age ($\beta = -0.132$, $P = 0.029$)

Note: CD = Crohn's Disease; UC = Ulcerative Colitis; CDAI = Crohn's Activity Index; HBI = Harvey-Bradshaw Index; GIBDI = German Inflammatory Bowel Disease Questionnaire; PDAI = Pouchitis Disease Activity; MIBDI = Manitoba IBD Index; BDI-II = Beck Depression Inventory-II; PGWBI = Psychological General Wellbeing-Index; OAS = Ostomy Adjustment Scale; HADS: Hospital Anxiety and Depression Scale; HADS- D = Hospital Anxiety and Depression Scale (German Version) ; BIQ = Body Image Questionnaire; RS: Resilience Scale; SES: Self-efficacy Scale; SIS: Social Impact Scale; PROMIS : Patient -Reported Outcomes Measurement Information System

Postoperative Psychological Functioning in Inflammatory Bowel Disease (IBD)

Seven studies (Ref. no. 1, 2, 3, 4, 5, 6, 7) examined postoperative levels of psychological functioning in people diagnosed with IBD, four investigating surgical interventions for CD (Ref. no. 1, 2, 5, 7) and the remaining three for UC exclusively (Ref. no. 3, 4, 6). The other two studies examined the wider implications of an ostomy (Red. no. 8, 9).

Of the seven studies examining postoperative associations, three established an individual baseline prior to the surgery (Ref. no. 1, 3, 5) and three made comparisons with non- operated groups of people diagnosed with IBD (Ref. no. 2, 4, 7). One study (Ref. no. 2) has recruited a control group but did not discuss any relevant comparisons. Of note, four studies investigated associations within the context of planned procedures (Ref. no. 1, 2, 3, 5), with the remaining three failing to provide contextual and procedural details. There were no investigations identified comparing impact of elective to emergency surgeries nor between short versus long-term implications.

Amongst all studies, nine different measures of psychological wellbeing were used often precluding direct comparisons. Broadly speaking, levels of depression, measured by the BDI-II, have been found to decrease up to 6 months after the surgery (Ref. no. 1). However, any possible postoperative effects seemed to disappear in studies examining later time-periods (Ref. no. 1) and those using the PGWBI whilst considering disease activity (Ref. no. 1, 2). Also, no significant relationships between general demographics and/or disease characteristics and depression, measured using the BDI-II, were found in people who have an ostomy (Ref. no. 8). However, no comparison with control group performed limits significance of these associations.

Furthermore, two studies used the HADS (Ref. no. 4, 6) and one study used the PROMIS (Ref. no. 7) to determine levels of depression and anxiety. Of these, two found no interactions between surgery status and distress (Ref. no. 4, 7) whereas one argued that amongst operated individuals, anxiety is more prevalent in women than in men and psychological distress is associated with lack of full-time employment (Ref. no. 6). However, as no comparison with control group was performed again, the significance of these associations is limited.

Studies that investigated the impact of surgery on patients' body image found it to be lowered amongst young women specifically (Ref. no. 6) and somewhat better following laparoscopic versus open procedures even years after the surgery took place (Ref. no. 5).

In terms of psychological adjustment, one study (Ref. no. 3) examined post-surgery differences between two groups, UC patient who were medically treated and those who already had a well- established ileostomy. The study found postoperative improvement within combined adjustment scores and pointed out an interesting factor that appeared to be distinct between these groups. The item *'I am more able to enjoy sexual activities because of my ostomy/IPAA'* has significantly deteriorated in individuals who were only medically treated prior to their surgery but improved for individuals who already had ileostomy prior to the subsequent procedure.

Finally, a study examining the relationships between depression, perceived stigma, and self-efficacy in people with IBD-related ostomy with IBD (Ref. no. 9) suggested that levels of depression may be heightened amongst people with ostomy who are younger and/or of lower SES as well as those that may experience interpersonal difficulties around their disease.

CD versus UC

In relation to differences between IBD subtypes, only one study (Ref. no. 8) compared depression and resilience scores between CD and UC patient with a stoma. The study found associations between socioeconomic variables and depression scores in CD group *but not* UC group. Also, negative association were found between depression and resilience scores in both groups. This suggests that ability to 'bounce back' from setbacks might influence levels of psychological wellbeing in people with IBD-related ostomy. However, given significant variability in relation to the 'time since surgery' variable and the lack of stratification strategy regarding type of stoma the link between the surgical intervention and these variables may have been lost.

Disease Outcomes

Overall, three studies accounted for disease activity when investigating impact of surgical interventions for IBD on psychological variables (Ref. no. 1, 2, 7). Although studies used different tools, all showed improvement in IBD-related symptoms following surgical intervention in significant proportions of patients (Ref. no. 1, 2, 7). Therefore, it remains possible that postoperative levels of wellbeing are simply linked to the effectiveness of surgery in reducing burdensome symptoms. Of note, one study has indicated that ostomy might reduce social satisfaction irrespective of disease activity status (Ref. no. 7).

Quality (Risk of Bias) Assessment

Table 8 shows an overview of the quality assessment for each study. Overall, the majority of included studies stated their questions and objectives clearly. Most were also able to select appropriate study designs. Of note, all studies were observational in nature with seven out of nine being retrospective with no baseline data. This invites the confounding by indication bias often reported in observational studies. This means that a risk exists that underlying profiles of patients who are offered a particular type of intervention by a medical health professional might influence the reported associations. This threatens the internal validity of findings (Psaty & Siscovick, 2010). Although some unmeasured residual effect of confounding variables is generally accepted, insufficient adjusting for possible confounders and lack of propensity measures and matched controls, makes it difficult to interpret the data in most studies (Benedetto et al., 2018). This is also the reason why presented findings should be interpreted within a very cautious frame.

Most studies struggled to recruit unbiased samples, often choosing methods of convenience, and failing to explain to the reader their inclusion and exclusion criteria sufficiently. Naturally, this increases likelihood of a selection bias meaning that the reported associations might be inaccurately estimated. Selection of opportunistic samples with little to no information regarding demographic characteristics also limits generalisability.

Broadly speaking, studies were able to define their psychological outcome measures adequately with some description of its content and response options. All studies relied on self-report measures, which have limitations. These measures are usually subject to several biases related to the 'social desirability' effects, participants' recall ability, personal interpretation of items and/or an individualistic tendency to provide certain type of responses compromising internal validity (Furnham et al., 1982; Lacko et al., 2022). Also, self-report measures show only weak associations with behavioural measures supposedly capturing the same constructs

(Dang et al., 2020) raising question of validity if used in isolation. Moreover, studies have shown that self-report measures such as questionnaires and surveys, suffer from poor instrument equivalence and measurement invariance in cross-cultural research (Lacko et al., 2022). Taken together, this threatens not only internal validity of each study but also this review's capacity to summarise studies conducted cross-culturally.

Moreover, some studies made references to the levels of 'anxiety' and/or 'depression' using subscale analysis, which even if pragmatic, can be easily misinterpreted. Also, there was a surprising lack of widely used measures of psychological distress, namely, the PHQ-9 and the GAD-7, with most studies failing to report psychometric properties of utilised measures. Additionally, some studies did not specify applied cut-off points (Ref. no. 1) or applied them differently when determining distress levels (Ref. no. 4, 6), which prevents direct comparison.

Most studies did not have an adequate sample size and seven failed to comment on a priori power calculations to guide the reader. This makes it challenging to comment on power of statistical inferences and effectiveness of recruitment strategies. Of note, one study (Ref. no. 7) recruited significantly larger sample in comparison to the others which possibly invites bias when considering overall findings.

In relation to the analytic methods, most studies were able to select and describe this at least partially. Most provided succinct overview of the approach and tests used with some commenting on various aspects of statistical assumptions in relation to variables of interest. A significant proportion of studies reported problems with normality, failing to provide a clear narrative around possible transformation attempts, approach taken to handle missing data and/or outliers. Related to this, most studies did not offer enough information regarding attrition rates making it difficult to interpret the data. In some studies (Ref. no. 3, 5) the comparisons were performed between groups of uneven sizes, and it remains unclear how this was dealt with. This could have affected the power of statistical analysis and rates of Type 1 error (i.e., incorrectly rejecting a true null hypothesis) (Field, 2013). Furthermore, most studies selected non-parametric tests, consequently losing power of statistical inferences. Also, all studies are susceptible to the reporting bias, arguing for novel contributions to the evidence-base and using two-tailed tests at $\alpha = 0.05$ (Field, 2013).

Furthermore, to an extent, most studies struggled to account for confounding variables in a systematic and clear way and therefore are more susceptible to bias. Majority of studies failed to account or provide sufficient amount of information regarding disease severity/activity, the precise number and type of previous surgeries, other co-morbidities, preoperative psychological states, postoperative complications and use of ‘talking therapies’. Also, none of the included studies considered impact of other factors such as a surgical skill or disease and treatment beliefs when discussing intervention of interest. The studies have not been able to sufficiently account for socioeconomic variables. Overall, this might, at least partially, explain fragmented and inconsistent findings making it hard to interpret the data.

Most studies were able to present sufficient detail regarding their major outcomes with usually justified conclusions. However, taken together presented results should be considered tentatively.

Finally, given the fact that all nine studies included in this review evaluate the association(s) between variables alongside significant inconsistency in how studies present their summary statistics and their limited number, it has not been possible nor recommended to perform subgroup analysis, calculate summative effect sizes nor perform meta-analysis (Ellis, 2010; Sterne et al., 2008).

Table 5.

Summary of Quality Assessment Performed for Each Study.

Ref. No.	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**X (%)**
1	2	2	1	1	N/A	N/A	N/A	1	0	1	2	1	1	1	**59.09**
2	2	2	2	1	N/A	N/A	N/A	2	1	2	2	1	2	1	**81.82**
3	2	2	1	1	N/A	N/A	N/A	1	0	1	2	0	2	1	**59.09**
4	2	2	1	1	N/A	N/A	N/A	1	0	1	2	1	2	2	**68.18**
5	2	1	1	1	N/A	N/A	N/A	1	0	2	2	1	1	1	**59.09**
6	2	2	2	1	N/A	N/A	N/A	2	1	2	2	N/A	2	2	**85.71**
7	1	2	1	1	N/A	N/A	N/A	1	2	1	2	1	2	2	**72.73**
8	2	2	1	1	N/A	N/A	N/A	2	2	2	2	1	2	2	**86.36**
9	2	2	1	1	N/A	N/A	N/A	2	1	2	2	N/A	2	1	**76.19**

Note: Definitions and Instructions for Quality Assessment Scoring: 1. Question/objective sufficiently described? 2. Study design evident and appropriate? 3. Method of subject/comparison group selection or source of information/input variables described and appropriate? 4. Subject (and comparison group, if applicable) characteristics sufficiently described? 5. If interventional and random allocation was possible, was it described? 6. If interventional and blinding of investigators was possible was it reported? 7. If interventional and blinding of subjects was possible, was it reported? 8. Outcome and (if applicable exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported? 9. Sample size appropriate? 10. Analytic methods described/justified and appropriate? 11. Some estimates of variance is reported for the main results? 12. Controlled for confounding? 13. Results reported in sufficient detail? 14. Conclusions supported by the results?

Possible Scores: Yes (2), Partial (1), No (0); For items 3, 5, 6, 7, 8, 9, 10, 11, 12, it is possible to use N/A and remove item from analysis

The summary score is calculated according to the following equation: $x = \frac{(\text{number of 'yes'}*2)+(number\ of\ 'partial'*1)}{28-(\text{number of 'not applicable'}*2)}$

Discussion

The review aimed to examine the impact of surgical interventions on levels of broadly understood psychological functioning in ‘working-age’ adults diagnosed with IBD. This review identified nine papers published internationally in relation to postoperative psychological wellbeing of people diagnosed with IBD. Although it is a surprisingly small number of studies, our comprehensive search strategy and its application to four relevant databases allows a degree of confidence that all pertinent research was included in this review and that our conclusions are based on the synthesis of all currently available evidence.

Broadly speaking, results were mixed, with three studies finding a direct association between surgery and a measure of psychological distress whereas two did not. Furthermore, four studies reported associations between an aspect of psychological functioning and demographics and/or socioeconomic factors amongst people with IBD who had been operated on, but as no direct comparisons with non-operated individuals and/or other control groups were conducted nor baseline measurements established, these are to be interpreted cautiously. Furthermore, the review showed that there might be a distinct period shortly after the surgery within which medical procedures might impact on psychological wellbeing. This suggests a discrete area of need, which remains currently unsupported with minimal guidance from the National Institute for Health and Care Excellence and limited direction to nursing practices (NICE, 2019). Limited and inconsistent findings might be at least partially explained by variability and inadequacy in the selection of outcome measures, length of follow-up or time elapsed since surgery as well as small sample sizes, selection biases, lack of high quality pre-/post designs, and insufficient control of cofounding variables across studies. Of note, group comparisons reported in a few studies were performed between groups that were relatively unequal in sizes. Although it is unclear how this was dealt with it might have affected statistical power of performed inferences as well as rates of Type I error (Rusticus & Lovato, 2014).

Regarding postoperative psychological functioning in people diagnosed with CD specifically, a study by Tillinger et al., (1999) showed reduction in depressive symptomology up to six months postoperatively. However, to what extent this is driven by disease activity or perhaps wider narratives around surgical intervention being a patient's last chance to achieve 'symptom control' (Hwang & Yu, 2019), remains unknown with studies failing to show associations after one to ten years since the surgery when comparing with individuals in remission. Secondly, a study by Eshuis et al., (2010) showed that body image scores can differ between people who underwent open versus laparoscopic procedure many years after the actual surgery.

In relation to postoperative psychological functioning in UC, results have indicated the possibility of better adjustment following reconstructive surgery, a similar pattern of depression/anxiety distribution to that of non-clinical population and increased rates of psychological distress amongst younger women and people without full-time employment. However, findings are based on a surprisingly small number of participants given the fact that around 15 in 100 people with UC may need surgery over the course of their disease (C&C UK, 2022). Studies have also failed to take into consideration emergency problems as well as sufficiently examining the difference between reversable and non-reversable procedures.

Regarding self-report measures of psychological wellbeing, it has been surprising to note that none of the studies have utilised measures with a well-documented global reputation and very good psychometric properties, such as the

PHQ-9 and/or the GAD-7 (Kroenke et al., 2009; Spitzer et al., 2006). The Hospital Depression and Anxiety scale (Zigmond & Snaith, 1983) has been used widely and is validated across many different health populations (Snaith, 2003; Yamamoto-Furusho et al., 2018). It is relatively simple to administer and is often seen as a time-effective which makes it still a popular choice within hospital settings (Snaith, 2003). However, in recent years, the HADS has been the subject of an animated debate within the scientific community as it has been postulated that it lacks the sensitivity to discriminate between depression and anxiety, and its underlying structure depends on the statistical methods used (Coyne & van Sonderen, 2012). Moreover, it seems only in moderate agreement with the PHQ-9 in its ability to detect clinical symptomology (Hansson et al., 2009) and is culturally- biased, requiring substantial linguistic freedom when administered cross-culturally (Maters et al., 2013). Therefore, it would be beneficial for future evaluative efforts and clinical practice to review its position in relation to the HADS.

Also, it has been noted that most studies have not reported demographic characteristics in a consistent and sufficient manner. Concepts of ‘class’, ‘race’ and ‘educational systems’ appear difficult to ‘translate’ cross-culturally (Lacko et al., 2022). This presents a significant challenge to the generalizability of findings and caution should be exercised when considering the international literature. It is also possible that different narratives around IBD exist cross-culturally (Boyapati et al., 2014) and are positioned within different healthcare models which might impact on people’s relationship and expectations of help and surgical outcomes (Gilgen et al., 2005), which has not been examined in any of the studies.

The studies included in this review inconsistently highlighted the possibility of associations between both individual and socioeconomic factors, such as age, resilience, employment status, social support, and overall levels of postoperative psychological functioning (Cohen et al., 2005). This is in line with wider literature showing that an individual characteristic, namely coping style, personality traits, and social support may impact how a person copes with IBD and/or after the surgery (Jordan et al., 2016; Moskovitz et al., 2000) as well as studies showing the relationship between personal experience of stigmatization and illness related distress in IBD (Taft et al., 2009). Therefore, it is possible that it is not the actual 'surgery type' per se and its objective metrics that drive the psychological distress but perhaps its individual narrative. This would be further supported by the Common-Sense Model of self-regulation (Leventhal, 1970), which emphasizes the importance of personal evaluations of illness and its consequences that have been linked to coping strategies and outcomes (Han et al., 2005, MacInnes, 2014; Richardson et al., 2016). As such, it may prove useful to expand current screening/outcome measures to capture pre-existing characteristics as well as idiosyncratic evaluations of treatment more sensitively. This might lead to the establishment of routine screening methods able to detect some of the vulnerability profiles which in turn, might help to mitigate the risk of postoperative distress. This also highlights the importance of psychological formulation to help makes sense of individuals' pre-/post- surgical distress (Johnstone, 2018). Psychological formulation has been proposed as an 'alternative to psychiatric diagnosis' (Johnstone, 2018). It has been suggested that by stepping away from confides of largely 'labelling' and 'stigmatising' approaches origins of one's subjective distress can be understood within their personal context. Said approach offers a way of thinking that encourages compassion and person-centred lens (Johnstone, 2018). The psychological formulation has shown its utility in various healthcare settings, including physical health (Christofides et al., 2011; Shalev et al., 2021). In terms of application, psychological formulation can be thought of as an intervention itself (Hewitt, 2007) and/or springboard to tailored and more effective interventions (Johnstone, 2018).

Furthermore, the psychological distress might not be the outcome of surgical procedures, but a consequence of wider socioeconomic implications and cultural narratives driven by the challenges of an active disease. Factors observed postoperatively in people diagnosed with IBD, namely, reduction in social and workforce participation, have been found to contribute towards poorer psychological health (Van Bulck, 2018). Therefore, drawing on the Bronfenbrenner's ecological system theory (1992), which emphasizes the inter-related nature of the microsystem (i.e. most immediate environmental setting) and wider systems, such as mesosystem, exosystem (i.e., extended family and neighbours), macrosystem (i.e., attitudes and ideologies) and chronosystem (i.e. environmental changes over the life course) it seem probable that individual's pre-/post- operative emotional wellbeing may largely depend on his/her/their relationship with these systems and wider contextual narratives. This is also in line with broader theoretical underpinnings of community psychology postulating that psychological distress simply reflects the realities of 'disadvantaged' groups which often relates to insufficient opportunities and lack of resources across various domains (Hernandez-Plaza et al., 2010; Makki Alamdari, 2020). As such, it seems likely that IBD symptomology creates many barriers for people in relation to their social participation and engagement with meaningful activities increasing likelihood of isolation, lower SES as well as reduced confidence and/or sense of self-worth (Van Bulck et al., 2018). These negative effects on psychological wellbeing might be further compounded by pervasiveness of 'ageism', 'mentalism' and 'ableism' present within modern societal narratives and experiences of ‘microaggressions’ (Kattari et al., 2020; Rabheru & Gillis, 2021). Therefore, it is also important that therapeutic efforts are not detached from the wider implications of power distribution within society which impacts on people who are chronically ill (Burstrom et al., 2000; Van der Wel et al., 2011) and that within both research and clinical communities opportunities are sought to address wider systemic factors that appear to hinder patients’ psychological health. Broadly speaking, this is also in line with societal aspirations of ‘levelling up the UK’ (Connolly et al., 2021; Department for Levelling Up, Housing and Communities, 2022) and critical appraisal of current mainstream therapeutic approaches rooted mainly in individualistic perspectives, which often locate the nature of psychological distress within the individual who is thought to present with a form of deficit (Harrist & Richardson et al., 2014).

Furthermore, despite the fact, that the NICE guidelines emphasize the importance of providing quality information prior to the surgery for IBD (NICE, 2019), a recently published IBD survey (IBD, 2019) highlighted several shortcomings in relation to what is currently being provided. Specifically, patients reported insufficient focus on ‘long-term effects of surgery’ and ‘long-term support’ that might be available to them (Baker et al., 2018). Therefore, the present review highlights the gap in our collective understanding of the impact surgeries might have on psychological wellbeing, providing direct explanations for why the clinical need might not have been fulfilled to date. Additionally, it may be argued that people’s capacity to make an informed decision about elective procedures is negatively affected by our lack of understanding of psychological implications of surgeries for IBD. This might result in people not being adequately prepared for the procedures which puts them at risk.

Of note, as there is also a possibility of mismatch between the patients' and clinicians' opinions regarding 'optimal' outcome of surgical interventions (Byrne et al., 2014), it becomes paramount to strengthen evidence-base and to address these discrepancies to prevent clinical subjectivity and reduce patient dissatisfaction (Golin et al., 2002). As such, the present review has not only identified a clinically significant gap in the current evidence-base but has also highlighted new opportunities for future research. High-quality experimental studies, standardisation of methodological approaches and systematic incorporation of better psychological measures when evaluating pre-/post- operative experiences might positively influence quality and/or provision of care offered to people diagnosed with IBD who experience treatment failure and are left with no option but to consider the surgical intervention. Also, as a lack of evidence-base inadvertently informs the establishment of care pathways, development of statutory guidance and care provisions it becomes vital that future research addresses highlighted gaps.

In terms of the limitations of the included studies, outpatient settings with convenience sampling were most prevalent with most studies failing to recruit control populations that did not undergo the surgery. This introduces bias and limits comparisons. The participants samples were often inadequate in size and were usually captured after the surgery preventing pre-/post- operative comparisons. Overall, studies failed to consistently report surgery characteristics or time since the surgery was performed, which varied for many studies and introduced a confounder. Studies have also failed to provide information regarding the history of psychological interventions within their samples and majority did not consider psychological functioning shortly before the surgery. Furthermore, studies examining the ostomy struggled to account for the fact that different types exist, namely, temporary, and permanent, missing a potentially important aspect of patients' experience. Also, response rates to the survey-based studies varied meaning that the findings may be subject to a non-response bias. Furthermore, surveys conducted online invertedly excluded people with limited access to the Internet, who were likely to be from more disadvantaged socioeconomic backgrounds, thereby introducing selection bias. Lastly, variability in measures used has contributed to inconsistency in the literature.

Taken together, methodological limitations hinder generalisability and cast doubts over the presented findings. The results of our systematic review share similarities to other reviews conducted in the field arguing for more rigorous and consistent methodology (McCombie et al., 2013). It is possible that service user involvement in research and co-production might offer exciting new opportunities and address current limitations in the area (Fudge et al., 2008; Mingoue et al., 2005).

Limitations

This review has number of limitations. Firstly, non-English publications and 'grey literature' were excluded from this review. This was motivated by pragmatic reasons, namely, time-constraints and limited resources available, given the fact that constructed search strategy yielded over 2,000 publications for initial screening. However, this choice might have inadvertently linked presented results to wider publication bias and blinded the review to other valuable scientific contributions. Furthermore, given limited number of studies included in this review it could be useful if future research expands on this.

Another limitation of this review was restricting the age ranges of participants. Although, we do strongly believe that lifespan perspective should be considered within psychological research, our criteria failed to consider that the definition of a 'working-age' adult varies internationally and changes with time. Therefore, excluding studies falling even slightly short of our criteria could possibly have limited data available to the review. It might prove useful for future reviews to consider the impact of surgical interventions across the lifespan, which may enable further comparisons.

The choice to focus this review on quantitative studies, specifically those with validated psychological measures was in some ways limiting. For example, this review was unable to review literature pertaining to the 'sexual satisfaction' and/or 'intimacy' given that the quantitative methodology focused on purely functional postoperative metrics and/or used non-validated approaches. This meant that comprehensiveness of the present review has been reduced. In hindsight, this review could have been augmented by incorporation of qualitative studies as some psychological constructs are difficult to quantify or simply no standardised measures exist. It is possible that personality traits, relationship with medical teams, perceived involvement in decisions around the surgery, beliefs about surgery and its impact alongside levels of support postoperatively all influence psychological wellbeing yet no obvious instruments are available. Perhaps the richness and complexities involved in the experiences of surgical interventions cannot be captured within this restricted frame and research should prioritise development of more robust means of literature consolidation.

It is also important to acknowledge that in our formation of the search strategy related to the construct of psychological wellbeing some terms have been missed. Although number of search strategies containing some sort of error is extremely high amongst peer-reviewed publications (Salvador-Olivan et al., 2019), the precision of the present review could have been improved by augmentation of terms such as ‘negative/positive affect’, ‘hedonistic’ and ‘eudemonic’.

The final limitation relates to the exclusion of quality-of-life measures. Upon reflection, popularity of such measures in this area became an obstacle for pragmatic reasons. However, given novelty of this review and limited number of studies included it is possible that this review’s inclusivity and depth could have been augmented by quality-of-life measures analysis. It is also imaginable that some of the excluded studies measured levels of depression and anxiety utilising subscale analysis incorporated within larger scales, such as the 36-Item Short Form Survey (SF-36) (Hays et al., 1995) which could have been of interest.

Conclusions

In short, the impact of IBD-related surgical interventions on psychological wellbeing in ‘working-age’ adults remains largely unknown with studies reporting mixed results owning to fragmented and methodologically limited literature. This review highlights the poverty of high-quality experimental studies, identifying significant gap in the evidence-base and creating exciting new research opportunities. Evidence presented in this review fails to create a convincing narrative and further research is needed, focusing upon standardizing methodological approaches and/or reporting styles, consistent incorporation of better psychological measures when evaluating surgical interventions.

The role of prospection as a function of subjective well-being in people diagnosed with Inflammatory Bowel Disease.

Abstract

Our ability to imagine future possibilities is closely related to psychological wellbeing. Onset of a physical health condition presents a potential challenge to those personal future representations in turn increasing the risk of psychological difficulties. The present study aims to examine how people diagnosed with Inflammatory Bowel Disease (IBD) think about their personal futures and if this relates to variable levels of subjective wellbeing.

Eighty-eight individuals diagnosed with IBD were recruited through 'Crohn's & Colitis UK', the UK's leading charity for IBD and 'GetYourBellyOut', a patient lead not-for-profit organisation. Participants were invited to complete self-report measures of psychological wellbeing before thinking aloud about their personal futures within three distinct time periods.

Hierarchical regression analysis was used to analyse the relationship between levels of positive and negative future expectancies and subjective wellbeing. Furthermore, a novel coding scheme was developed to investigate the content of prospective cognitions. Overall, we did not find a significant association between the number of future-directed thoughts and wellbeing. However, a meaningful relationship was found between the content of prospective cognitions and psychological distress.

The present study offers support for the postulation that the more intertwined someone's prospective cognitions are with their illness the more likely it is that their psychological health will suffer. This provides an important implication for prevention, assessment, and treatment of psychological distress in IBD.

Keywords: *future, prospection, expectancies, depression, anxiety, satisfaction with life, psychological wellbeing, Inflammatory Bowel Disease, Crohn's Disease, Colitis, hierarchical regression, coding, content*

Introduction

The complex interplay between various brain regions and structures gives rise to human's unique ability to 'time-travel' in their minds (Gilbert & Wilson, 2007). The ability to imagine future possibilities is often referred to as 'future-directed thinking' and encompasses a range of different forms of cognitive processes (Bronk & Mitchell, 2021) which subsequently guides one's behaviour (Baumeister et al., 2016).

Prospective thinking has been associated with psychological well-being (Gilbert & Wilson, 2007; MacLeod, 2017). For example, in both clinical and subclinical adult populations, a reduction in positive future anticipation alone has been linked to depression, hopelessness, and suicidality (MacLeod, Tata, Kentish, & Jacobsen, 1997), whereas an increase in negative future events expectancy has been shown to correlate with worsening symptoms of anxiety and depression (MacLeod & Conway, 2005). Moreover, engagement in future-directed thinking can often serve numerous and nuanced functions and gives rise to an array of consequences (MacLeod, 2017). For example, constructs such as 'hope' and 'optimism', measured as a function of positive future expectancies, has been linked to positive emotional wellbeing (Gallagher & Lopez, 2009). Also, novel interventions attempting to explicitly target prospection (i.e., mental representations of future events) either through cognitive bias modification (Namaky et al., 2021) or 'mental contrasting' (Oettingen & Reiningen, 2016) show some capacity to reduce symptoms of depression and/or anxiety, enhance self-efficacy, and assist people with finding and moving towards their personal goals. Therefore, future-directed thinking may be viewed as a normative and adaptive process which, when disturbed, triggers widespread consequences.

MacLeod (2017) has suggested that a subjective future life trajectory is an important aspect of human experience and when it becomes disrupted psychological well-being is impacted. Onset of a physical health condition is one way in which a person’s subjective future life trajectory could be challenged.

The common-sense model of self-regulation (CSM) (Leventhal, 1970) explains how individuals respond to and manage ongoing health threats. It emphasizes the importance of personal evaluations of illness, specifically its five components: identity, cause, timeline, consequences, and controllability, enabling individuals to make sense of their symptoms and subsequently guiding their behaviours. Broadly speaking, these subjective evaluations (i.e., ‘illness representations’) have been linked to coping strategies and even clinical health outcomes (Dorrian et al., 2009; Han et al., 2005, MacInnes, 2014; Richardson et al., 2016; Stapersma et al., 2019). In relation to the ‘identity’ component, a chronic illness presents a clear challenge to the ‘self-concept’, which for many centres around being healthy. Following diagnosis, the newly encountered gap between the ‘ideal’ and ‘current’ self will inevitably spark attempts to create and/or regain a more coherent sense of self (Leventhal et al., 1999; Morea et al., 2008). Yet, the extent to which a chronic illness penetrates and warps the newly constructed sense of ‘self’ is commonly referred to as ‘illness identity’ and may takes many forms varying from the ‘engulfment’ and ‘denial’ to the ‘acceptance’ and ‘enrichment’ (McCay & Seeman, 1998; Oris et al., 2016; Van Bulck et al., 2018; 2019). These various expressions of ‘illness identity’ have been linked to psychological functioning. For example, people whose identity has been dominated by illness (i.e., ‘engulfment’) are more likely to report emotional distress (Andonian et al., 2021). Furthermore, lower self-esteem and higher levels of depression associated with ‘engulfment’ have been found amongst caregivers (Skaff & Pearlin, 1992). This highlights particular vulnerability people diagnosed with chronic illness need to navigate. Moreover, regarding the 'timeline' component of the CSM, a chronic illness may also challenge how individuals perceive and/or relate to time, given dominant narratives around more 'linear' life-trajectories and expected roles/milestones (Davies, 1997; Gibson et al., 2009; MacLeod 2017). Even though many chronic illnesses do not objectively shorten life expectancy, ideas around time being limited and/or what may be possible within the new subjective timeframe seem to restrict one's ability to think about future possibilities. This might be particularly true in relation to chronic illnesses either of uncertain and/or progressive courses, which directly threaten these fundamental assumptions of what 'normal' life looks like. Here, research has shown the association between shifts in temporal orientation that simultaneously threaten valued personal goals and increased likelihood of psychological distress alongside utilisation of maladaptive coping strategies in people who are ill (Alberts & Dunton, 2008). Therefore, it is possible that a chronic illness alters prospection in rather unique ways and that its properties can explain varying levels of subjective wellbeing in people who have been diagnosed with long-term physical health conditions (LTCs).

However, to date, only a few studies have focused on the role of future-directed thinking in physical illness specifically using the Future Thinking Task (FFT; MacLeod & Byrne, 1996). In this task participants are invited to think about any positive and negative future experiences that might realistically happen to them at three different future time-period (i.e., 'the next week', 'the next year' and 'the next five to ten years'). The total FFT score is based on a simple count of instances across conditions with any repetition of thoughts not being included.

Amongst current literature, only two previous studies have investigated the quantitative, and to limited extent qualitative, aspects of cognitive prospections and its relationship to the variable levels of psychological wellbeing using the FFT. Firstly, a study by Rusu and Pincus, (2016), examined future- thinking in four groups of participants: those with chronic pain and depression, those with chronic pain but without depression, those with depression but without pain, and healthy controls. Here, participants with depression showed increased levels of negative future expectancies as well as lowered levels of positive anticipation compared to controls. Furthermore, participants who experienced chronic pain and had been diagnosed with depression showed significant elevation in anticipation of negative health- related future events compared to individuals who experienced chronic pain only. However, as suggested by the authors, further investigations incorporating anxiety/fear as well as extending the coding method are desirable to address some of the limitations. Secondly, a study by Moore et al., (2006) investigated the link between positive and negative expectancies in people with relapsing-remitting multiple sclerosis (MS) and depression. The argument put forward linked positive psychological well-being in illness with intact ability to anticipate future events detached from disease (Moore et al., 2006). However, these findings cannot be generalized to other physical conditions due to the uniqueness of different physical conditions, a small sample size and the involvement of cognitive impairments in MS.

Inflammatory Bowel Disease (IBD) refers to the three conditions of the gut, Ulcerative Colitis (UC), Crohn's Disease (CD) and Indeterminate Colitis (IC) (Flynn & Eisenstein, 2019). It is a physical health disease of recurring nature, oscillating between 'active' and 'remission' phases with varying levels of severity (Mikocka-Walus, 20018). Broadly speaking, IBD is associated with a malfunction of any portion of the digestive tract, and most commonly results in persistent abdominal pain, diarrhoea, bleeding, and nausea (Yangyang & Rodrigez, 2017). Although ultimate cause remains unknown, several possible risk factors have been implicated, namely, genetics (Katakure et al., 2013) and environmental factors affecting the development of the gut microbiome, such as frequent use of antibiotics (Koloski et al., 2008) and nonsteroidal anti-inflammatory drugs (Molodecky & Kaplan, 2010), diet changes (Sakamoto et al., 2005; Amre et al., 2007), smoking and oral contraceptives (Koloski et al., 2008; Bernstein, 2017). Furthermore, IBD is linked with increased risk of other physical health conditions, such as asthma, arthritis (Mikocka- Walus, 2018) or colorectal cancer (Karvellas et al., 2007) as well as amplified levels of fatigue (Borren et al., 2019), depression and anxiety (Dubinsky et al., 2021).

The precise incidence and prevalence rates of IBD remain hard to confidently estimate given various classification and diagnostic challenges (Freeman et al., 2021; Geboes & Hertogh, 2003). Most cited publications postulate that there are over five million people currently living with IBD around the world (Mikocka- Walus, 2018) with global stabilising trend in Western countries (Siew et al., 20017). Probable rates of IBD in the UK adult general population are 142.1 per 10,000 patients (Freeman et al., 2021) with slightly higher incidents rates for males than females (Mikocka-Walus, 2018).

Living with IBD can be overwhelming and emotionally challenging as the disease course is often uncertain, medical regimen burdensome and there is no cure (Banez & Cunningham, 2003). Several factors have been relatively consistently established as related to psychological well-being and distress in IBD. These are: disease activity and its severity (Abautret-Daly et al., 2017; Mikocka- Walus et al., 2016; Panara et al., 2014), type of IBD (Mikocka- Walus et al., 2016), fatigue and pain levels (Deberry et al., 2014; Norton et al., 2015), age of symptoms onset (Walker et al., 2008), age and gender (Ennaifer et al., 2014; Marrie et al., 2018; Zandman-Goddard et al., 2012), educational level and socio-economic status (Nahon et al., 2012; van der Have, 2013), perceived social support (Sewitch et al., 2001), employment status/levels of functioning (van der Have, 2013), years since diagnosis (Choi et al., 2019) and type of medical intervention (Terricone et al., 2017; van der Have, 2013). Furthermore, patients with IBD consistently report poorer quality of life (Bernklev et al., 2005), which at least partially, can be explained by lower psychological wellbeing, negative self-image, poor social functioning, stigma (van der Have et al., 2014) as well as reduced workforce participation (Mikocka-Walus, 2018). However, despite significant co-morbidities and the negative impact of psychological distress on health outcomes, psychological health is under-studied in IBD (Taft et al., 2017), leading to the inability to meet patients' needs effectively. Psychosocial difficulties associated with IBD are similar to those found in other chronic conditions. The prevalence rates of psychiatric disorders, namely anxiety and depression, are elevated and quality of life lowered compared to the public (Knowles et al., 2018). However, it is largely unknown why clinically significant distress manifests in only a subset of IBD patients (Maddux et al., 2013) as few have considered the role of intrapersonal factors.

Aim

The present study aims to further our understanding of variations in wellbeing and psychological distress in people diagnosed with IBD through examining one factor that might account for these differences – future-directed thinking.

Study Overview

Participants diagnosed with IBD were asked to complete various self-report measures relating to their basic demographics, disease characteristics and psychological wellbeing as well as to think aloud about number of things they looked forward to as well as number of things they *did not* look forward to at three distinct future time- periods. Responses were coded using an adapted coding scheme to investigate the associations between certain characteristics of the future-directed thinking and wellbeing (Godley et al., 2001; Moore et al., 2006).

The hypotheses of this study were as follows:

- **Hypothesis 1:**
    - Higher levels of positive future expectancies will be related to lower levels of depression and higher levels of life satisfaction.
    - Higher levels of negative future expectancies will be related to higher levels of anxiety and lower levels of life satisfaction
- **Hypothesis 2:**
    - A greater proportion of future thoughts related to IBD will be related to higher levels of anxiety and depression and lower levels of life satisfaction.

Method

Ethical Approval

This study obtained the ethical approval from the Royal Holloway's Psychology Research Ethics Committee (REC) in July 2021 and was registered with the Open Science Framework (OSF) in August 2021.

Participants

Individuals of 'working-age' diagnosed with Inflammatory Bowel Disease were recruited through 'Crohn's & Colitis UK', the UK's leading charity for IBD and 'GetYourBellyOut', a patient lead not-for-profit organisation, between August and October 2021. Inclusion criteria for this group included: a) age between 18 – 64, b) a diagnosis of CD, UC and IC as a primary physical health problem given by a medical health professional, c) sufficient comprehension of spoken English, and d) capacity to give informed consent. Although, no formal verification was conducted in relation to these self-report measures, command of English and capacity to consent were assessed informally upon meeting with a potential participant.

In total, eighty-eight participants took part in the present study. Of the sample, 28.4% were male (N = 25) and 70.5% were female (N = 62) with one participant choosing not to disclose this information. For further details regarding the sample characteristics please see the Results section.

Power Calculation

The power calculation carried out a priori using the G*Power software (Version 3.1.9.6) recommended the sample size of 84 to ensure that the study is sufficiently powered to carry out the planned hierarchical regression analysis with alpha set to 0.05 and power set to 0.8 for a large to medium effect size (Cohen, 1992; Faul et al., 2007; 2009). This is predicted based on previous studies using similar methodology (MacLeod et al, 2004; Moore et al., 2006; Sevmour, 2012).

Design

A correlational and a cross-sectional design was used. All participants completed self-report demographics, and disease variables questionnaires which were developed for this study. Participants also completed validated measures ascertaining levels of subjective wellbeing, namely, depression (i.e., The Patient Health Questionnaire, [PHQ-8]; Kroenke et al., 2009), anxiety (i.e., The Generalised Anxiety Disorder Assessment, [GAD-7]; Spitzer et al., 2006), general satisfaction with life (i.e., The Satisfaction with Life Scale, [SWLS]; Diener et al., 1985) and health-related quality of life (i.e., The Inflammatory Bowel Disease Questionnaire, [IBDQ]; Guyatt et al., 1989). Additionally, all participants completed the verbal fluency (FAS; Lezak et al., 2004) and the future thinking tasks (FTT; MacLeod & Byrne, 1996).

Service Users Involvement

Two individuals diagnosed with IBD and associated with the ‘GetYourBellyOut’ organisation were approached during the study development stage. Guidance regarding proposed procedures, namely, its acceptability and feasibility was sought, alongside feedback regarding the general impressions of the survey, tasks and language used.

Feedback suggested considering ways in which we could alleviate any possible performance anxieties as well as offer reasonable adjustments to account for IBD symptomology during the study appointment. As such, we provided participants with a clear outline of the session, explicitly discussing virtual appointment etiquette and comfort breaks, and explored any need for further modifications at the start of each appointment.

In relation to the proposed measures, significant concerns were raised. Firstly, the Patient Health Questionnaire's (PHQ-9) final item around suicidality and risk of harm was perceived as intrusive and blunt. To increase acceptability, we have diverted from The National Institute of Clinical Excellence guidance (NICE, 2009) and common practice in both clinical and scientific communities (Kroenke, 2021) and used the PHQ-8 (Kroenke et al., 2009) instead. This was further supported by the evidence suggesting lack of superiority of PHQ-9 over PHQ-8 (Smith et al., 2010). Similarly, disease activity stratification tools, such as the Harvey-Bradshaw Index (Harvey & Bradshaw, 1980) for CD and Simple Clinical Colitis Activity Index (Walmsley et al., 1998) for CD/IC were abandoned in relation to feedback suggesting their lack of robustness and perceived inaccessibility (Ringel & Drossman, 2001; Falvey et al., 2015).

Finally, communication style has been carefully reviewed and adapted to employ more compassionate and approachable stance. For example, by referring to the 'Future-thinking task' as a 'conversation about the future' and providing participants with a 'Thank you card' instead of 'Debrief sheet'.

For further details regarding our consultation with service users and more examples of nuanced ways in which this study has been modified please refer to a comprehensive summary produced and agreed with the service users (Appendix A).

Materials & Measures

Demographic Questionnaire

The demographic questionnaire detailing age, gender, ethnicity, nationality, relationship status, highest level of education attainment, and employment status was developed based on a wider literature search in relation to empirical studies investigating adult populations, psychological wellbeing, and chronic illness (See Appendix B).

Disease variables questionnaire

The questionnaire was devised detailing an exact diagnosis, disease duration, years since first symptoms were noticed, type of prescribed medication/medical intervention, incident of previous surgery, presence of perianal disease (i.e., fistula), presence of stoma, disease activity index and number of flares (See Appendix C). This was based on a wider literature search in relation to IBD symptomology and commonly described characteristics.

The questionnaire was constructed as currently no validated self-report measures exist and commonly used disease severity stratification tools have been widely criticised and are limited (Falvey et al 2015; Ringel & Drossman, 2001). Furthermore, it has been postulated that patients diagnosed with IBD are able to report their fundamental disease characteristics and medical history accurately and reliably (Kelstrup et al., 2014), which for the purpose of this study seemed appropriate.

Depression

The Patient Health Questionnaire (PHQ-8) is a self-administered, eight-item scale that was used to assess levels of depressive symptomology (Kroenke et al., 2009). It consists of items from the diagnostic criteria for major depressive disorder in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) excluding suicidal ideation and thoughts of self-harm. The participant is invited to indicate the presence and frequency of symptoms over the past two weeks. Each item is scored from 0 (‘not at all) to 3 (‘nearly every day’) and the overall score can range from 0-24. The PHQ-8 score of 10 or higher indicates the presence of depressive episode (Kroenke at al., 2001; Wu et al., 2021).

The PHQ-8 has been proven to be a valid and reliable measure of depressive symptomology in many adult populations, including physical health populations (Razykov et al., 2012; Shin et al., 2019). It was shown to demonstrate a Cronbach’s alpha of .82 (Pressler et al., 2011), and 77% sensitivity and 62% specificity (Smith et al., 2010). It may also be favoured over PHQ-9 (Kroenke et al., 2001) in population-based studies where direct questioning around suicidal ideation might be problematic (Shin et al., 2019).

Anxiety

The Generalised Anxiety Disorder Assessment (GAD-7) is a self-administered, seven-item scale that was used to gauge levels of anxiety symptoms (Spitzer et al., 2006). Participants rate on a scale between 0 (‘not at all’) and 3 (‘nearly every day’) the frequency of their symptoms over the last two weeks. Cut off points are identified from scores for mild, moderate, and severe anxiety.

The scale has been shown to have good reliability, with a Cronbach’s alpha of 0.89 (Löwe et al., 2008), as well as criterion, construct, factorial, and procedural validity (Spitzer et al., 2006), with a sensitivity of 83% and specificity of 84% (Plummer et al., 2016) in population based-studies. Findings are largely replicated in many populations living with chronic physical health conditions, for example, migraine (Seo & Park, 2015) and rheumatoid arthritis (Hitchon et al., 2010). Its validity and efficiency as a screening tool make it a regularly used tool in clinical practice as well as research (NICE, 2011).

Satisfaction with Life

The Satisfaction with Life Scale (SWLS) is a short 5-item instrument designed to measure global cognitive judgments of satisfaction with one's life (Diener et al., 1985). The participant is invited to consider five statements, such as ‘*In most ways my life is close to my ideal’*, ‘*The conditions of my life are excellent’*, ‘*I am satisfied with my life*’, ‘*So far I have gotten the important things I want in life’*, ‘*If I could live my life over, I would change almost nothing’*, and estimate their level of ‘agreement’/’disagreement’ with each statement using a 7-point scale that ranges from 7 (‘strongly agree’) to 1 (‘strongly disagree’). The overall score falls somewhere between 5 (‘extremely dissatisfied with life’) and 35 (‘extremely satisfied’).

The coefficient alpha for the scale has ranged from .79 to .89, indicating that the scale has high internal consistency as well as discriminant validity from emotional wellbeing measures (Lorenzo-Seva et al., 2019; Pavot et al., 1991, Pavot & Diener, 2009). The scale was also found to have good test-retest correlations (.84, .80 over a month interval) and shows a degree of temporal stability (Pavot & Diener, 2009).

The Inflammatory Bowel Disease Questionnaire (IBDQ)

Originally developed as a clinician-administered questionnaire regarding patient's disease status during most recent weeks, the IBDQ is often used as a measure of health-related quality of life (Guyatt et al., 1989). The measure consists of four dimensions: bowel, systemic, emotional distress, and social functioning. Every question has graded responses from 1 (worst) to 7 (best), and thus the total score ranges from 32 to 224 with higher scores representing better quality of life.

The original IBDQ is a well-established measure, proven to be a valid and reliable assessment tool that reflects important changes in the quality of life of patients with IBD (Irvine et al., 1994; Muller et al., 2008; Verissimo, 2008). Moreover, a self-administered version of the questionnaire has been validated and found to be reliable (Irvine et al., 1996; Ramos et al., 2018). Most recently, a comprehensive investigation into the psychometric properties of the IBDQ confirmed its excellent content validity and reasonable internal consistency. However, the review has also highlighted that most studies lack investigations into further psychometric properties, such as measurement error or factor analytic investigation of its structure (Alrubaiy et al., 2015)

The Standard Verbal Fluency Control Measure* (FAS) - *Lezak (1995)

This task assesses phonemic fluency and acts as a control measure for general verbal fluency (Lezak et al., 2004) involved in the FTT. Participants are given a minute to name as many words as they can beginning with letters 'F', 'A' and 'S' in that fixed order. The total number of acceptable words produced divided by three translates into a verbal fluency score. However, in addition to offering insight into verbal fluency and higher- level cognitive skills this task also familiarises participants with imposed expectations of generating as many responses as possible within a set time limit, which is involved in the FTT (Conway & MacLeod, 2007).

***The Future Thinking Task* (FTT) – MacLeod & Byrne (1996)**

In the future thinking task participants are given three different future time periods (i.e., 'the next week', 'the next year' and 'the next five to ten years') and are invited to think about any positive and negative future experiences that might realistically happen to them at each time-period. Participants are expected to say aloud potential future expectancies within a minute for each condition and are encouraged to generate as many responses as they can. For full instructions given to the participants please refer to Appendix D. The future thinking task produces two variables, positive and negative expectancies. The total FFT score is based on a simple count of instances across three time-periods with any repetition of thoughts not being included. It has also been suggested that distinct effects relating to time periods are rare (Conway & MacLeod, 2007), therefore analyses focused on the total scores.

Coding scheme

The recordings of the future thinking task were transcribed by the lead researcher and data ranged from a single word (i.e., 'wedding', 'Christmas') to a few words (i.e., 'going back to the office', 'meeting up with a friend'), often with limited grammatical input. The responses were split into meaningful units, capturing various life- domains (Flanagan, 1978). Although, the main categories were not determined in advance, but constructed through the analysis (Krippendorff, 2018), similar coding schemes have been used within the area of future-directed thinking (Godley et al., 2001) and were used as the basis for the coding scheme in the present study. Figure 2 shows eleven constructed categories (i.e., life domains) and offers a comprehensive overview.

Figure 2.

Adapted Coding Scheme for Types of Future-oriented Cognitions.

A. **Own Physical Health** – Any item relating to comments around subject's health status that were made explicitly and/or any items where such meaning can be confidently inferred. This can include statements linked to events such as getting ill, dying, having accidents, being in pain, nutrition, and diet, experiencing IBD-related symptoms, undergoing medical treatments and/or attending various medical appointments. Sleep-related items are also in this category. Finally, any items that stretch across multiple categories but contain health-related sentiment have been incorporated here.

B. **Physical Health of Others** – Any item relating to comments around health status of other people/pets, for example, relatives, friends etc., that were made explicitly and/or any items where such meaning can be confidently inferred. For example, this can include references to surgery outcomes and recovery process, becoming frail or ill as well as undergoing medical investigations/treatments and/or attending hospital appointments.

C. **Intrapersonal** – any item which exists within the mind of the subject, the item has to do with the subject and nobody else, such as personal feelings and beliefs. For example, items such as ‘being happy’, ‘being less self-critical’ or ‘appreciating own achievements’.

D. **Financial Security & Home** – any item relating to significant money matters, purchasing/selling/renting and moving house, which can also include remodelling/decorating etc. This category also includes items referring to significant purchases, for example, paying for holidays and/or getting a new car.

E. **Employment & Occupation–** any reference to any job/occupation related achievements and/or failures, such as, starting a new job/losing employment, volunteering, getting promoted/demoted etc. This category also includes skills development within employment context and career progression.

F. **Education & Academia -** any reference to any academic achievements, aspirations and/or failures. This includes vocational training programmes.

G. **Social/Interpersonal** – any item which focuses on relational aspects of the activity/event, such as, ‘going to a party’, ‘grabbing a coffee with a friend’, ‘trying to repair a relationship’. This category also includes marriage, separation, having children, since these events involve more than just the subject.

H. **Skills Development & Personal Growth** – any item relating to ongoing efforts to learn new things, acquire new skills and grow as a person outside of education and employment contexts. For example, learning a new language, learning to sing, passing a driving test.

I. **Leisure & Fitness** – any item relating to events which are done for sense of pleasure, leisure and/or relaxation and inner-peace. These events may be sociable, however since nobody else is mentioned and because it is possible to do this activity alone, they are coded in this category. For example, events such as 'going for a walk', 'traveling to Wales', 'resting over the weekend', and 'retiring'.

J. **COVID Outlook –** any item focusing on the future outcome of the pandemic, which cannot be best explained by other categories. For example, this category includes statements, such as, 'going back to normal', 'having another lockdown', 'pandemic no longer being a thing' or 'things being less scary'.

K. **Other -** If the coder is in any doubt under which category an item should be coded then this classification can be used.

To address issues of validity, during development of the coding scheme any doubts and/or inconsistencies were negotiated with the project supervisor. Furthermore, the second rater, who was independent of the research group, was trained in the coding scheme and blindly coded 13 of 88 transcripts, which represented 458 (16%) of 2,782 statements, to check reliability. Both positive and negative expectancies were rated (using eleven categories) and inter-rater agreement was kappa = 0.945, indicating very good agreement between the raters (Landis & Koch, 1977).

Lastly, the content of both 'Own Physical Health' and 'Physical Health of Others' categories was further broken down into items related to IBD and those that did not. To illustrate, a statement *'to be able to take a train without a flare'* would be classed as a positive future expectancy related to IBD whereas *'ageing and dealing with risk of other diseases'* or *'my brother's health deteriorating'* would represent a negative future expectancy linked to health but not specifically to IBD. This was done to enable quantitative analysis of idiographic content. IBD-related items were grouped into less formalised categories to provide a supplementary narrative.

Procedure

Following the receipt of ethical approval, the study was advertised by two selected organisations, namely 'Crohn's & Colitis UK' and 'GetYourBellyOut', on their respective websites and through various social media accounts. This included Facebook, Twitter, and Instagram.

Individuals who expressed interest in taking part in the study were contacted via email. The introductory email consisted of an information sheet outlining details of the study and participation, including information around consent and right to withdraw (See Appendix E, F, G).

Virtual appointments were held using either Zoom or MS Teams platforms, depending on participants preference and level of competence. To increase acceptability efforts were made to offer broad range of appointments, often outside of typical 9 – 5 constraints.

In line with previously discussed consultation with two individuals diagnosed with IBD, we agreed to share link to all questionnaires with participants 24 hours prior to their scheduled appointment to offer choice and flexibility as well as reduce time-pressure (See Appendix H). The questionnaires were administered online using Qualtrics.

The study meeting itself followed a semi-structured protocol, starting with brief introductions and discussion related to any aspects of consent form ensuring participants' full understanding and ability to provide informed consent. Next, if necessary, participants were assisted in completion of all measures in a fixed order, starting from demographic and illness characteristics questionnaires through the PHQ-8, the GAD-7 and the SWL before proceeding to the Future-Thinking Task (FFT) with no counterbalancing across participants.

To conclude the appointment participants were thanked for their time, offered an opportunity to ask questions and verbally debriefed on the study. All participants also received a written 'Thank you' sheet, which included details of mental health support (See Appendix I). Lastly, all participants were offered the opportunity to be entered into a monetary prize draw as well as receive a written summary of study findings upon thesis completion.

Results

Data Entry

The data were analysed using the IBM SPSS Statistical Data Editor version 25. Prior to the statistical analysis all data were checked for accuracy. Missing values were detected on variables such as the 'date of diagnosis' (n = 1), the 'initial onset of symptoms' (n = 1), the 'overall number of flare-ups' (n = 19) as well as open- ended questions in relation to the perceived impact of IBD on employment (n = 1) and/or education (n = 1), and the precise nature of disability status (n = 1). These were coded, but not used for statistical inferences. There was only one participant who failed to complete all items on the Inflammatory Bowel Disease Questionnaire (IBDQ) therefore, to maintain integrity of the dataset a personal average score was imputed on three missing items.

Skew and kurtosis were investigated for normality using a $z > 3.29$, $p > .001$ (Field, 2013) and boxplots were inspected for outliers. This revealed several possible outliers across different variables, namely, IBDQ scores, the 'time living with the condition', 'the number of flare-ups' and positive prospective cognitions across 'next week' and 'five to ten years' future time periods. Outliers were limited through winsorization. Consequently, no data were excluded from the analysis.

Anxiety scores were positively skewed ($z_{GAD} = 3.08$, $p > .01$) and required square root transformation. The distribution of the IBDQ was negatively skewed ($z_{IBD} = -3.08$, $p > .001$) and was effectively transformed through mirroring the distribution, finding both the positive square root and log10 followed by -1 multiplication for directionality. Finally, distribution of time living with IBD ($z = 3.29$, $p > .001$) and number of flare-ups ($z = 5.6$, $p > .01$) variables were not normally distributed and required square root transformation. All transformations were effective, establishing normal distribution for all relevant variables, meaning, the z scores were all below 3.29, $p > .001$ (Field, 2013).

Furthermore, internal consistency was tested for all psychological measures, with a Cronbach's alpha of .89, .91, .81, .95 for the PHQ-8, the GAD-7, the SWL and the IBDQ, respectively, showing good to excellent reliability (Cronbach, 1988).

Participant Characteristics

The participant sample consisted of 88 adults residing in seven countries. Sample was largely White British female. In relation to the national identity, 76.1% identified as British or English with the rest being split between nine other nationalities. Majority (96%) being resident in the UK with remaining 4% indicating Canada, USA and Poland as their country of residency. Comprehensive summary of their baseline characteristics is shown in Table 6.

Table 6.

Baseline Characteristics of Participants Recruited for this Study.

Demographic Variables	
Gender	
N Female (%)	62 (70.50%)
N Male (%)	25 (28.40%)
N Not disclosed	1 (1.14%)
Age Category	
N 18-24 (%)	15 (17.00%)
N 25-34 (%)	30 (34.10%)
N 35-44 (%)	20 (22.70%)
N 45-54 (%)	13 (14.80%)
N 55+ (%)	10 (11.40%)
Ethnicity	
N White – English/ Welsh/ Scottish/ Northern Irish/ British (%)	71 (80.70%)
N Any other White Background (%)	8 (9.10%)
N Mixed – White and Asian (%)	3(3.40%)
N Asian – British (%)	1 (1.10%)
N Asian – Indian (%)	1 (1.10%)

N Asian – Pakistani (%)	2 (2.30%)
N Other – Arab (%)	1 (1.10%)
N Other – Not specified	1 (1.10%)
Relationship Status	
N Single (never married or never had a civil partnership) (%)	25 (28.40%)
N Married (including separated) (%)	38 (43.20%)
N Living with a long-term partner without entering a formal union (%)	20 (22.70%)
N Divorced (including those who have legally dissolved their civil partnership) (%)	5 (5.70%)
Employment	
N Employed (full- time) (%)	40 (45.50%)
N Employed (part- time) (%)	16 (18.20%)
N Employed (zero hours contract) (%)	1 (1.10%)
N Self- employed (including contractors, freelancers, and gig economy opportunities) (%)	3 (3.40%)
N Unemployed looking for work (%)	3 (3.40%)
N Unemployed unable to look for work (%)	1 (1.10%)
N Homemaker/ Stay at home parent (%)	1 (1.10%)
N Retired (%)	2 (2.30%)
N Student (full- time, part- time) (%)	20 (22.70%)
N Not disclosed (%)	1 (1.10%)
Highest Educational Attainment	
N Higher Education and Professional/vocational equivalents (%)	67 (76.10%)
N A- levels, vocational level 3 and equivalents (%)	16 (18.20%)
N GCSE/ O- level grade A* - C, vocational level 2 and equivalents (%)	4 (4.50%)
N Other qualifications, not specified (%)	1 (1.10%)
Disability Status	
N Yes (%)	43 (48.90%)
N No (%)	44 (50.00%)

N Not disclosed (%)	1 (1.10%)

Of note, around a third of our participants felt that their experience of IBD had a negative impact on their career and education (See Table 7).

Table 7.

Perceived impact of IBD on Employment and Education.

Impact of Inflammatory Bowel Disease (IBD) on Employment	
N Yes (%)	33 (37.50%)
N No (%)	44 (50.00%)
N Not sure (%)	10 (11.40%)
Impact of Inflammatory Bowel Disease (IBD) on Education	
N Yes (%)	34 (38.60%)
N No (%)	48 (54.50%)
N Not sure (%)	6 (6.80%)

21.6% (N = 19) of participants were prescribed psychotropic medication and 11.40% (N = 10) were engaged with a form of 'talking therapy' at the time of this study.

Regarding disease characteristics, the sample was largely made of those with a diagnosis of Crohn's disease (CD) or Ulcerative Colitis (UC) with a small number of other diagnoses and were prescribed a broad range of medications to relieve IBD symptoms (See Appendix J). Diagnostic labels were received by participants between 1983 and 2021 and the length of diagnostic process ranged from 0.5 to 360 months

(*M=21.87, Median = 7, SD=51.76, IQR= 21.00)*. Of our sample, participants lived with the condition anywhere from six months to 41 years (*M= 13.03, Median = 12, SD= 9.85, IQR= 14.00)* and reported between 1 to 27 'flare-ups' since diagnosis *(M = 6.37, Median = 4, SD = 6.58, IQR = 9.00)*. Table 8 shows an overview of baseline disease characteristics in more depth.

Table 8.

Baseline IBD Characteristics of Participants Recruited for this Study.

Disease Variables	
Diagnosis Type	
N Ulcerative Colitis (UC): Ulcerative Proctitis, Left-Sided Colitis, Extensive Colitis (%)	33 (37.50%)
N Crohn's Disease (CD): Ileocolitis, Ileitis, Gastoduodenal, Jejunoileitis, Granulomatous (%)	52 (59.10%)
N Other (%)	3 (3.40%)
Presence of Fistula	
N Yes (%)	18 (20.50%)
N No (%)	57 (64.80%)
N Not sure (%)	13 (14.80%)
Presence of Stoma/Pouch	
N Yes (%)	12 (20.50%)
N No (%)	76 (86.40%)
Disease Stage	
N 'Flare-up' (%)	24 (27.30%)
N Remission (%)	53 (60.30%)
N Not sure (%)	11 (12.50%)

Baseline analysis of associations

Significant associations were found between all four baseline wellbeing measures, see Table 9.

Table 9.

Associations (Pearson's r) Between Measures of Subjective Wellbeing.

Baseline Variable	PHQ-8	GAD-7	SWL	IBDQ
PHQ-8	1	**.78****	**-.60****	**-.73****
GAD-7	**.78****	1	**-.48****	**-.67****
SWL			1	**.45****
IBDQ	**-.73****	-.673	**.45****	1

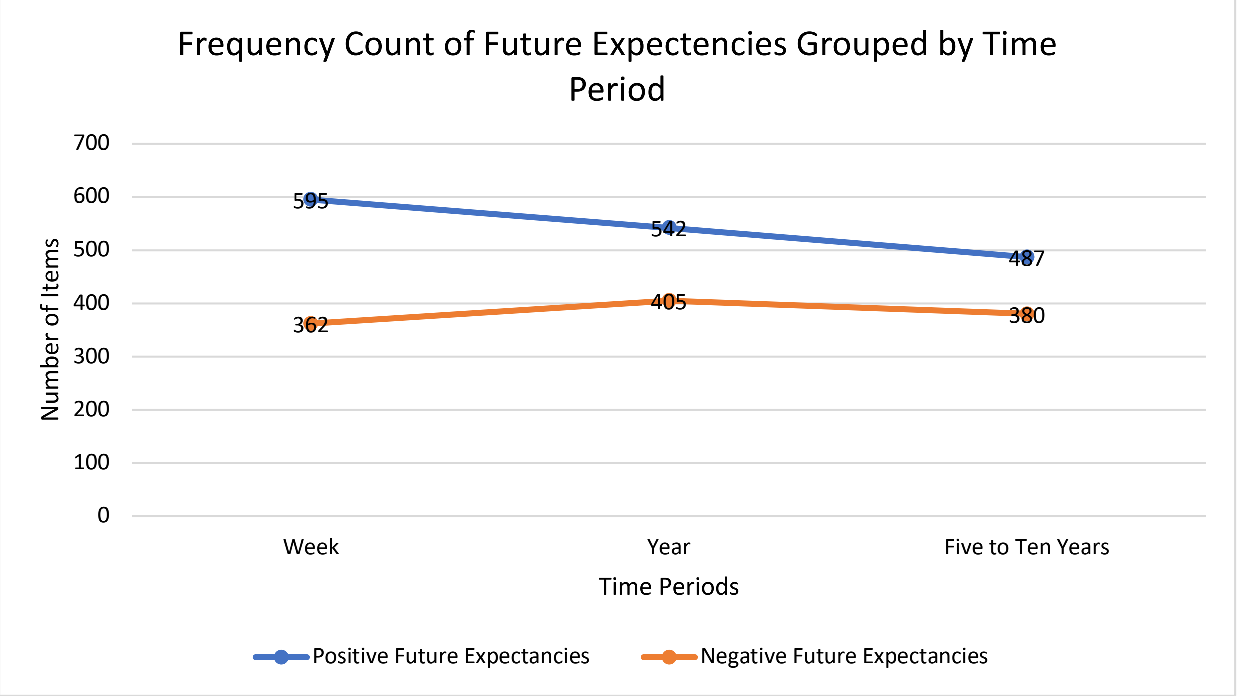
** Correlation is significant at the .01 level (2-tailed)
* Correlation is significant at the .05 level (2 – tailed)

Number of future positive and negative thoughts and subjective well-being

Participants were able to express between 8 and 30 things they looked forward to (*M= 18.45, SD= 5.30*), and 4 and 22 things they did not look forward to *(M= 13.03, SD= 4.28)* across the combined time periods of the FFT (See Figure 3).

Figure 3.

Frequency count of both 'Positive' and 'Negative' Future Expectancies at Each Time Period of The Future-Thinking Task.



Before examining the relationship between well-being and future-thinking, correlations were carried out between verbal fluency and each of the well-being measures. Verbal fluency correlated with overall number of 'positive' future thoughts *($r = .30, p <.001$)* and with overall number of 'negative' future thoughts ($r = .30, p < .001$). Number of 'positive' and 'negative' thoughts also correlated with each other ($r = .621, p < .001$).

To ascertain the unique associations between each wellbeing variable and both positive and negative expectancies over and above verbal fluency four hierarchical multiple regressions were carried out. Each wellbeing variable was entered as the dependent with verbal fluency held constant and number of things looked forward and not looked forward to as independent variables.

Verbal fluency did not significantly contribute to variance in depression (F(1,86) = 1.10, p = .30, R^2 *= .01, adjusted* R^2 = .001). Adding positive and negative expectancies at Step 2 did not significantly increase the variance explained *(F(2,84) = .70, p = .50,* R^2 *= .03, adjusted* R^2 *= - .01)* and the partial regression coefficients showed that neither positive *(t(84) = -1.11, p = .27)* or negative *(t(84) = .98, p = .33)* expectancies made significant unique contributions to depression scores.

Similar non-significant patterns were found across other wellbeing measures. In relation to variance in anxiety (*F(2,84) = 2.07, p = .13,* R^2 *= .05, adjusted* R^2 *= .01; t(80) = 1.42, p = .24)* and the partial regression coefficients showed that neither positive *(t(84) = -.15, p = .88),* nor negative *(t(84) = 1.74, p = .09)* made unique contributions*;* general satisfaction with life *(F(2,84) = .34, p = .72,* R^2 *= .01, adjusted* R^2 *= - .02; t(80) = .40, p = .76)*, and the partial regression coefficients indicating no significant unique contributions from positive *(t(84) = .26, p = .80),* or negative *(t(84) = -.781, p = .44)*. Finally, health-related quality of life showed a similar pattern: *(F(2,84) = .66, p = .52,* R^2 *= .03, adjusted* R^2 *= - .01; t(80) = .78, p = .51)* with positive *(t(84) = .65, p = .52),* nor negative *(t(84) = -1.15, p = .25)* partial regression coefficients. Therefore, in relation to Hypothesis 1, we did not find significant associations between levels of either positive or negative future expectancies and subjective wellbeing in our sample of ‘working-age’ adults who are diagnosed with IBD.

Furthermore, an exploratory analysis of these associations at each future time-period of the FFT task was conducted in case any different effects were present. The three future time periods were added at Step 2 for positive and negative expectancies.

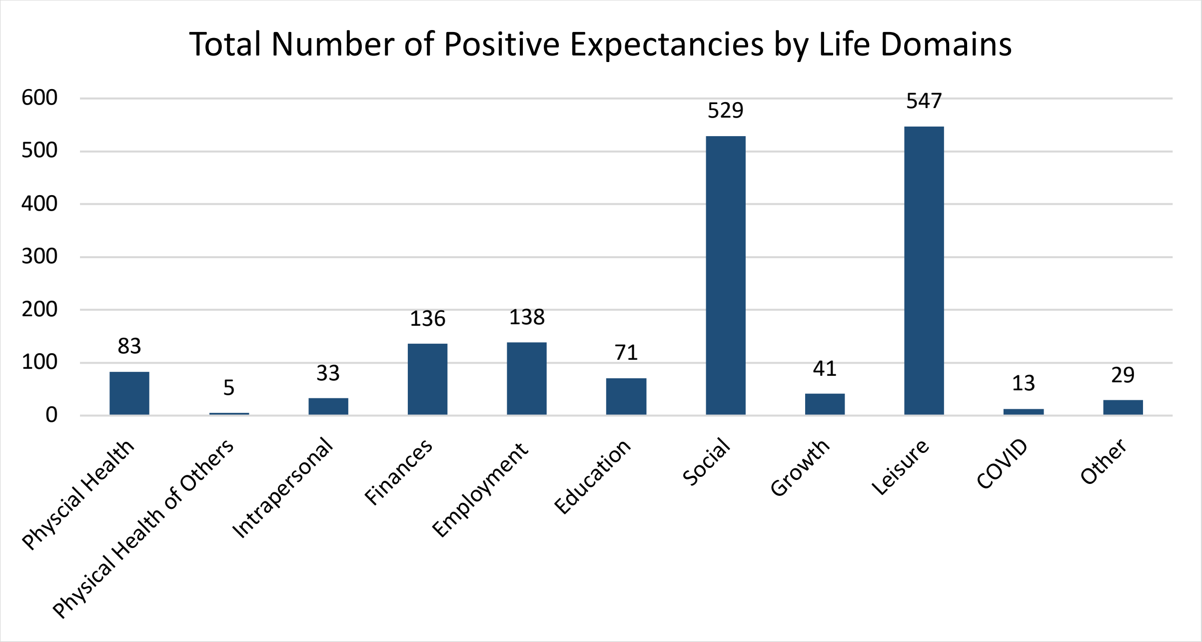
In relation to anxiety levels and both negative and positive expectancies within the next week, the predictor variables at Step 2 contributed to a significant increase in variance explained from 0% to 8%, a change that was statistically significant *($F(2,84) = 3.76, p < .05, R^2 = .08$, adjusted $R^2 = .05$)*. In the final equation, only anxiety made a significant unique contribution to explaining number of things not looked forward to within next week ($t(80) = 2.72, p < .05$), meaning a higher number of things not looked forward to in the next week predicting higher anxiety.

Content of Thoughts and Wellbeing

In relation to number of things participants looked forward to the most referenced life domains were overwhelmingly interpersonal and leisure activities followed by items related to employment and finances (See Figure 4).

Figure 4.

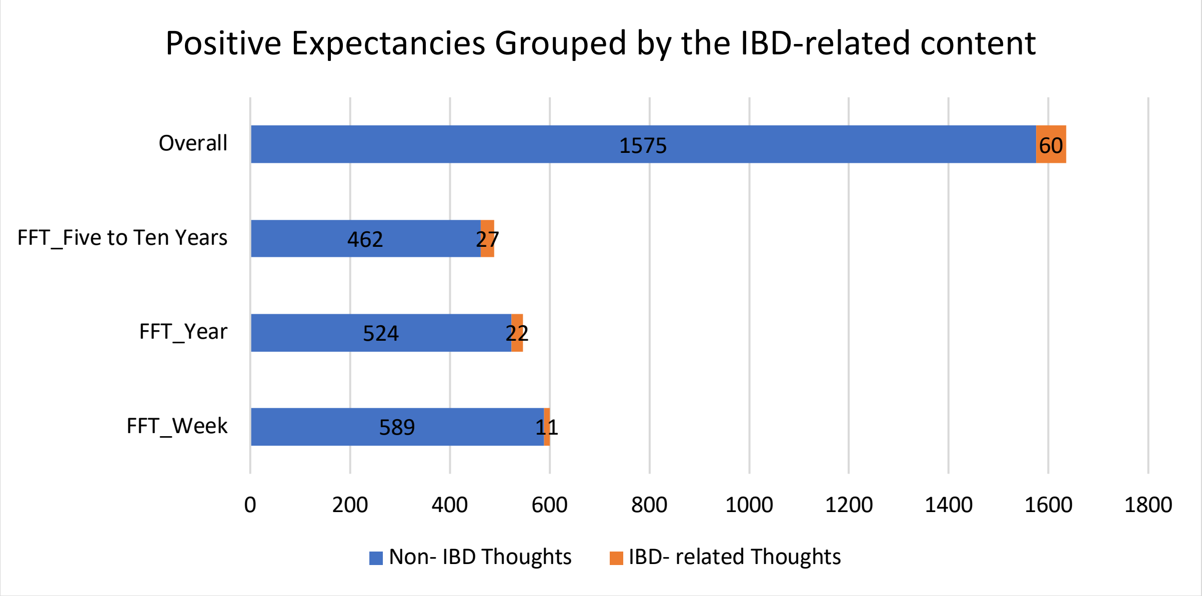
Frequency Count Illustrating Total Number of 'Positive' Future-directed Thoughts Grouped by Life Domains.



The content of thoughts was explored further by examining if content relates to IBD or not. Overall, out of all items relating to the number of things people looked forward to (n = 1635) only 3.67 % (n = 60) were linked to IBD (See Figure 5).

Figure 5.

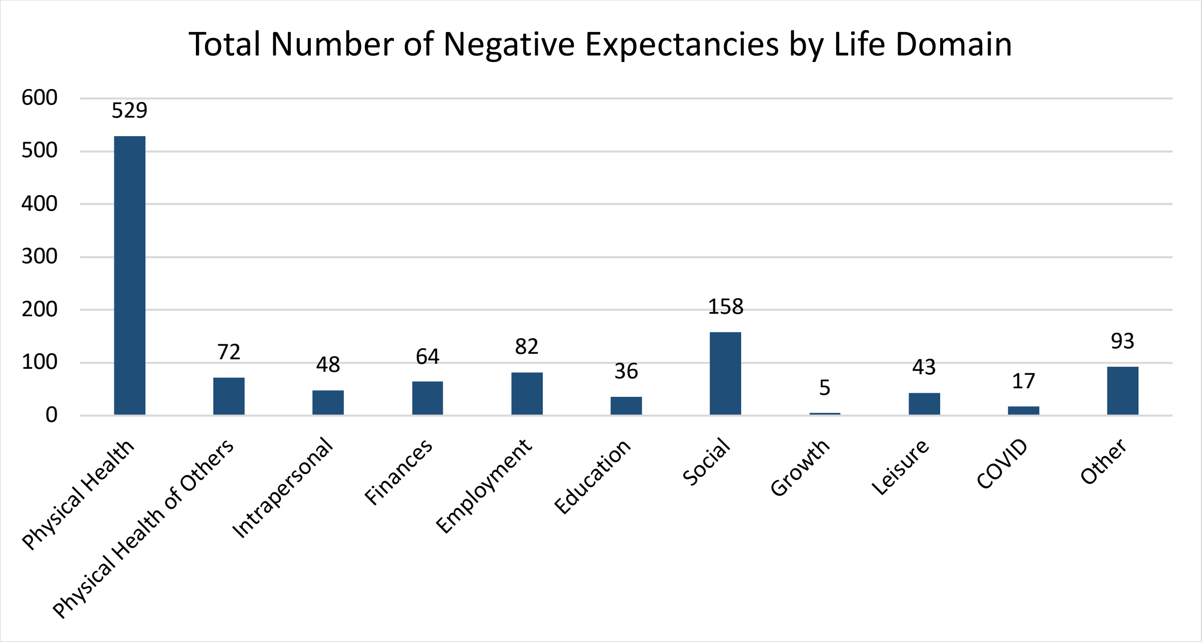
Frequency Count of 'Positive' Expectancies for all Life Domains Broken Down by Content Relating to IBD or not.



In relation to number of things participants did not look forward to most referenced life domains included, physical health and interpersonal activities (See Figure 6).

Figure 6.

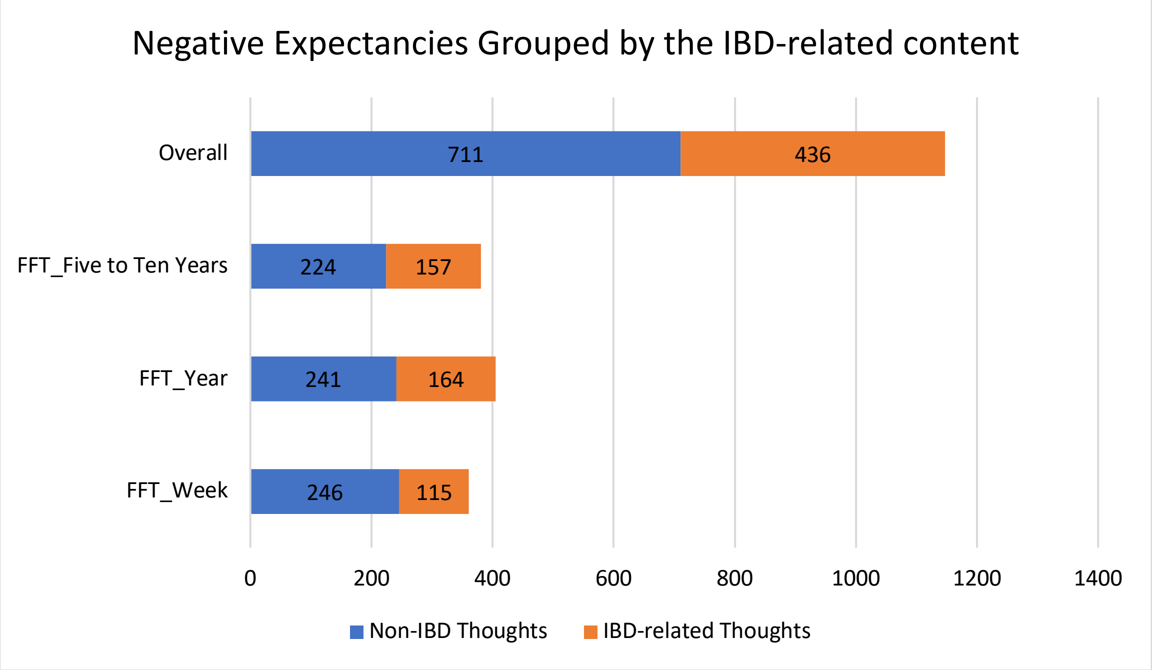
Frequency Count Illustrating Total Number of 'Negative' Future-directed Thoughts Grouped by Life Domains.



The content of negative future expectancies was explored in the exact same way as described previously. Overall, out of all items relating to the number of things people did not look forward to (n = 1147) 38.01% (n = 436) were linked to IBD (See Figure 7).

Figure 7.

Frequency Count of 'Negative' Expectancies for all Life Domains Broken Down by Content Relating to IBD or not.



Sense of Absorption

Hypothesis 2 was that a greater proportion of future thoughts related to IBD will be related to higher levels of anxiety and depression and lower levels of life satisfaction. For example, a future-directed positive thoughts linked to IBD included items such as *'the hospital treatment next week will make me feel better', 'In five to ten years I will be managing condition properly'* or *'continuing lack of flares'* whereas negative thoughts related to IBD included statements such as *'my treatment failing', 'having to take leave [at work] because of IBD'* or *'worrying about operation for Crohn's'*.

Therefore, to offer insight into this, 'sense of absorption' variables were created that represented the proportion of IBD-related thoughts as a function of total thoughts, calculated for positive and negative expectancies separately. These two variables were correlated with all four well-being measures. Subsequently, further exploratory analysis was conducted examining each time-period in case any temporal effects were present (See Table 10).

Table 10.

Association (Pearson's r) between proportion index of IBD-related to non-IBD related thoughts and subjective levels of wellbeing.

Baseline Variable	**Positive Expectancies**			
	Total	FFT_Week	FFT_Year	FFT_Five to Ten Years
PHQ-8	**.26***	.10	.18	**.23***
GAD-7	.15	-.01	.20	.13
SWL	-.11	.06	-.11	-.08
HRQoL	**-.33****	-.17	**-.22***	**-.31****
	Negative Expectancies			
	Total	FFT_Week	FFT_Year	FFT_Five to Ten Years
PHQ-8	- .02	.11	.03	-.17
GAD-7	-.02	.08	.02	-.11
SWL	.09	.02	-.01	**.22***
HRQoL	**-.25***	**-38****	-.17	-.01

** Correlation is significant at the .01 level (2-tailed)
* Correlation is significant at the .05 level (2 – tailed)

Overall, individuals who were more likely to link items that they look forward to with IBD showed higher levels of depression and lower health-related quality of life. This was also mainly the case when we examined longer-term positive expectancies, but not immediate future (See Table 10). Furthermore, individuals who were more likely to associate the number of things they *do not* look forward to with IBD showed overall lower health-related quality of life (r = -.25, p <.001). For the supplementary visualisation of the significant associations found between the total IBD-related 'sense of absorption' and psychological wellbeing measures see Appendix K.

Given the fact that health-related quality of life questionnaire showed the clearest correlations with proportion index of IBD-related to non-IBD related thoughts, a separate analysis investigating its four subscales was conducted (Table 11). Analysis revealed associations between all four subscales and overall 'sense of absorption' with IBD in positive future expectancies. However, links seem sensitive to temporal aspect of FFT and are somewhat stronger for the systemic *(r = -.41, p<.001)* and emotional subscales *(r = -.42, p<.001)*. In relation to negative future expectancies the overall negative association was found between the proportion index and the systemic symptoms *(r = -.28, p< .001),* meaning that individuals who proportionally identify more negative future expectancies related to IBD are more likely to report difficulties with fatigue and lack of energy, issues with weight and general wellness as well reduced ability to get a good night sleep. Lastly, all four subscales showed associations with higher proportion of IBD-related negative future expectancies within the context of immediate future.

Table 11.

Associations (Pearson's r) between IBDQ four subscales and participants subjective entanglement with IBD, expressed as a proportion of IBD-related content in their positive and negative future-directed thinking.

IBDQ Subscale	**Positive Expectancies**			
	Total	FFT_Week	FFT_Year	FFT_Five to Ten Years
Bowel Symptoms	**-.24***	-.14	-.08	**-.27***
Systemic Symptoms	**-.41****	-.21	**-.25***	**-.39****
Emotional Function	**-.42****	-.21	**-.30****	**-.37****
Social Function	**-.33****	-.17	**-.31****	**-.22***
	Negative Expectancies			
	Total	FFT_Week	FFT_Year	FFT_Five to Ten Years
Bowel Symptoms	-.20	**-.31****	-.12	-.04
Systemic Symptoms	**-.28****	**-.38****	**-.22***	-.03
Emotional Function	-.19	**-.31****	-.19	.09
Social Function	-.19	**-.34****	-.12	.03

** Correlation is significant at the .01 level (2-tailed)
* Correlation is significant at the .05 level (2 – tailed)

Discussion

The first aim of this study was to investigate how people diagnosed with Inflammatory Bowel Disease (IBD) think about their personal futures in terms of number of positive and negative expectancies using the FFT.

The present study did not find evidence supporting the link between quantitative disturbance in positive and/or negative future expectancies and levels of subjective wellbeing in people who are chronically ill. The results therefore fail to support previous studies postulating that higher levels of positive future expectancies relate to lower levels of depression/anxiety or that higher levels of negative future expectancies relate to higher levels of depression/anxiety and lower levels of life satisfaction (Godley et al., 2001; MacLeod et al., 1997; Macleod & Conway, 2005; Moore et al., 2006). Several factors might have contributed to this outcome. It remains possible that living during the global pandemic impacts on cognitive processes more fundamentally, for example, in terms of the frequency of engagement with prospective cognitions as well as its content (Niziurski & Schaper, 2021) inadvertently influencing our findings. It is also possible that when temporal orientation is restricted, through factors like the global pandemic, age, and/or presence of chronic illness, psychological wellbeing is preserved in individuals who switch to more value/purpose – driven thinking as postulated by the socio-emotional selectivity theory (Lang & Carstensen, 2002), which our study did not explore. This might explain why more consistent effects were observed within more immediate future, but not later time-periods. It is also possible that differences exist between participants with a childhood/adolescent versus adult onset IBD in terms of their perceptions of subjective life-trajectory disruptions and assumed roles, which our study did not consider in its methodology (Gibson et al., 2009). Again, this might at least partially explain inconsistent effects observed across future time-periods in the present study.

Furthermore, given the uniqueness of each physical illness it is possible that being diagnosed and living with the unpredictability of Inflammatory Bowel Disease alters prospective cognitions in more bespoke ways that this study was not sensitive enough to detect (Byron et al., 2019). Anecdotally, some participants spoke about finding the FFT task difficult as they tend to avoid thinking about their future in a such pre-determined way given perceived likelihood of disease interreference. It also seems likely that certain disease characteristics, for example, number of years living with the condition might influence and/or shift the way in which people engage with prospective cognitions. Therefore, with insufficient sample stratification our study was underpowered to detect any possible patterns. This might also explain inconsistent findings across different psychological measures found in the present study. For example, a study by Caroll et al., (2020) found associations between younger age at the time of diagnosis and/or shorter time since it was made and higher levels of distress in women diagnosed with Mayer-Rokitansky-Kuster-Hauser Syndrome. Taken together, it seems as though temporal orientation in relation to personal values and/or precise point of diagnosis within the context of subjective life-trajectory might be interesting avenues in IBD research and future studies could adopt a life-span perspective to allow direct comparisons.

Our results were also inconsistent across different wellbeing measures, indicating significant links between depression, anxiety and health-related quality of life more consistently than satisfaction with life. It is possible that the selected measures restricted our investigation and that perhaps other psychological constructs, namely, resilience (i.e., ability to ‘bounce back’) (Luo et al., 2019), interpersonal coping and support (Helgeston et al., 2017), self-compassion (Sirois, Molnar & Hirsch, 2015) or 'illness identity' (Oris et al., 2018; Van Bulck et al., 2018) are more significant for psychological wellbeing in individuals who are chronically ill. It might be useful if future research broadens the scope of subjective wellbeing measures to build on current findings.

Lastly, a non-significant finding might also support an argument that when it comes to certain chronic illnesses it may not be the quantitative disturbance of prospective cognitions, but its actual properties that are associated with psychological wellbeing.

The second aim of the study was to explore illness-related differences in relation to the content of prospective cognitions. Results suggest an association between individual 'sense of absorption' with the disease and levels of emotional wellbeing. Importantly, the entanglement was present in both positive and negative expectancies. Our findings support the argument made by Moore et al., (2006) that a greater proportion of prospective cognitions related to the disease might hinder levels of psychological wellbeing. This is also in line with wider literature pertaining to the impact of chronic illness on identity formation (Wicks et al., 2018), perceived identity changes (April et al., 2021), as well as ongoing management to identity threats (McGonagle & Barnes-Farrell, 2013) and navigating between illness centrality and compartmentalising (Bowins, 2012; Horky et al., 2017; Nwakego et al., 2020; Van Bulck et al., 2019) all linking the presence of cognitive pre-occupation with the disease to psychological distress. Of note, a very recent study examining the concept of 'illness identity' in adults diagnosed with IBD has found overall higher scores on 'rejection' and 'engulfment' domains compared to adults with congenital heart disease across its sample. These patterns were also correlated with higher depression scores and lower life satisfaction alongside poorer health-related quality of life directly corroborating our findings (Rassart et al., 2022).

The wider determinants of health cannot be overlooked when investigating the role of prospection as a function of subjective wellbeing in people who are chronically ill. In terms of the relationship between socio-economic factors and prospection, a study by MacLeod and Conway (2005) showed an association between reduced social network and lower earnings, and reduction in positive future anticipation. Similar pattern shown by those who are depressed and/or suicidal (MacLeod, 2017). Furthermore, the positive link between social and/or work participation, economic security and psychological wellbeing is well-documented across various populations, including people who are diagnosed with long-term physical health conditions (Bell et al., 1997; Dunstan et al., 2017; Tomaszewski et al., 2013; McPeake et al., 2019). Of our sample, a third of participants felt that either their employment and/or career had been negatively impacted by IBD. Some of the reasons provided included lack of flexibility and insufficient adjustments, issues around access and suitability of toilet facilities, missing out on opportunities and/or being penalised for incidents of absence, brain fog and fatigue impacting concentration and efficiency and being limited in terms of types of jobs/courses participants felt able/comfortable in applying for. This is particularly important as higher rates of ‘absenteeism’ have been noted amongst individuals who struggle to detach from their illness (Na et al., 2021) and lack of meaningful activities is associated with psychological distress, providing new preventative and treatment avenues. Related to this, nearly 50% of our sample identified with a form of disability. Although extensive framework exists protecting people with disabilities from unfair treatment (The Human Right Act 1998; The UN Convention on the

Rights of People with Disabilities, 2009; The Equality Act 2010; The Disability Act 2014), many continue to experience varying forms of discrimination, ranging from ‘microaggressions’ to the institutional and societal discriminatory practices and attitudes (Dovido et al., 2011; Kattari et al., 2018; 2020). This is particularly important as many studies have shown that experiences of discrimination are associated with poorer mental health (Lett et al., 2020; Nadal et al., 2018; Paludi et al., 2013), isolation, reduced social participation as well as reduction in earnings (Negi et al., 2013; Madden et al., 2004). For example, a study by Kattari (2020) showed that experience of ‘ableist’ microaggressions specifically, correlate with reduced scores on the Mental Health Inventory (MHI-18), meaning that those who have been discriminated against are more likely to experience poorer mental health. Therefore, drawing on the Bronfenbrenner’s ecological systems theory (1992), it seems probable that creation of inclusive and equalitarian opportunities for people with chronic illnesses might help detach from illness and/or think about their future more broadly which seems to have a positive influence on psychological health.

Finally, it is important to note that associations found in our sample between number of positive and negative thoughts were much stronger ($r > .60$) than previously found in research (Godley et al., 2001; Macleod & Conway, 2005). Although our analysis has been mindful of the problem of data-based multicollinearity (Farrar & Glauber, 1967) it remains possible that suppressing effects between these two variables negatively affected precision of our analysis.

Limitations

This study had number of limitations. Given strict social distancing rules imposed at the time, the present study was advertised and conducted exclusively online, inadvertently imposing expectation on access to the means and certain level of digital competence (Watts, 2020). The study sample is female- dominated, relatively academically accomplished with the majority of participants identifying as 'White', limiting generalizability of our findings. Further research would benefit from capturing experiences of the more representative sample of people who are diagnosed with IBD, and efforts should be made to address barriers populations traditionally referred to as 'harder-to-reach' face regarding research participation (Dawson, 2018).

Furthermore, the present study utilises the correlational design, preventing detection of any causal links. It also remains possible that prospection has significant but only a small effect on psychological wellbeing in illness, which our study might have been underpowered to detect. As such, it might prove useful if future research focuses on the more rigorous methodology and benefits from recruitment of a control group of healthy individuals to enable direct comparisons.

A further limitation relates to the measures, which were exclusively self-reported. As such, it remains possible that disease characteristics were inaccurately reported and the concept of 'psychological wellbeing' too reductionist to capture meaningful effects. Related to this, it is possible that the FFT, which aims to elicits cognitive processes is not immune to social desirability effects (Dodou & de Winter, 2014), consequently preventing people from speaking openly about less comfortable topics, like sex, body image, defecation or stigma associated with IBD. It is also likely that lack of vocabulary or individual level of confidence have further influenced items reported by the participants.

It is also important to acknowledge that both blocks (i.e., positive and negative expectancies) of the FFT were not counterbalanced across the participants. The counterbalancing refers to a purposeful manipulation of the order in which experimental conditions are administered and is usually recommended in experimental studies to minimise the influence of any carryover and/or order effects (Pollatsek & Well, 1995). This has been omitted in this study motivated by the feedback received from the service users and counterbalancing not being a core part of the FFT. However, such omission might have negatively affected internal validity of this study, reduced its power of statistical inferences and is not in line with some of the previous studies using the FFT (Lavender & Watkins 2004; MacLeod et al., 2005). In hindsight, counterbalancing would be recommended for future studies.

The final limitation is around difficulties encountered when attempting to account for disease severity. To the best of my knowledge, IBD severity is most conceptualised through measure of disease activity, an approach that is also widely criticised (Falvey et al., 2015; Ringel & Drossman, 2001) and has been unacceptable to the service users we consulted during the study development stage. Furthermore, it is possible that a discrepancy exists between 'medical parameters' of the disease severity and patient's subjective evaluations of it. Yet, it is the personal evaluations that have been linked to psychological states rather than the objective metrics (Callus et al., 2013). Nevertheless, disease severity accounts for a small amount of variance in reports of subjective wellbeing in people diagnosed with IBD (Reed-Knight et al., 2016) and is a common confounder. Unfortunately, it proved insufficient to simply ask participants to indicate if they are in 'remission' or 'active' stage of their disease as a significant proportion of people recruited in this study did not feel able to answer this question. This prevented us from 'controlling' for this variable and it remains possible that our findings have been affected by this. Future research would benefit from prioritising standardisation of methodological approaches.

Conclusion

In summary, the present study furthered our understanding of variations in wellbeing and psychological distress in people diagnosed with IBD through examining one factor that might account for these differences – future-directed thinking. The current study found some evidence to support the argument that it is the content not the quantity of the future-directed thoughts that relates to psychological wellbeing in illness, providing important implications for the prevention, assessment, and treatment of psychological distress in IBD.

Integration, Impact, and Dissemination Summary

Integration

To offer a more personal view, I suspect that if there was an origin story to the current thesis, it should probably start in a small therapeutic room with a relatively novice therapist simply conversing with another person. I have found myself in this proverbial 'therapeutic' room many times over the course of the clinical training. There, I was exposed to the subjective life-trajectories that, at least at the first glance, often appeared different to my own. Still, it remains a humbling experience to recognise how much is actually being shared between two people in that 'therapeutic' space and perhaps this is what gave rise to the subject of this thesis.

A presumption exists in many cultures that when '*we plan, God laughs*[4]', yet it is unequivocally human to picture future possibilities even if things have a way of

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[4] *"Mann Tracht, Un Gott Lacht"* is an old Yiddish proverb

not always turning out exactly as we had imagined. This predisposition has been argued to be both adaptive and important to our psychological health and when disrupted can spark widespread consequences (MacLeod, 2017). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) a hallmark of common mood disorders, such as depression and anxiety, is the preoccupation with adverse events (APA, 2013), whereas proponents of 'positive psychology' argue that it is precisely this skewed perception of the future specifically that is central to the psychological distress (Seligman, 2011). As such, it has been argued that future directed- thinking may impact present feelings and more immediate behaviours (Gilbert & Wilson, 2007). Moreover, a chronic illness is a good example of how future-directed thinking may be challenged, putting mental health of a steading growing population at risk (DOH, 2012). Yet, it remains an area largely neglected, creating a significant gap in our knowledge. It may also present an interesting avenue for prevention and treatment efforts in relation to psychological distress in people who are diagnosed with long- term physical health conditions.

In short, the overarching aim of the current research is best thought of in terms of augmentation of the well-known cultural reference through consideration of what can be done *to make people laugh again after their plans had changed* due to chronic illness. As such, I set out to investigate how interruptions to the personal life-trajectory relate to the levels of psychological wellbeing in people who are physically unwell, as well as to study one's ability to think prospectively as potentially influential factor related to the subjective wellbeing. It was hoped that this might offer further insight into the role of prospection in chronic illness and identify possible opportunities for future research and clinical practice. To this end, a systematic review was conducted investigating postoperative levels of psychological wellbeing in adults diagnosed with Inflammatory Bowel Disease (IBD) and an empirical study examined the role of prospection in explaining variable levels of wellbeing in similar population. These investigative efforts were partially able to address my aim.

To a certain degree, I was surprised to observe the poverty of the psychological discourse within the field and limited use of validated measures to assess levels of postoperative distress in IBD specifically. The lack of studies investigating preoperative period, religiosity, or impact of these invasive procedures on intimate relationships and caring roles has been noted. This is particularly surprising given the presence of wider literature in relation to pre-/post- operative psychological distress across other clinical populations (Ai et al., 2007; Palapattu et al., 2004; Sorel et al., 2019; Syeinsdottir & Skuladottir, 2012) and high prevalence rates of surgical interventions in IBD (Cosnes et al., 2022). Upon reflection, the decision to restrict our eligibility criteria in favour of a quantitative methodology inadvertently positioned our discourse within a relatively narrow epistemological lens. It is probable that many pre-/post- operative experiences simply cannot or are impractical to be captured using standardised measures, consequently enabling me to present only a partial narrative. In some qualitative studies pertinent descriptions around surgeries for IBD spoke to anxiety, worries and expectations within preoperative period, a sense of involvement in decision-making, possible gender differences regarding intimate relationship and issues around body image in young adults as well as challenges of the ‘transition into a new life’, memories of the disease and ideas around long-term outcomes all impacting levels of postoperative subjective emotional wellbeing (Allison et al., 2013; Dibley et al., 2018; Morris & Leach, 2017). Therefore, it might prove useful if future research considers its epistemological stance by reviewing its assumptions carefully and endeavours to build on our findings in more balanced way.

Another area of reflection for me has been the unsuccessful attempts made to form a supervisory connection with an IBD healthcare professional, which has been a limitation of the current research. The fact that the review benefited from input from the Information Services Consultant during conception of the search strategy alongside support of an independent reviewer, service user input and close supervision during the process are relative strengths, in the absence of professionals within IBD services. However, the lack of established relationships within academic structures alongside bureaucratic barriers I have encountered have been surprising to me and made me wonder about potential benefits of a longer-term strategy regarding research requitements for the degree of Doctor in Clinical Psychology and how these are supported. I personally found it challenging to systematically search for and review publications which often were very technical and 'medicalised'. The process has not only been a very time-consuming one but at times difficult and overwhelming. It remains possible that without expert guidance some of our language is 'too simplistic' and bleaches complexities of the medical field. Therefore, establishing close multidisciplinary working relationships might prove useful to future research in the field addressing methodological flaws and broadening focus towards neglected areas (Gobet, 2018).

Upon reflection, the pragmatic decision taken to review publications only written in English has not only restricted data available to this research but also presented a personal dilemma. According to the World Migration Report (2022) we are currently experiencing unprecedent levels of mobility driven by socio-political contexts and globalisation trends. As such, fabrics of many societies are changing, comprising of rapidly expanding groups of culturally diverse people (Moleiro et al., 2018). This presents a challenge to many services given presence of individual and systemic barriers minority groups face when accessing support (Conner et al., 2022; Mayeda & Ward, 2019; McFadden et al., 2018). At the same time, minority groups are more likely to experience higher rates of poorer mental health often related to experiences of marginalisation, discrimination, and socioeconomic disadvantage (Molerio et al., 2018). Furthermore, there are well-documented patterns of under-representativeness of the Clinical Psychology workforce of the population it serves (Health & Social Care Information Centre, 2013). Of note, in 2020, only 5% of applicants reported non-UK based residency with nearly 65% of accepted applicants identifying as 'White British' (Clearing House, 2020). This continues to present challenge and might have far-reaching consequences, to name a few; lack of adequate support and training within areas of difference and diversity, poverty of thought and perspectives further perpetuating status quo in health services (Wood, 2020). Therefore, as a person who identifies with a minority status and a bilingual practitioner, I was presented with a unique opportunity to highlight more internationally inclusive literature. Now, I wonder if by not moving towards potentially different pool of available publications a chance was missed to consider contributions towards minimising the dominance of Western-culture narratives in the scientific discourse (Kerr, 2014). My personal detachment is surprising and particularly saddening given the NHS Knowledge and Skills Framework (DOH, 2004) recognising diversity as one of the six core dimensions for skills development and existing competence during clinical training. In hindsight, I suspect that procedural barriers and lack of adequate support in helping me to navigate a 'dual sense of self' (Marcos et al., 1997) meant that my personal anxieties have been stiffening in this area (Cormier & Davis, 2012). This also made me wonder if existing training frameworks (BPS, 2019) are sufficient in supporting personal and professional growth of trainees who are uniquely positioned to continue to challenge 'monoculturalism' within the field (Sue, 2001).

Furthermore, the empirical study explored the role and properties of the future-directed thinking in people diagnosed with IBD and its unique contributions to variability in levels of subjective wellbeing. The study was supported by two large organisations within the IBD community which meant that I was extremely fortunate to meet the recruitment targets outside of the NHS structures. Establishing working-relationships with these organisations also meant that the present study benefited from their good standing and already established level of trust within the IBD community. This most likely enabled people to consider our study and readily engage with conversations about their personal futures. I was personally very moved by participants collective determination to improve psychological care in this area through research participation. Simultaneously, having to navigate sense of responsibility and personal anxieties as a relatively novice researcher was a challenge.

Furthermore, the Future Thinking Task has been traditionally administered during face-to-face appointments, which has not been possible to replicate given the rise of the global pandemic and strict social distancing measures put in place at the time this study was conducted. Upon reflection, although I was somewhat forced to utilise virtual platforms, this might have been another factor that contributed to the successful recruitment strategy. The remote appointments meant that I was able to have conversations with people across different settings (even countries) and managed to recruit people reporting significant disease activity. Participants spoke about feeling more comfortable in their own environment and appreciated reduction of additional burden such as time, costs and travel-related stress usually associated with more traditional research participation. On the other hand, I regret that due to pragmatic and safety reasons, it was not possible to expand our recruitment strategy to various medical and community settings creating opportunities for more diverse and representative population to be recruited into the study limiting the generalizability of results. Therefore, to a large extent, the present study contributes towards our understanding of prospection and postoperative levels of subjective wellbeing of people from 'Western, Educated, Industrialized, Rich and Democratic' society (WEIRD; Henrich et al., 2010). Taken together, the present study highlights the benefits of making bespoke adjustments and increasing flexibility in relation to study designs/procedures to maximise recruitment efforts and highlights the perpetual challenges of addressing issue of representativeness within psychological research.

Furthermore, the study design benefited from an input from two service users. Their valuable contributions encouraged me to revisit some of the presumptions I have initially made and highlighted some disconnect between my language, proposed methods and the 'real- world' applicability. Upon reflection, this might have been driven by my relatively limited experience in conducting experimental studies of this magnitude and simply replicating methodological frames that are commonly used to manage my initial anxieties. I believe that having an opportunity to consult with service users about their experiences and ideas enabled me to critically appraise the original research proposal and to make positive changes. I suspect this also contributed to all the recruited participants completing the study in its entirety with no missing data being encountered. However, this involvement also presented a challenge regarding proposed use of disease stratification methods. I was personally unsure how to strike balance between participants' acceptability and rigorous methodological approach alongside mixed views expressed in the literature in relation to disease activity indexes (Evertsz et al., 2013; Sexton et al., 2019; van Andel et al., 2020). This was helpfully attended to through the use of supervision. In hindsight, my consultation with the service users could have been strengthened by a co-production of a disease stratification tool which would have augmented our investigation. Similarly, due to pragmatic reasons, it was not possible to consult our participants regarding my approach to the process of quantification of prospective cognitions nor expand further on IBD-related coding. Although, the methodology seems robust and offers novel way of incorporating idiosyncratic experiences into frames of quantitative statistical analysis (Moore et al., 2008), it could have benefited from additional input from individuals diagnosed with IBD to increase its validity.

My final reflections relate to my own positioning within the present research. Drawing on a notion of the 'insider/outsider' status in research (Gair, 2012), I must acknowledge my position of an 'almost outsider' as I have personally not been diagnosed with IBD nor do I regularly work with people diagnosed with this disease. However, I would be guilty of omission if I did not acknowledge my indirect experience. Having witnessed IBD-related havoc to one's subjective life- trajectory with its particularities cloaked in silence inadvertently must have left an impression. I believe that having an 'almost outsider' lens has enabled me to be truly curious and open throughout the process. It also meant that collaboration with the service users and recruited participants occurred within more equal and balanced context, which forged stronger working- relationships and offered positive research experience. It also enabled me to build my knowledge incrementally and systematically contributing to my professional development. However, not being on the 'inside' personally had its downfalls. This meant I had to navigate my own anxieties around not only a relatively novel ‘researcher’ identity but also manage this within less familiar context of Inflammatory Bowel Disease. I also found myself frustrated with a slow pace of my progress often stalled by inaccessibility of the ‘insider language’ (Wright et al., 2018). Moreover, at present I am still left with a worry that my ‘outsider’ position meant that I was unable to develop a comprehensive enough perspective to invite all relevant views (Wright et al., 2018).

Impact

The present thesis has been positioned in a relatively novel context and responds to the public health priorities stipulated in the NHS long-term plan by focusing on the healthcare needs of people with long-term physical health conditions (LTCs) (NHS, 2019). The population of people with LTCs is growing in the UK (DOH, 2012) and studies have shown that people who are diagnosed with LTCs are much more likely to experience poorer mental health (Naylor et al., 2012). However, despite the fact that an extensive framework exists encouraging integration of traditionally separate ‘physical’ and ‘mental health’ services (King’s Fund, 2016; NHS Long Term Plan, 2019; NHS Parity of Esteem Report, 2016), psychological health of people with LTCs continues to suffer (Oliver, 2021). Therefore, this thesis reflects a collective aspiration to improve mental health of the population (Steptoe et al., 2015).

Moreover, according to the national IBD survey (2019), individuals who have reportedly experienced disease-related stigma are more likely to report difficulty in coping with the disease (Marshall et al., 2021). Therefore, it is hoped that by raising awareness of mental health and wellbeing within the IBD community, the present study supports an ongoing public conversation about IBD, harmful impact of stigma and encourages efforts to normalise IBD and mental health further (Muse et al., 2021).

Findings of this thesis have also highlighted the existence of a significant gap in our understanding of the implications, various surgical interventions for IBD might have on peoples' emotional wellbeing. As such, the present research responded to direct clinical need identified through the National IBD survey (2019), which showed that individuals who report insufficient knowledge regarding the disease and its treatment find it harder to cope with IBD (Marshall et al., 2021). It is hoped that by highlighting unmet needs of this population alongside significant gaps in the evidence-base and limited NICE guidelines the present study contributes towards calls for future research and further investment in the field. It seems likely that augmentation of the evidence-base will positively impact depth of the clinical guidelines in turn informing clinical consultations and improving patients' experiences of services and care provided. This also has a potential of strengthening the provision of psychological care through establishment of new care pathways, attracting new workforce and updating national policies (BPS Core Purpose and Philosophy of the Profession, 2001).

The present thesis also identified several methodological inconsistencies and limitations of the available evidence- base, which supports previous calls for action within scientific community (Olivera et al., 2019). It became clear that gaps exist between various stakeholders in relation to disease stratification, meaningful outcome measures and standard ways of reporting postoperative outcomes. It is paramount that a consensus is reached regarding outcome measures, should future research be able to build on these findings. Moreover, the present research reminds the scientific and clinical communities about the existing problem relating to the selection and participation biases in psychological research contributing to significant homogeneity of participants profiles and limited generalizability of reported findings (Thalmayer et al., 2021). A perpetual problem of the lack of diversity in psychological settings and research is a complex one and requires innovative approaches, which might be beyond the scope of the present research. Yet, I hope that the current thesis continues to open conversations about the challenges of incorporating diversity within limited and often systemically biased frames within which this thesis was constructed (Neblett, 2019). By highlighting personal reflections around challenges of navigating 'dual identity' and alluding to discrete and so far unmet needs of minority status trainees (The Alternative Handbook, 2021), the present thesis emphasises to the governing bodies of doctoral programmes in the clinical psychology improvement opportunities.

The present research also highlighted a few factors that contributed to the successful recruitment and participation strategy which included: working together with well- established organisations, making adaptations and being flexible with proposed procedures alongside utilisation of digital platforms (Falco & Kleinhans, 2018). This provides support for arguments put forward in relation to the importance of tailoring 'traditional' approaches to meet the needs of people with LTCs which positively impacts their subsequent engagement and satisfaction with services (Stamboglis & Jacobs, 2020). This is also in line with wider aspirations to harness the benefits of digital revolution in addressing various challenges within modern healthcare (NHS Long Term Plan, 2019). This might also be of interest to clinicians and organisations committed to working in the area of LTCs by adding to wider discourse in relation to benefits of supporting peoples' preferences and offering more favourable options (Beck et al., 2019).

The present study also supports the argument that to address complex healthcare needs of people diagnosed with IBD an effective model of multidisciplinary working is needed (IBD UK, 2021). As such, the present research is positioned within wider debate around further integration between somewhat fragmented and/or historically divided services (NHS Long Term Plan, 2019). To illustrate, the process of embedding mental health practitioners within traditionally 'physical' healthcare settings might help to raise the profile of mental health needs championing for research and quality improvement efforts in less common areas (BPS, 2010). This might also raise the profile and perceived utility of psychological formulation within 'physical' healthcare settings. As such it may encourage person-centred formulation of treatment plans identifying and addressing needs across various domains. It may also invite consistency in a way emotional needs of people diagnosed with LTCs are attended to.

Another way in which existing gaps could be bridged, is through increasing service user awareness and involvement in research and services by means of co-production and/or co-operative models of service delivery (Durose et al., 2012; Edelman & Barron, 2015; Horobin, 2016; Verschuere et al., 2012). The service user and recovery movements have been steadily growing in the UK and have some success in challenging 'traditional' ways of care delivery (Pemberton & Wainwright, 2014). Promoting service-user engagement might result in development of services that are closely embedded within the community and increase the overall knowledge regarding population needs. Consequently, this may create new opportunities for bespoke, effective, and sustainable health interventions (Gupta et al., 2019; Jo &

Nabatchi, 2018). It may also be possible that through strengthening public engagement of people who are both directly and indirectly affected by IBD, development of new knowledge and skills occurs. It may also be argued that positive psychological wellbeing can be achieved through increasing public engagement as service users might regain ownership and influence over their healthcare needs (Palumbo et al., 2019; Price et al., 2022). This might also support psychological wellbeing of the wider population by increasing sense of mastery, self-efficacy, and self-actualisation (Efendi et al., 2021). However, it is important to note, that such endeavours must not be tokenistic, and stakeholders should be mindful of an on-going commitment required (Romsland, 2019).

Furthermore, the main findings of the present study suggested that individuals who are 'absorbed' with their illness and consider their future to be closely intertwined with the disease are at risk of psychological difficulties. This furthers our understanding of the role of prospection in illness and contributes to psychological thinking around mental health difficulties in IBD. This may positively impact on psychological models, assessments and treatments offered within services (BPS, 2010). To date, research has shown that people with LTCs do not always find current therapeutic modalities effective (Delgadillo et al., 2018; Dickens et al., 2013) nor particularly acceptable, showing patterns of significantly higher drop-out rates and lower completion rates compared to people without LTCs (Geraghty & Scott, 2020). At the same time, it has been argued that many mainstream 'therapeutic' interventions seem somewhat removed from contextual realities of people with LTC, which when misapplied can unhelpfully locate 'the problem' within an individual (Grant, 2011). Therefore, offering inadequate support in relation to the challenges of the welfare systems, reduction in workforce participation and earnings, experiences of discrimination, marginalisation, and stigma as well as having to face pervasive societal ‘ableism’ narratives and inaccessibility of many public domains increases likelihood of rapture in therapeutic relationships and further alienation from mental health services (Caroll et al., 2020; Marks, 1996; O’Connell, 2012). Moreover, many clinicians express concerns regarding their ability to tailor therapeutic approaches appropriately, and feel deskilled when working with people with LTCs (Carroll et al., 2020). This might present a particular challenge in services oriented within a singular therapeutic modality and/or those with strongly embedded performance monitoring systems (Binnie, 2015; Steel et al., 2015). In such context it is possible that higher levels of stress and uncertainly reported by the therapists working with people with LTCs (Caroll et al., 2020) alongside increased likelihood of ‘poorer clinical outcomes’ people with long-term physical conditions report and/or are associated with, might lead to various negative outcomes. To name a few, relationship raptures, further alienation between this client group and mental health services as well as workforce burnout (Owens et al., 2021; Westwood et al., 2021). Therefore, incorporation of more purposeful therapeutic efforts to address disruptions within prospective thinking offers clinicians another useful avenue addressing their professional anxieties when working with people with LTC(s) (Caroll et al., 2020). Moreover, being mindful of societal narratives both patients and clinicians might benefit from shift within psychotherapy towards tackling impact of ‘ableism’ within personal narratives and healthcare system (Campbell, 2008; Kattari et al., 2018). This has potential to positively affect therapeutic relationships, clients’ engagement and deliver more satisfying clinical outcomes (Raynolds, 2018). The use of more comprehensive psychological formulations might not only assist in ‘making sense’ of clients’ distress but also help therapists to connect with feelings of empathy and compassion for clients that they might find personally ‘challenging’ to work with (Berry et al., 2008). As such, it is hoped that the present thesis offers further support and reassurance to therapists who are committed to working with people diagnosed with IBD and backs discussions around how therapeutic services are designed, monitored, and evaluated (Carroll et al., 2020; NHS England, 2019). It is also possible that the present study contributes towards tackling wider systemic issues around workforce burnout and high turnover of staff by enriching clinical repertoire and offering new directions (Johnson et al., 2018).

Finally, the present research highlighted and found some evidence to advocate for incorporation of wider socio-economic perspectives and cultural narratives within psychological discourse. It also supports proactive, multi-level efforts tackling societal ‘ableist’ narratives pertinent to positive psychological health of people with IBD. Drawing on the social GGRRAAACCEEESSS framework (Burnham, 2013; 2018) and paying attention to the exosystem level of the Bronfenbrenner’s ecological system theory (1992) it is also important that organisations and clinicians continue explorations, self-reflections around issues of difference and cultural diversity to address pervasive stance of ‘neutrality’ and ‘monoculturalism’ and be able to create safe and inclusive environments (Rauk, 2021; Wood & Patel, 2017).

In short, the findings of this thesis have further impact on various stakeholders, namely, the public and people directly/indirectly affected by IBD, therapists and healthcare organisations. By highlighting areas of some tension, the present thesis continues to champion for the idea of providing equal access to care for all (NHS Constitution, 2021), which is embedded within socio-economic context and supports the societal ambition of ‘levelling up the UK’ (Connolly et al., 2021; Department for Levelling Up, Housing and Communities, 2022).

It might also be useful to acknowledge that several areas require further investigations. The present thesis was unable to definitively describe impact of surgeries for IBD on psychological health. In the absence of clear understanding individualised formulations and collaborative working will be paramount to support patients during this potentially stressful time. The systematic review highlighted need for high-quality design studies, preferably considering pre-/post- designs. It also highlighted that methodology can be improved by consistent recruitment of control groups and better sample stratification methods to enable direct comparisons. It was also acknowledged that the use of broader psychological measures might augment evidence-base and inform clinical practice. The present thesis also left several questions unanswered in relation to the role of prospection in illness. It remains unclear if IBD characteristics relate to aspects of prospection in a unique way and if our findings have been influenced by the extraordinary context within which it occurred– a global pandemic. As such, it remains important to replicate and build on our findings in order to continue positive impact research might have on the 'real-world'.

Dissemination

Firstly, the findings from the empirical study were presented to and discussed with the cohort of Trainees Clinical Psychologists and Lecturers at Royal Holloway University of London during the 'Research Masterclass' held on the 6th of May 2022. It was hoped that this might spark interest in the field, lead to new research opportunities building on our findings as well as influence the practice of future

Clinical Psychologists who may play an instrumental role in design of future services (BPS, 2011).

Secondly, we also intend to share a written synopsis of our findings and key discussion points with interested study participants as well as representatives of the organisations, which assisted with the recruitment process. The findings might be disseminated through their respective social media accounts as well as emailed to a well-established research network widening reach of this work substantially. It may also be possible to join ‘Crohn’s & Colitis UK’ and/or ‘GetYourBellyOut’ research webinars to discuss the present thesis with wider audience.

Thirdly, to reach broader scientific and clinical communities we might explore traditional publication routes in established IBD and wellbeing journals, namely, The IBD Journal and The British Journal of Clinical Psychology. Selected journals are highly impactful and of good scientific grounding.

Lastly, another possible avenue to reach wider audience and maximise impact of the present research is through future attendance and poster presentations at the Crohn’s & Colitis UK Congress and/or European Crohn’s and Colitis Organisation (ECCO) Congress which reflects my personal aspiration to integrate my minority heritage within professional identity.

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Appendices

Appendix A

A Written Summary Produced Following a Consultation with Individuals Diagnosed with IBD at Study Development Stage.

Royal Holloway University of London

DClinPsy

Principal Investigator: **removed for confidentiality,* Trainee Clinical Psychologist

Contact details: **removed for confidentiality*

Project Supervisor: **removed for confidentiality*

Contact details: **removed for confidentiality*

Project title: Does IBD impact how people think about their personal futures?

SERVICE USERS' INVOLVEMENT IN RESEARCH

BRIEF SUMMARY OF INITIAL MEETING

Date: Virtual meeting was held on the 29th of July 2021, 10:00 – 11:00am

Present: VM, HB, JK

Introductions were made as well as purpose of the meeting reviewed and agreed upon.

Agreed Agenda:

- Study Procedure
- Materials
- Acceptability and Language
- Dissemination Ideas

Meeting Content:

SUs felt that research investigating psychological factors within IBD context is important and were happy to contribute towards an area that has been described as somewhat neglected.

In relation to proposed methodology, SUs viewed virtual appointment as feasible and more acceptable option compared to traditional approaches requiring participants to travel long distances to participate in person. This was much preferred given symptomology of the condition as well as opening an opportunity to recruit ‘harder to reach’ individuals, for example, in ‘active’ stages of the disease. However, SUs emphasised the importance of making participants comfortable during the recruitment process as well as settling down any possible anxieties around the research appointment making it more acceptable to participants. Here, we discussed issues around ‘virtual appointments etiquette’ and emphasising participants’ right to switch cameras on/off as/when needed as well as discussing comfort breaks with participants to account for common symptoms of IBD, namely, fatigue, pain, and frequent urgency to go to the toilet. Additionally, SUs encouraged researchers to consider impact of using complicated terminology and/or jargon and postulated for more approachable language. For example, by referring to the Future-Focused-Task as a 'conversation about the future'.

SUs felt it would be more acceptable for the study appointment to start with questionnaires, to ease people into the rhythm of the appointment. No need for counterbalancing was identified. Although, SUs thought it might be easier to complete questionnaires prior to the research appointment (i.e., 'not putting people on the spot'), it was acknowledged that it may also be helpful to some participants to have access to a researcher if something is unclear. Therefore, choice was offered, and all participants were asked for their preference prior to the study appointment.

In relation to the proposed questionnaires and measures SUs invited researchers to expand their demographics questionnaire in areas related to nationality, residency, and disability as well as highlighted importance of offering more understanding and compassionate terminology in relation to education, employment, and marital status.

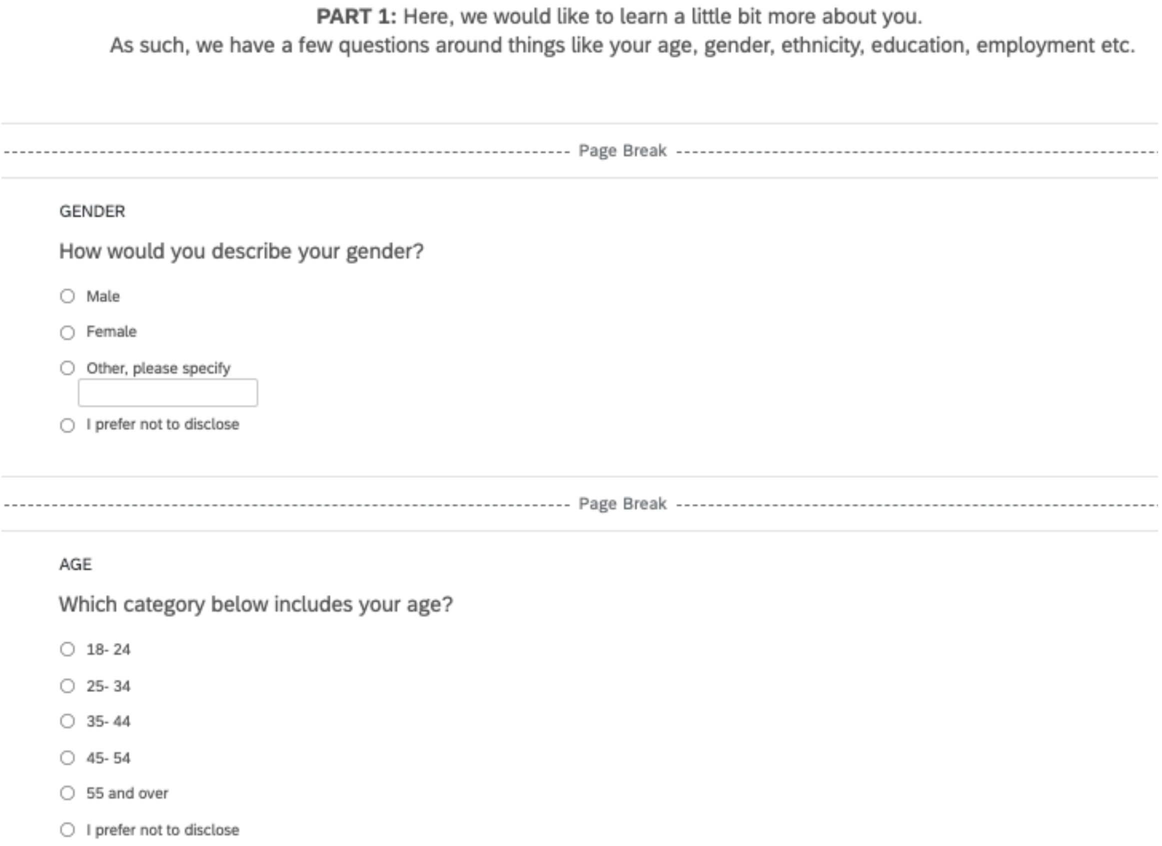
It was also noted that previously conceptualised criterion of 'having formal diagnosis of IBD' might be too rigid and lacks appreciation of patients often complicated journeys. SUs invited researchers to expand their questions to account for array of disease profiles present within the community as well as encouraged researchers to offer examples and/or explanations of terminology used to ensure clarity, understanding and minimise attrition.

SUs did not believe that commonly used and proposed by us methodology of disease severity stratification based on adapted and self-reported questionnaires, such as Harvey-Bradshaw and Simple Clinical Colitis Activity Indexes were accessible. It was argued that these lack sensitivity to varying IBD profiles and may lead to confusion. SUs felt it was preferrable to utilise more descriptive methodology enabling people to describe things in their own way. It was also postulated that utilisation of Inflammatory Bowel Disease Questionnaire (IBD; Guyatt et al., 1989) will offer participants opportunity to share their experiences holistically and in more depth and it was not considered too strenuous. In turn, it was argued that it may increase sense of being listened to and understood. Regarding measures of psychological wellbeing, SUs expressed concerns around wording of item 9 on PhQ-9, highlighting possible perception of intrusiveness and bluntness of this question.

Finally, SUs stated that it might be important for individuals volunteering to take part in the study to learn about its findings and encouraged researcher to email a summary to those who express interest. We also considered other dissemination avenues, such as utilisation of social media and/or offering a Q&A evening. SUs emphasised importance increasing awareness of the link between IBD and mental health, which in turn might help with efforts to advocate for further care provisions.

Appendix B

Demographics Questionnaire Developed for This Study.



PART 1: Here, we would like to learn a little bit more about you.
As such, we have a few questions around things like your age, gender, ethnicity, education, employment etc.

GENDER

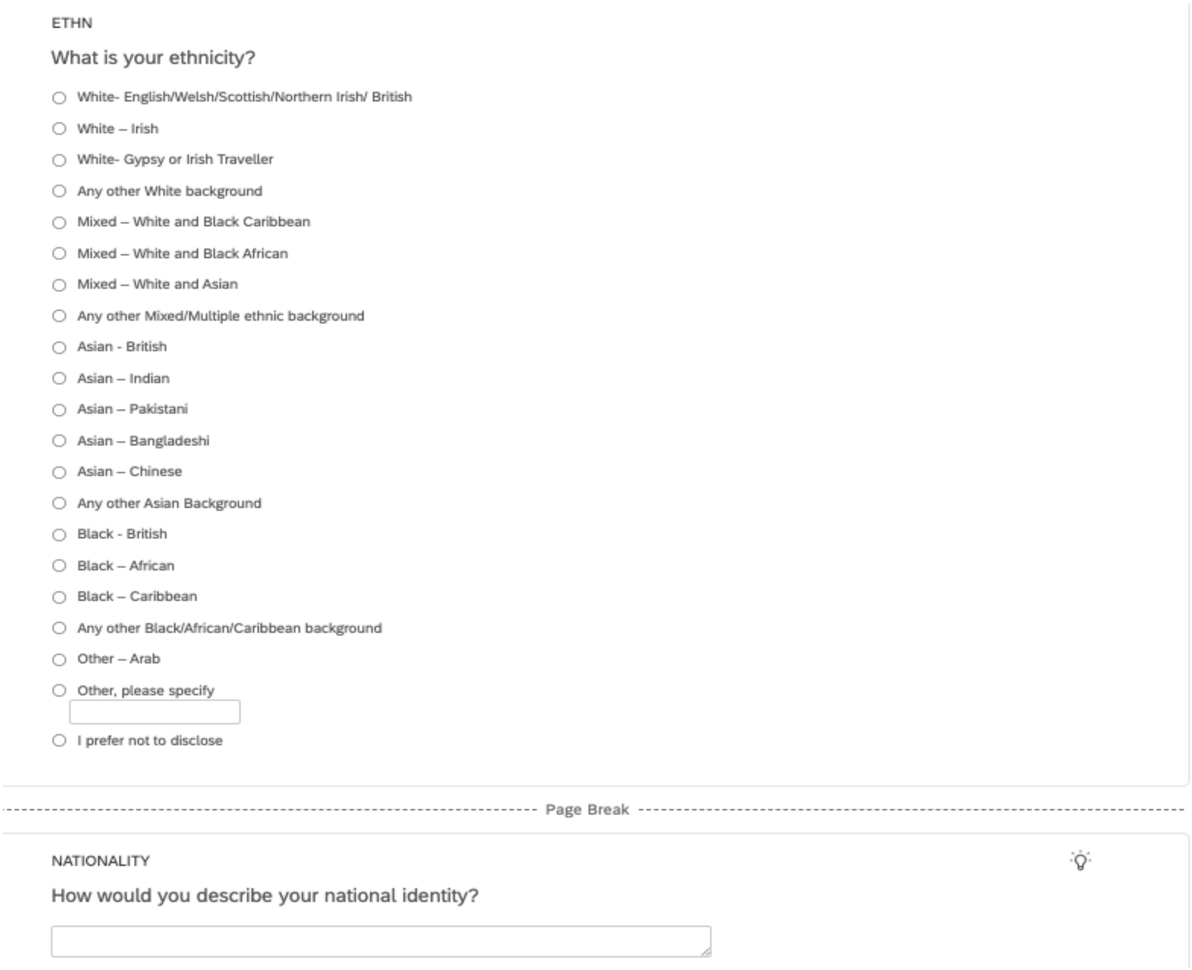
How would you describe your gender?

○ Male
○ Female
○ Other, please specify ☐
○ I prefer not to disclose

AGE

Which category below includes your age?

○ 18- 24
○ 25- 34
○ 35- 44
○ 45- 54
○ 55 and over
○ I prefer not to disclose



ETHN

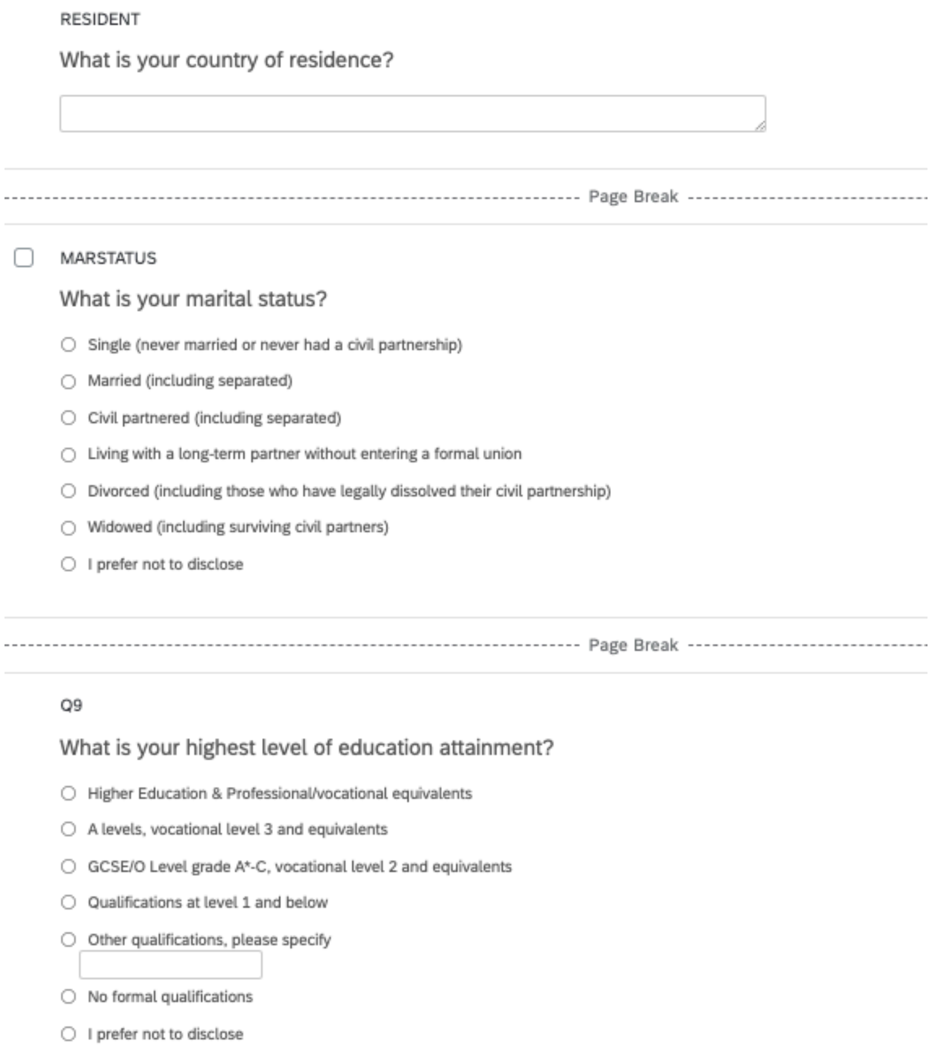
What is your ethnicity?

○ White- English/Welsh/Scottish/Northern Irish/ British
○ White – Irish
○ White- Gypsy or Irish Traveller
○ Any other White background
○ Mixed – White and Black Caribbean
○ Mixed – White and Black African
○ Mixed – White and Asian
○ Any other Mixed/Multiple ethnic background
○ Asian - British
○ Asian – Indian
○ Asian – Pakistani
○ Asian – Bangladeshi
○ Asian – Chinese
○ Any other Asian Background
○ Black - British
○ Black – African
○ Black – Caribbean
○ Any other Black/African/Caribbean background
○ Other – Arab
○ Other, please specify
○ I prefer not to disclose

Page Break

NATIONALITY

How would you describe your national identity?



RESIDENT

What is your country of residence?

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☐ MARSTATUS

What is your marital status?

○ Single (never married or never had a civil partnership)
○ Married (including separated)
○ Civil partnered (including separated)
○ Living with a long-term partner without entering a formal union
○ Divorced (including those who have legally dissolved their civil partnership)
○ Widowed (including surviving civil partners)
○ I prefer not to disclose

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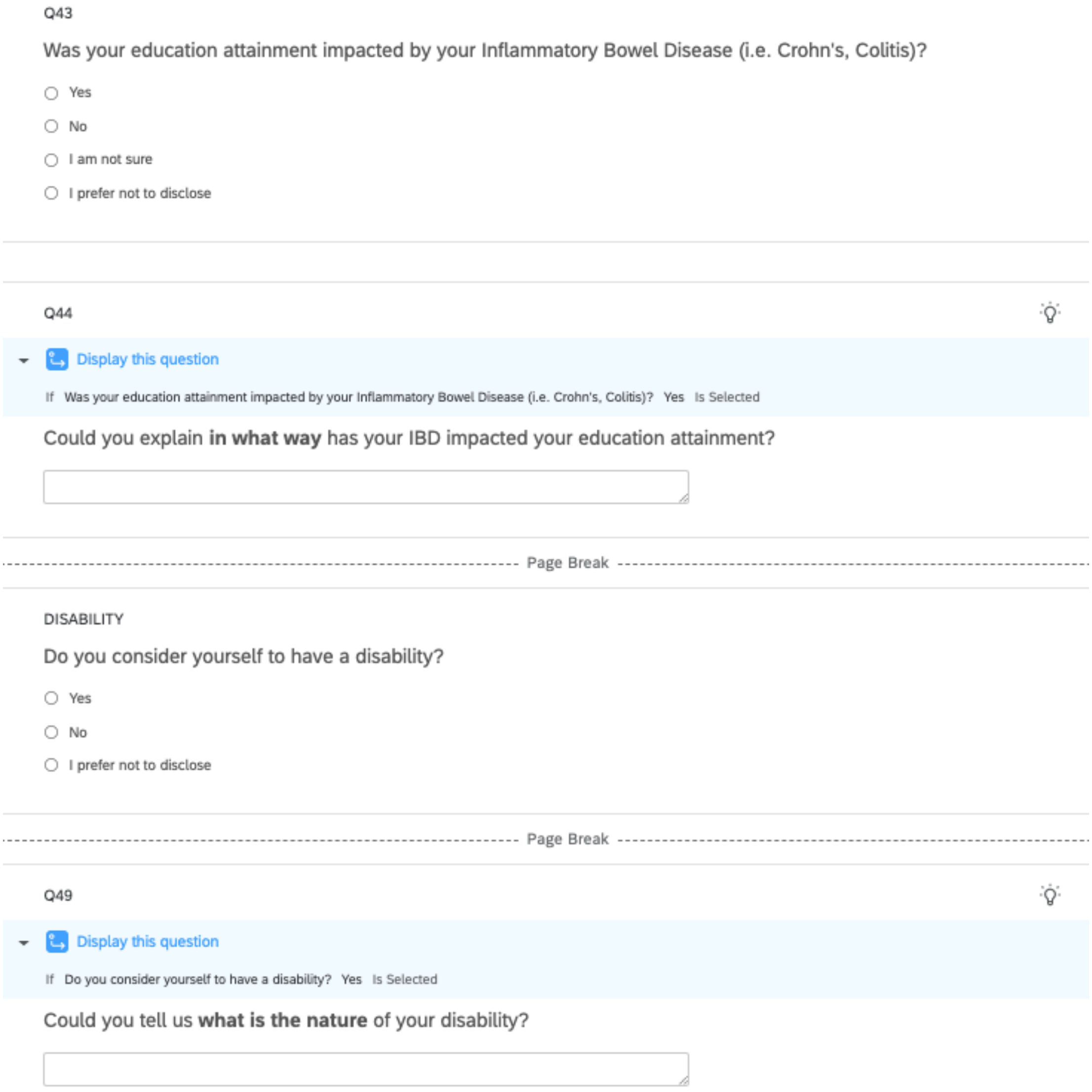
Q9

What is your highest level of education attainment?

○ Higher Education & Professional/vocational equivalents
○ A levels, vocational level 3 and equivalents
○ GCSE/O Level grade A*-C, vocational level 2 and equivalents
○ Qualifications at level 1 and below
○ Other qualifications, please specify
○ No formal qualifications
○ I prefer not to disclose



Q43

Was your education attainment impacted by your Inflammatory Bowel Disease (i.e. Crohn's, Colitis)?

○ Yes

○ No

○ I am not sure

○ I prefer not to disclose

Q44

If Was your education attainment impacted by your Inflammatory Bowel Disease (i.e. Crohn's, Colitis)? Yes Is Selected

Could you explain **in what way** has your IBD impacted your education attainment?

DISABILITY

Do you consider yourself to have a disability?

○ Yes

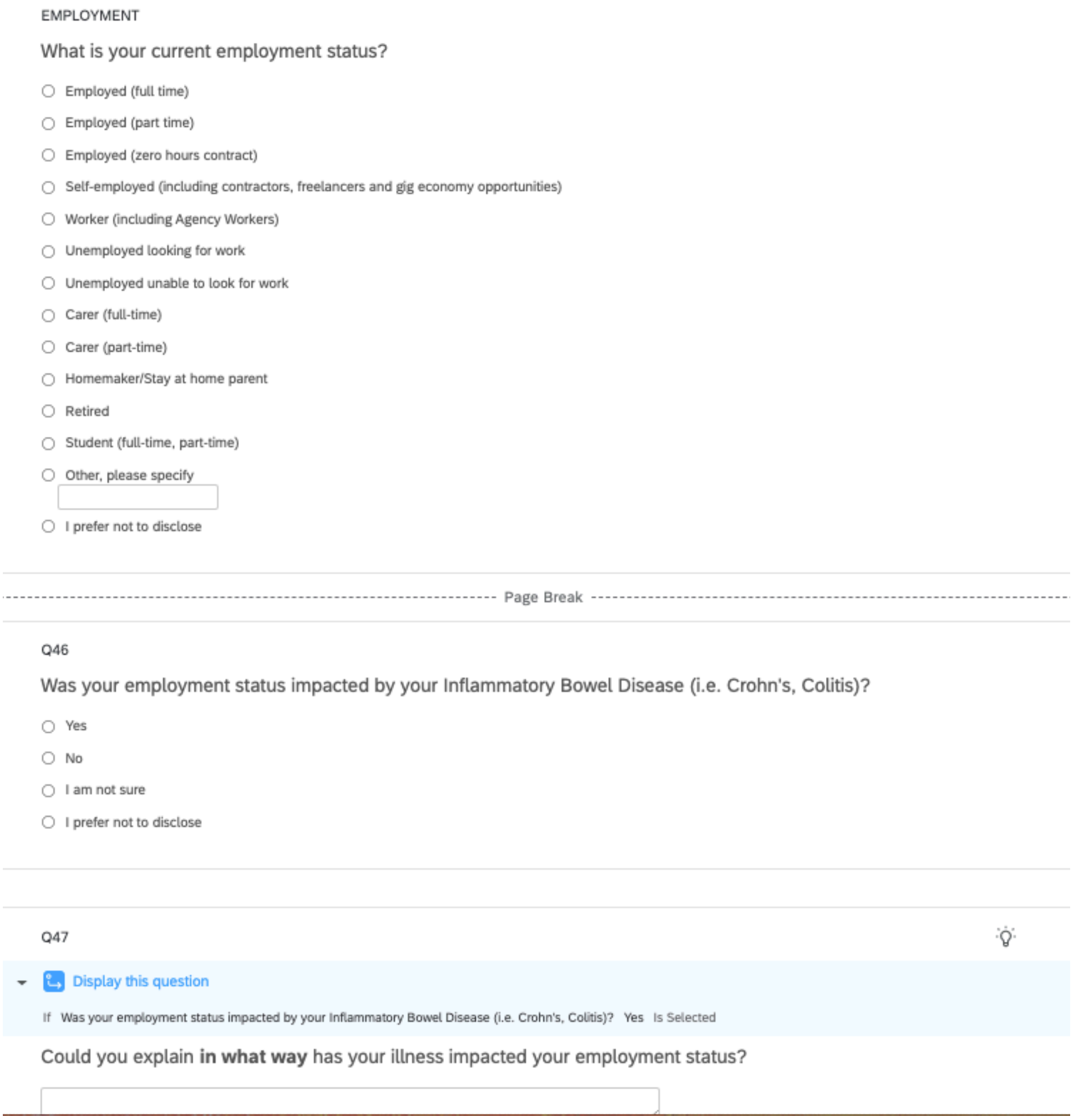
○ No

○ I prefer not to disclose

Q49

If Do you consider yourself to have a disability? Yes Is Selected

Could you tell us **what is the nature** of your disability?



EMPLOYMENT

What is your current employment status?

○ Employed (full time)
○ Employed (part time)
○ Employed (zero hours contract)
○ Self-employed (including contractors, freelancers and gig economy opportunities)
○ Worker (including Agency Workers)
○ Unemployed looking for work
○ Unemployed unable to look for work
○ Carer (full-time)
○ Carer (part-time)
○ Homemaker/Stay at home parent
○ Retired
○ Student (full-time, part-time)
○ Other, please specify
○ I prefer not to disclose

Q46

Was your employment status impacted by your Inflammatory Bowel Disease (i.e. Crohn's, Colitis)?

○ Yes
○ No
○ I am not sure
○ I prefer not to disclose

Q47

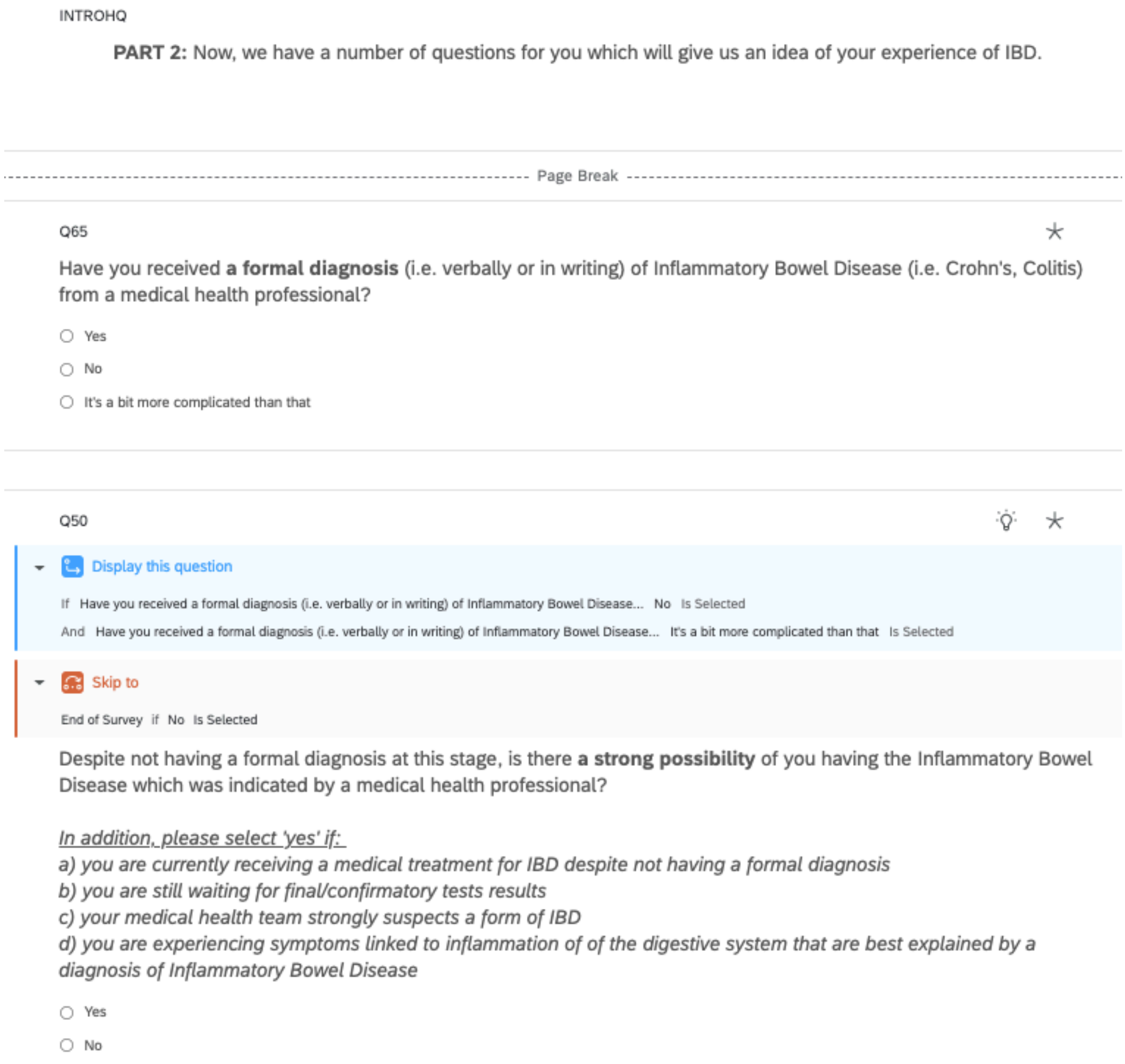
Display this question

If Was your employment status impacted by your Inflammatory Bowel Disease (i.e. Crohn's, Colitis)? Yes Is Selected

Could you explain **in what way** has your illness impacted your employment status?

Appendix C

Disease Characteristics Questionnaire Developed for this Study.



INTROHQ

PART 2: Now, we have a number of questions for you which will give us an idea of your experience of IBD.

Q65

Have you received **a formal diagnosis** (i.e. verbally or in writing) of Inflammatory Bowel Disease (i.e. Crohn's, Colitis) from a medical health professional?

○ Yes

○ No

○ It's a bit more complicated than that

Q50

If Have you received a formal diagnosis (i.e. verbally or in writing) of Inflammatory Bowel Disease... No Is Selected

And Have you received a formal diagnosis (i.e. verbally or in writing) of Inflammatory Bowel Disease... It's a bit more complicated than that Is Selected

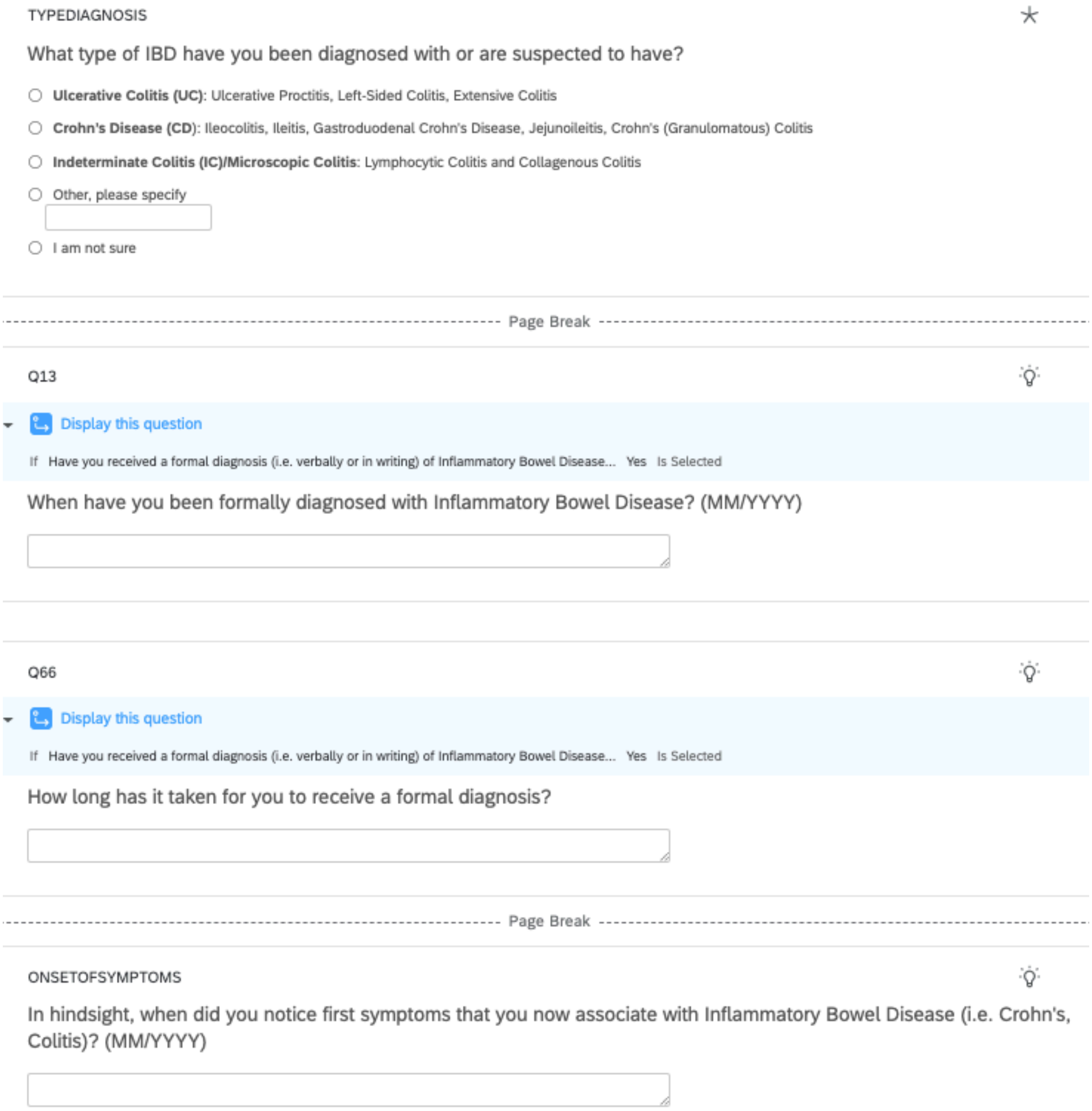
End of Survey if No Is Selected

Despite not having a formal diagnosis at this stage, is there **a strong possibility** of you having the Inflammatory Bowel Disease which was indicated by a medical health professional?

In addition, please select 'yes' if:
a) you are currently receiving a medical treatment for IBD despite not having a formal diagnosis
b) you are still waiting for final/confirmatory tests results
c) your medical health team strongly suspects a form of IBD
d) you are experiencing symptoms linked to inflammation of of the digestive system that are best explained by a diagnosis of Inflammatory Bowel Disease

○ Yes

○ No



TYPEDIAGNOSIS

What type of IBD have you been diagnosed with or are suspected to have?

○ **Ulcerative Colitis (UC)**: Ulcerative Proctitis, Left-Sided Colitis, Extensive Colitis

○ **Crohn's Disease (CD)**: Ileocolitis, Ileitis, Gastroduodenal Crohn's Disease, Jejunoileitis, Crohn's (Granulomatous) Colitis

○ **Indeterminate Colitis (IC)/Microscopic Colitis**: Lymphocytic Colitis and Collagenous Colitis

○ Other, please specify

○ I am not sure

Page Break

Q13

Display this question

If Have you received a formal diagnosis (i.e. verbally or in writing) of Inflammatory Bowel Disease... Yes Is Selected

When have you been formally diagnosed with Inflammatory Bowel Disease? (MM/YYYY)

Q66

Display this question

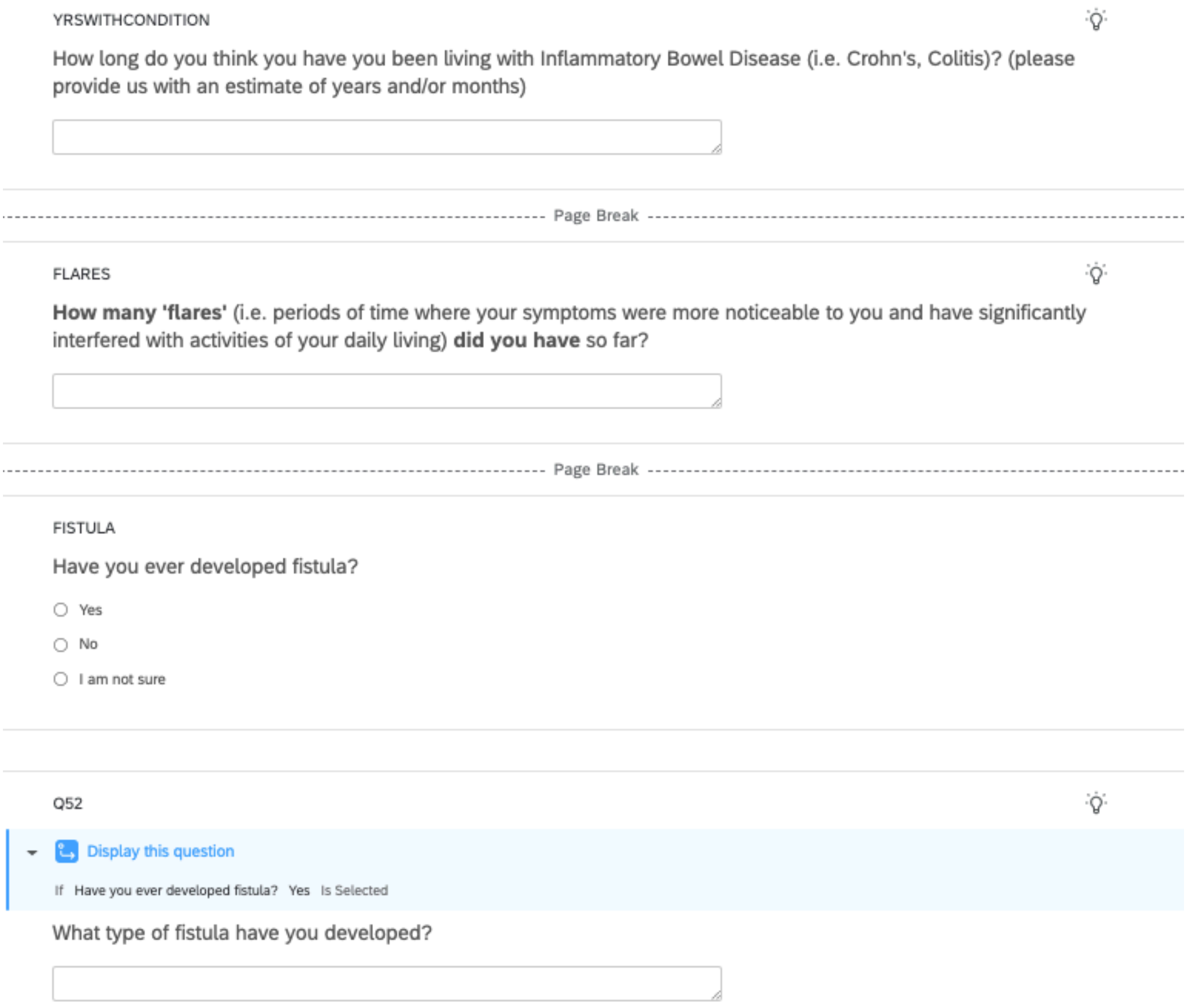
If Have you received a formal diagnosis (i.e. verbally or in writing) of Inflammatory Bowel Disease... Yes Is Selected

How long has it taken for you to receive a formal diagnosis?

Page Break

ONSETOFSYMPTOMS

In hindsight, when did you notice first symptoms that you now associate with Inflammatory Bowel Disease (i.e. Crohn's, Colitis)? (MM/YYYY)



YRSWITHCONDITION

How long do you think you have you been living with Inflammatory Bowel Disease (i.e. Crohn's, Colitis)? (please provide us with an estimate of years and/or months)

FLARES

How many 'flares' (i.e. periods of time where your symptoms were more noticeable to you and have significantly interfered with activities of your daily living) **did you have** so far?

FISTULA

Have you ever developed fistula?

○ Yes

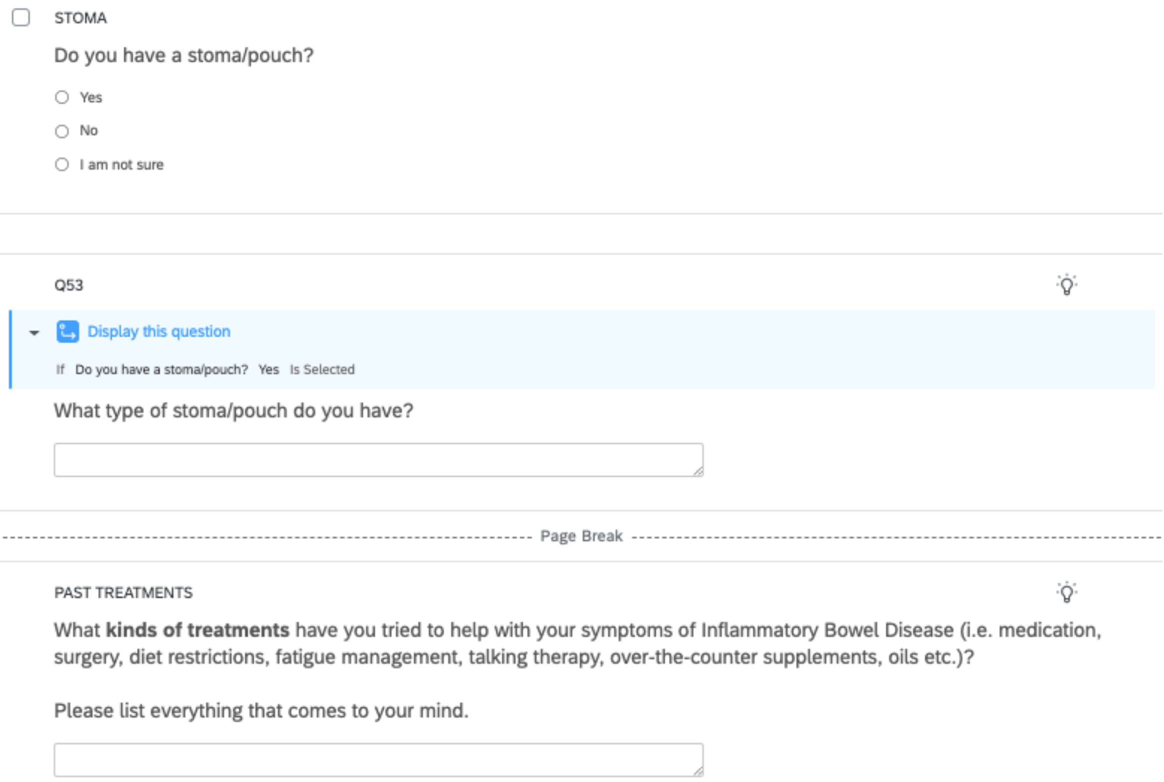
○ No

○ I am not sure

Q52

If Have you ever developed fistula? Yes Is Selected

What type of fistula have you developed?



☐ STOMA

Do you have a stoma/pouch?

○ Yes

○ No

○ I am not sure

Q53

Display this question

If Do you have a stoma/pouch? Yes Is Selected

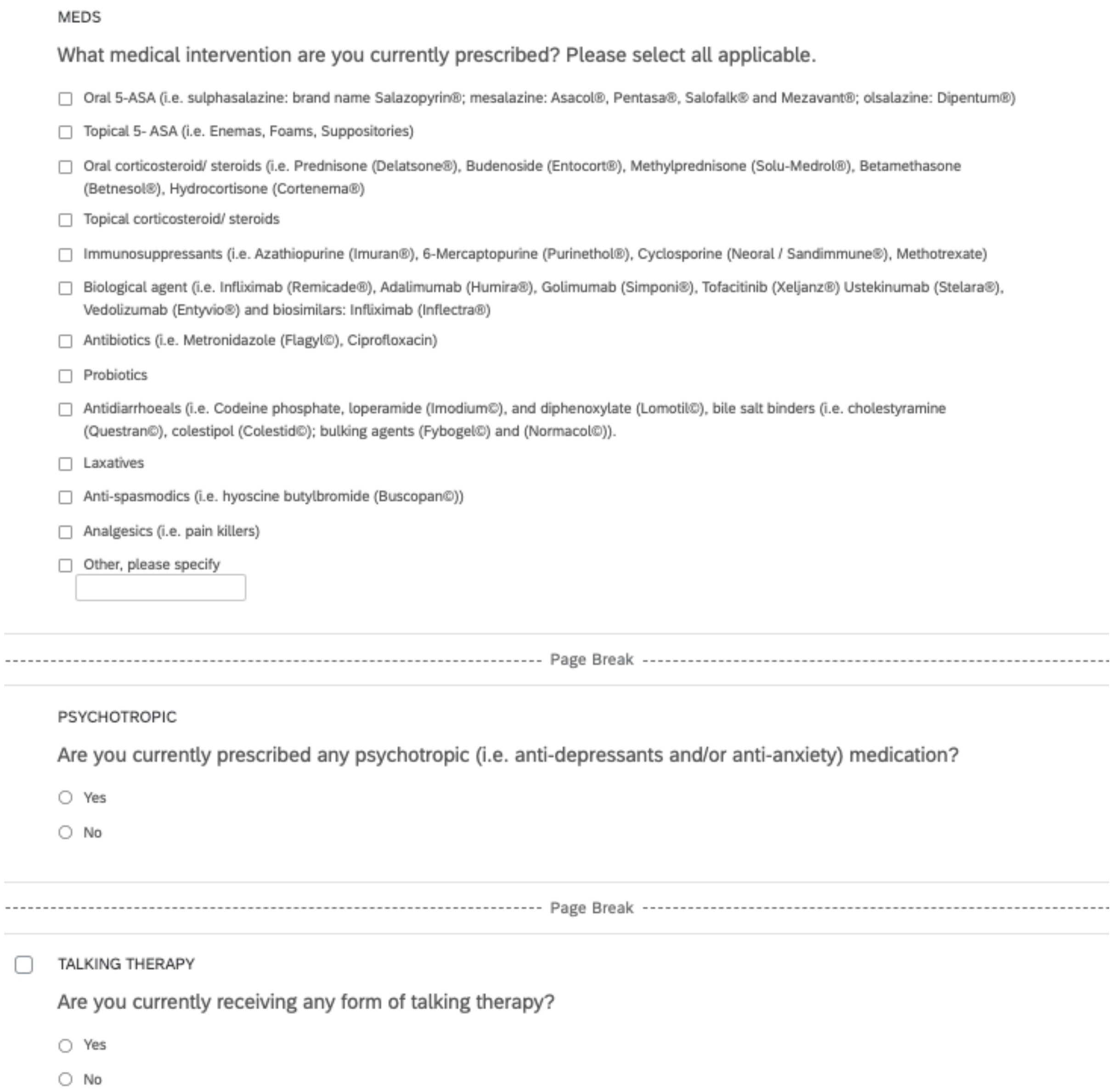
What type of stoma/pouch do you have?

Page Break

PAST TREATMENTS

What **kinds of treatments** have you tried to help with your symptoms of Inflammatory Bowel Disease (i.e. medication, surgery, diet restrictions, fatigue management, talking therapy, over-the-counter supplements, oils etc.)?

Please list everything that comes to your mind.



MEDS

What medical intervention are you currently prescribed? Please select all applicable.

☐ Oral 5-ASA (i.e. sulphasalazine: brand name Salazopyrin®; mesalazine: Asacol®, Pentasa®, Salofalk® and Mezavant®; olsalazine: Dipentum®)

☐ Topical 5- ASA (i.e. Enemas, Foams, Suppositories)

☐ Oral corticosteroid/ steroids (i.e. Prednisone (Delatsone®), Budenoside (Entocort®), Methylprednisone (Solu-Medrol®), Betamethasone (Betnesol®), Hydrocortisone (Cortenema®)

☐ Topical corticosteroid/ steroids

☐ Immunosuppressants (i.e. Azathiopurine (Imuran®), 6-Mercaptopurine (Purinethol®), Cyclosporine (Neoral / Sandimmune®), Methotrexate)

☐ Biological agent (i.e. Infliximab (Remicade®), Adalimumab (Humira®), Golimumab (Simponi®), Tofacitinib (Xeljanz®) Ustekinumab (Stelara®), Vedolizumab (Entyvio®) and biosimilars: Infliximab (Inflectra®)

☐ Antibiotics (i.e. Metronidazole (Flagyl©), Ciprofloxacin)

☐ Probiotics

☐ Antidiarrhoeals (i.e. Codeine phosphate, loperamide (Imodium©), and diphenoxylate (Lomotil©), bile salt binders (i.e. cholestyramine (Questran©), colestipol (Colestid©); bulking agents (Fybogel©) and (Normacol©)).

☐ Laxatives

☐ Anti-spasmodics (i.e. hyoscine butylbromide (Buscopan©))

☐ Analgesics (i.e. pain killers)

☐ Other, please specify

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PSYCHOTROPIC

Are you currently prescribed any psychotropic (i.e. anti-depressants and/or anti-anxiety) medication?

○ Yes

○ No

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☐ TALKING THERAPY

Are you currently receiving any form of talking therapy?

○ Yes

○ No

Appendix D

An Overview of Instructions to the Future-thinking Task.

Control task (FAS)

"First I'd like you to think of as many words as you can beginning with a certain letter of the alphabet. I will ask you to do this for 3 different letters. You will have a minute in each case to think of as many words as you can beginning with that letter. Please say the words aloud and I will write them down. The words can be anything that comes to mind except that they shouldn't be proper names, that is names of people or places, or numbers or sequences involving the same basic word, for example, run, runner, running, and so on. I want you to give me as many words as you can beginning with the letter F".

Future-thinking Task (FTT)

"Now I'd like to ask you to think about things that might happen to you in the future. I will give you 3 different time periods in the future, one at a time, and I'd like you to try to think of things that might happen to you in those time periods. Like before, I will give you a minute to try to think of as many things as you can. It doesn't matter whether the things are trivial or important, just say what comes to mind. But they should be things that you think will happen or are at least quite likely to happen. If you can't think of anything or if you can't think of many things, that's fine, but just keep trying until the time limit is up.

First, I'm going to ask you to think of positive things in the future. So, I'd like you to try to think of things that you are looking forward to, in other words, things that you will enjoy. So, I want you to give me as many things as you can that you're looking forward to over the next week including today".

(R gives one minute and writes down as close to verbatim as time allows what subject says)

Now, I'd like you to do the same but this time I want you to give me things that you're looking forward to over the next year.

(R does same as for one week)

Now, I'd like you to do the same but this time I want you to give me things that you're looking forward to over the next five to ten years.

(R does same as for previous)

"Now, I'd like you to think of things that you're worried about or not looking forward to, in other words, things that you would rather not be the case or rather not happen. So, I want you to give me as many things as you can that you're worried about or not looking forward to over the next week including today".

(R does same as for previous)

"Now I want you to give me as many things as you can that you're worried about or not looking forward to over the next year"

(R does same as for previous)

Finally, I want you to give me as many things as you can that you're worried about or not looking forward to over the next five to ten years"

(R does same as for previous)

Appendix E

Study Information Sheet

Department of Psychology
Royal Holloway University of London
Egham, Surrey, TW20 0EX
www.royalholloway.ac.uk/psychology

Study Title: Thinking about personal future and wellbeing.

Thank you for considering taking part in this research study. Please take time to consider the information presented below and feel free to discuss it with people who are important to you if you wish. If anything is unclear or you would like more information, please use the contact details at the end of the sheet to ask any questions you have.

What is the purpose of this study?

This research study aims to understand the impact of how we think about our personal futures and how this links with our mood. It is being conducted by **removed for confidentiality,* a Trainee Clinical Psychologist, as part of her doctoral training.

Why have I been invited?

This study aims to recruit 84 people of working-age (18 – 64) diagnosed with Inflammatory Bowel Disease who acquired reasonable proficiency in English.

As an individual of working-age and diagnosed with Crohn's Disease (CD), Ulcerative Colitis (UC) and Indeterminate Colitis (IC) as a primary health problem given by a medical health professional who is an English speaker you are eligible for the study.

Do I have to take part?

The participation is this study is voluntary. If you choose to arrange a meeting with the researcher, the study will be explained further, and this information sheet talked through with you. You are free to withdraw at any time, without giving a reason.

What will I have to do if I take part?

The research appointment will take no longer than half an hour. You will be asked to attend one appointment with the researcher, which will be held virtually. During the appointment you will be asked for some basic demographics' information, such as your age, gender and ethnicity and expected to complete a short questionnaire regarding your illness and medical treatment alongside ratings of your mood. Next, you will be asked to think about your future and talk about positive and negative things you envisage. An audio recording will be used to capture this so that the researcher can analyse it later. In line with data protection guidelines all recordings and data will be stored securely and anonymously, and will be deleted once it serves its purpose. Each participant in the study will be assigned a number to ensure your data is anonymous and can be deleted upon your request.

What are the possible disadvantages and risks of taking part?

It is possible that thinking about your future might impact how you feel. The researcher will check in with you at the end of the study and may direct you towards appropriate support if you would like this.

What are the possible benefits of taking part?

Your participation in this study will contribute to enriching our understanding of the potential link between thinking about the future and wellbeing in people who are managing ongoing challenges associated with living with a chronic illness. In turn, this can inform clinical practice and contribute to advancements in psychological treatments for people who struggle.

What if there is a problem?

Although, it is hoped that this would not be the case, if you have concerns about any aspect of this study, we would like to encourage you to speak to the researcher who will do her best to answer your questions. You can contact her using the details at the end of this sheet.

If you remain unhappy and wish to complain formally, you can do this through:

- Contacting **removed for confidentiality*, supervisor for this research study
- Using the Royal Holloway complaints procedure, which can be found at https://intranet.royalholloway.ac.uk/ecampus/academicsupport/complaints/thecomplaintprocess.aspx.

Will my taking part in the study be kept confidential?

Your data will be recorded using audio recordings and paper forms. All data and personal information are anonymised and stored safely according to strict university research protocols. Any personal details are stored separately to the research data and participants are assigned a number that is not identifiable by anyone else. All data will be destroyed once it serves its purpose.

What will happen if I don't carry on with the study?

If you decide to withdraw from the study, all the information and data collected from you will be destroyed.

What will happen to the results of the research study?

It is intended that the results will be disseminated in academic publications with all individuals' data averaged and nothing identifiable. Interested participants would be sent an email outlining overall findings and implications when the research project has been completed and typed up as a report.

Who is organising or sponsoring the research?

Royal Holloway University of London is the sole sponsor for this research.

Who has reviewed this study?

This project has received ethical approval from the Research Ethics Committee at the Royal Holloway University of London.

<u>Further information and contact details:</u>

If you are interested in participating or have questions about this study, please contact the researcher:
**removed for confidentiality* – Trainee Clinical Psychologist
e-mail address*: *removed for confidentiality*

GDPR statement

Important General Data Protection Information (GDPR) Royal Holloway, University of London is the sponsor for this study and is based in the UK. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Any data you provide during the completion of the study will be stored securely on hosted on servers within the European Economic Area'. Royal Holloway is designated as a public authority and in accordance with the Royal Holloway and Bedford New College Act 1985 and the Statutes which govern the College, we conduct research for the public benefit and in the public interest. Royal Holloway has put in place appropriate technical and organisational security measures to prevent your personal data from being accidentally lost, used or accessed in any unauthorised way or altered or disclosed. Royal Holloway has also put in place procedures to deal with any suspected personal data security breach and will notify you and any applicable regulator of a suspected breach where legally required to do so. To safeguard your rights, we will use the minimum personally-identifiable information possible (i.e., the email address you provide us). The lead researcher will keep your contact details confidential and will use this information only as required (i.e., to provide a summary of the study results if requested and/or for the prize draw). The lead researcher will keep information about you and data gathered from the study, the duration of which will depend on the study. Certain individuals from RHUL may look at your research records to check the accuracy of the research study. If the study is published in a relevant peer-reviewed journal, the anonymised data may be made available to third parties. The people who analyse the information will not be able to identify you. You can find out more about your rights under the GDPR and Data Protection Act 2018 by visiting https://www.royalholloway.ac.uk/about-us/more/governance-and-strategy/data-protection/ and if you wish to exercise your rights, please contact dataprotection@royalholloway.ac.uk

You may retain this information sheet for reference and contact us with any queries

Appendix F

Consent Form

Study Title: Thinking about personal future and wellbeing.
Name and email address of researcher: **removed for confidentiality*
Name and email address of supervisor: **removed for confidentiality*

Write your initials:

The nature and purpose as well as potential benefits and risks of the study have been explained to me. I have read and understood the Information for Participants sheet and understand what this study involves. I also had opportunity to ask questions and they have been answered fully to my satisfaction. ☐

I understand that my participation in the study is entirely voluntary and that I am free to withdraw at any time without giving a reason. ☐

I understand that I will be entered into a prize draw for my participation in this study. Should I win the prize draw, I agree to be contacted by the researcher at the end of the study to finalise the payment. ☐

I understand that my data will be anonymised and stored securely on a password protected external drive. I am also aware that my data will be stored for five years. I understand that my data will not be re-used for any other purposes. ☐

I agree to the research appointment being recorded and transcripts used by the researcher for further analysis. ☐

I understand that it is intended that the results of this study will be disseminated in academic publications. ☐

I agree to take part in the study ☐

Participant name:
……………………………………………………………………
Participant signature:
……………………………………………………………………
Date:
……………………………………………………………………

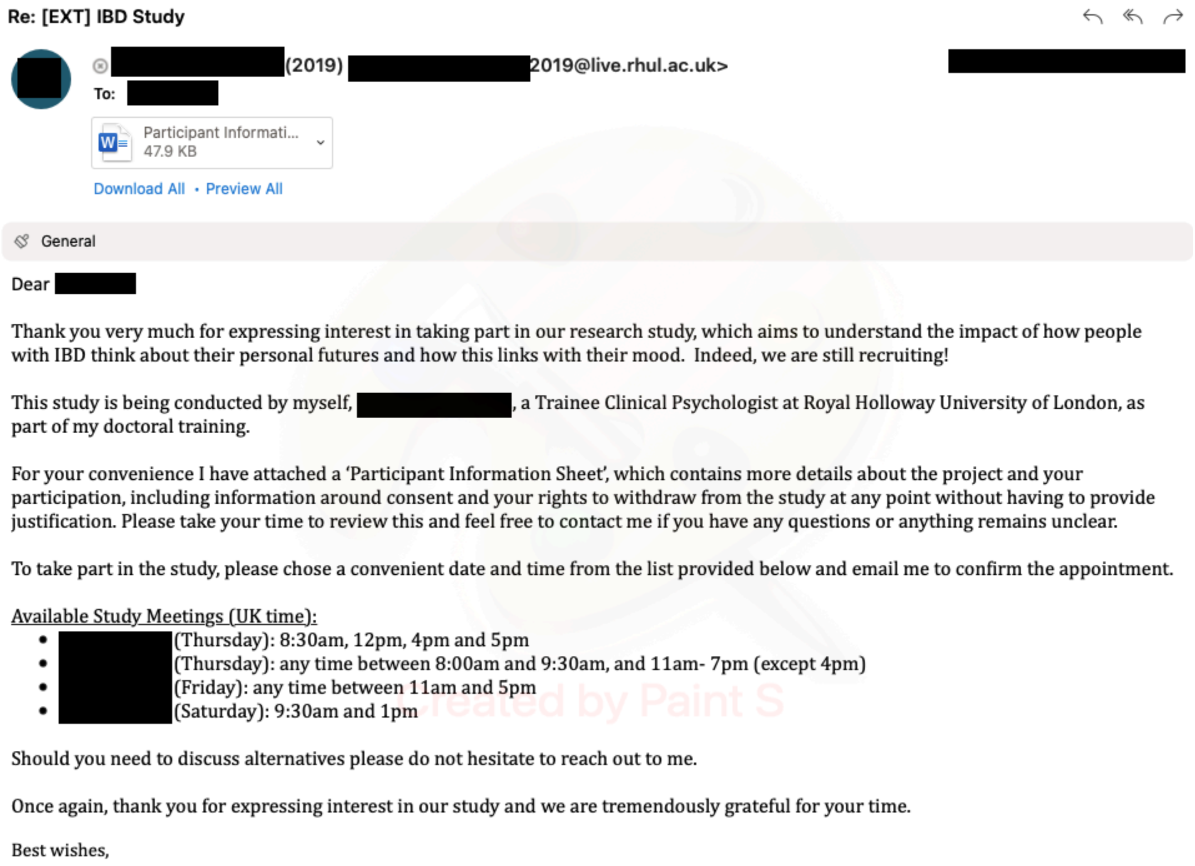
Researcher name:
……………………………………………………………………………
Researcher signature:
……………………………………………………………………………
Date:
……………………………………………………………………………

Please note that this Consent form will be stored separately from the responses you provide.

If you have any concerns about this research, please email **ethics@rhul.ac.uk.**

Appendix G

An Exemplar of an Introductory Email Sent to Individuals Interested in Taking Part in the Study.



Re: [EXT] IBD Study

[redacted] [redacted](2019) [redacted]2019@live.rhul.ac.uk> [redacted]
To: [redacted]

Dear [redacted]

Thank you very much for expressing interest in taking part in our research study, which aims to understand the impact of how people with IBD think about their personal futures and how this links with their mood. Indeed, we are still recruiting!

This study is being conducted by myself, [redacted], a Trainee Clinical Psychologist at Royal Holloway University of London, as part of my doctoral training.

For your convenience I have attached a 'Participant Information Sheet', which contains more details about the project and your participation, including information around consent and your rights to withdraw from the study at any point without having to provide justification. Please take your time to review this and feel free to contact me if you have any questions or anything remains unclear.

To take part in the study, please chose a convenient date and time from the list provided below and email me to confirm the appointment.

Available Study Meetings (UK time):
- [redacted](Thursday): 8:30am, 12pm, 4pm and 5pm
- (Thursday): any time between 8:00am and 9:30am, and 11am- 7pm (except 4pm)
- (Friday): any time between 11am and 5pm
- (Saturday): 9:30am and 1pm

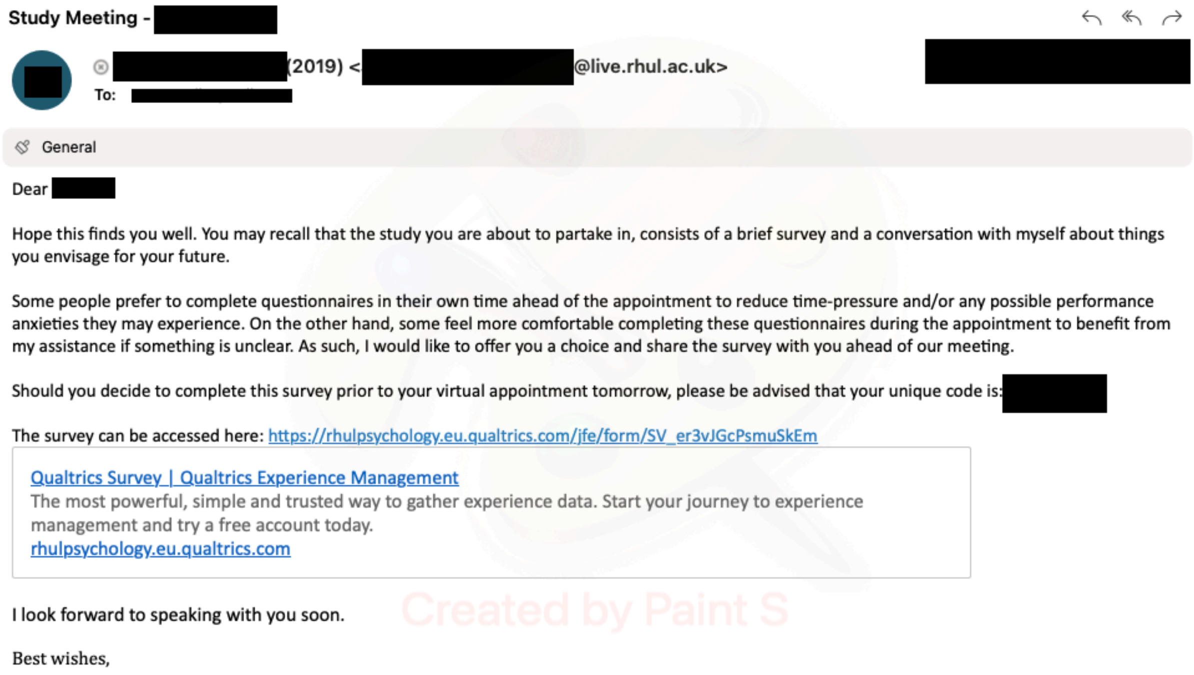
Should you need to discuss alternatives please do not hesitate to reach out to me.

Once again, thank you for expressing interest in our study and we are tremendously grateful for your time.

Best wishes,

Appendix H

An Exemplar Email Sent 24-hours Prior to the Scheduled Appointment.



Study Meeting - [redacted]

[redacted]

[redacted](2019) <[redacted]@live.rhul.ac.uk> [redacted]

To: [redacted]

Dear [redacted]

Hope this finds you well. You may recall that the study you are about to partake in, consists of a brief survey and a conversation with myself about things you envisage for your future.

Some people prefer to complete questionnaires in their own time ahead of the appointment to reduce time-pressure and/or any possible performance anxieties they may experience. On the other hand, some feel more comfortable completing these questionnaires during the appointment to benefit from my assistance if something is unclear. As such, I would like to offer you a choice and share the survey with you ahead of our meeting.

Should you decide to complete this survey prior to your virtual appointment tomorrow, please be advised that your unique code is: [redacted]

The survey can be accessed here: https://rhulpsychology.eu.qualtrics.com/jfe/form/SV_er3vJGcPsmuSkEm

Qualtrics Survey | Qualtrics Experience Management
The most powerful, simple and trusted way to gather experience data. Start your journey to experience management and try a free account today.
rhulpsychology.eu.qualtrics.com

I look forward to speaking with you soon.

Best wishes,

Appendix I

Debrief Sheet

Department of Psychology

Royal Holloway University of London

Egham, Surrey, TW20 0EX

www.royalholloway.ac.uk/psychology

Study Title: Thinking about personal future and wellbeing.

Name of researcher: **removed for confidentiality*

Name of supervisor: **removed for confidentiality*

Thank you for your participation in the above research study. The aim of this study is to improve our understanding of the relationship between psychological wellbeing and prospection in people with IBD. Here, we are particularly interested in whether quantity and quality of generated future positive and negative expectancies relate to levels of wellbeing as well as general life satisfaction. One particular aspect of interest is how well people are able to get on with anticipating and looking forward to other aspects of their lives, as opposed to IBD getting in the way of this, and how that relates to their overall levels of wellbeing.

If you have any concerns or questions about your participation in this study or if you would like to withdraw your data, please do not hesitate to contact a member of the research team using the contact details provided below.

Researcher Contact Details:

removed for confidentiality* **(Trainee Clinical Psychologist & Chief Investigator)

Email: **removed for confidentiality*

removed for confidentiality* **(Academic Supervisor)

Email: **removed for confidentiality*

We do not expect people to feel worse after completing this study, but sometimes taking part in research studies can raise difficult thoughts and feelings. If you have experienced this, please contact your GP if you would like support with difficult emotions or concerns about your mental health.

The following organisations may also be able to support you:

- **The Samaritans** - A charity which provides anonymous telephone support, which is available 24 hours a day.

  Tel: 116 123 (free)

  Email: jo@samaritans.org

Thank you again for taking the time to participate in our study.

Appendix J

An Overview of Different Types of Medication Being Prescribed Amongst Individuals Taking Part in this Study.

Type of Medication	N (%)
N Oral 5-ASA (i.e. sulphasalazine: brand name Salazopyrin®; mesalazine: Asacol®, Pentasa®, Salofalk® and Mezavant®; olsalazine: Dipentum®) (%)	29 (14.01)
N Topical 5- ASA (i.e. Enemas, Foams, Suppositories)	11 (5.31)
N Oral corticosteroid/ steroids (i.e. Prednisone (Delatsone®), Budenoside (Entocort®), Methylprednisone (Solu-Medrol®), Betamethasone (Betnesol®), Hydrocortisone (Cortenema®) (%)	19 (9.18)
N Topical corticosteroid/ steroids (%)	3 (1.45)
N Immunosuppressants (i.e. Azathiopurine (Imuran®), 6-Mercaptopurine (Purinethol®), Cyclosporine (Neoral / Sandimmune®), Methotrexate) (%)	46 (22.22)
N Biological agent (i.e. Infliximab (Remicade®), Adalimumab (Humira®), Golimumab (Simponi®), Tofacitinib (Xeljanz®) Ustekinumab (Stelara®), Vedolizumab (Entyvio®) and biosimilars: Infliximab (Inflectra®) (%)	46 (22.22)
N Antibiotics (i.e. Metronidazole (Flagyl©), Ciprofloxacin) (%)	5 (2.42)
N Probiotics (%)	3 (1.45)

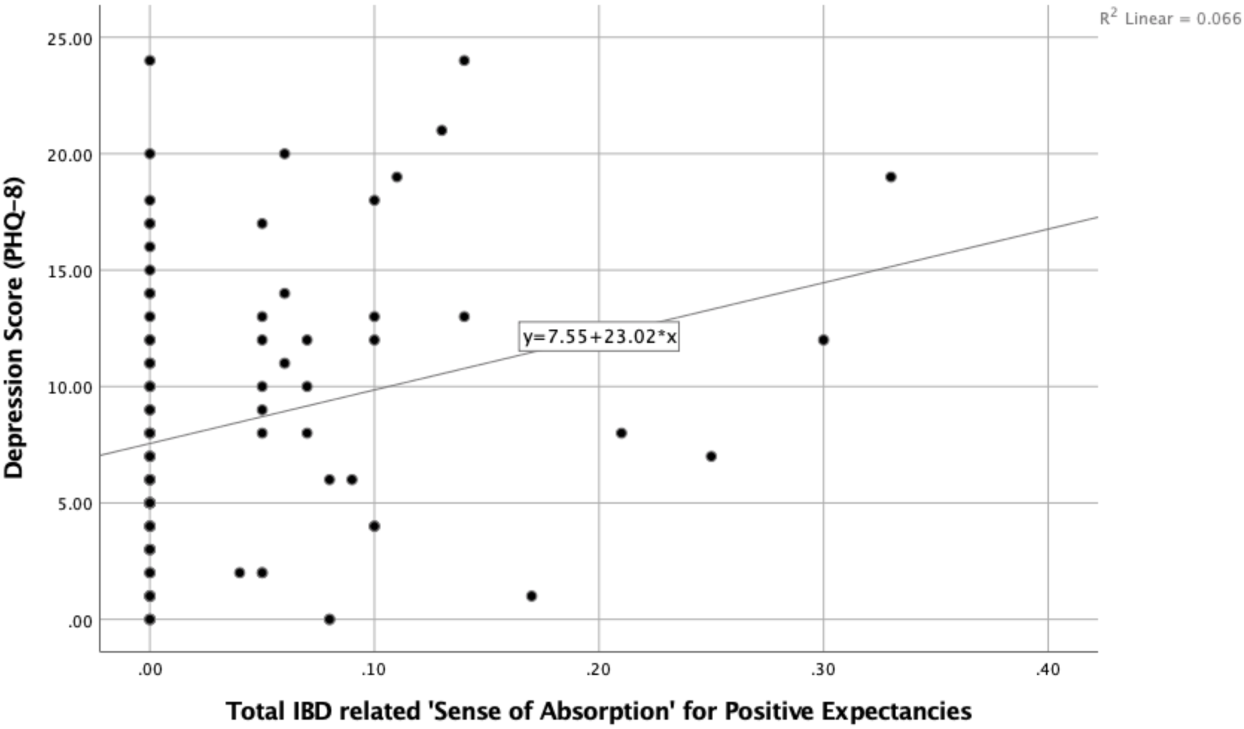
N Antidiarrhoeals (i.e. Codeine phosphate, loperamide (Imodium©), and diphenoxylate (Lomotil©), bile salt binders (i.e. cholestyramine (Questran©), colestipol (Colestid©); bulking agents (Fybogel©) and (Normacol©) (%)	11 (5.31)
N Laxatives (%)	4 (1.93)
N Anti-spasmodics (i.e. hyoscine butylbromide (Buscopan©) (%)	4 (1.93)
N Analgesics (i.e. pain killers) (%)	12 (5.80)
N Other[5] (%)	10 (4.83)
N None (%)	4 (1.93)

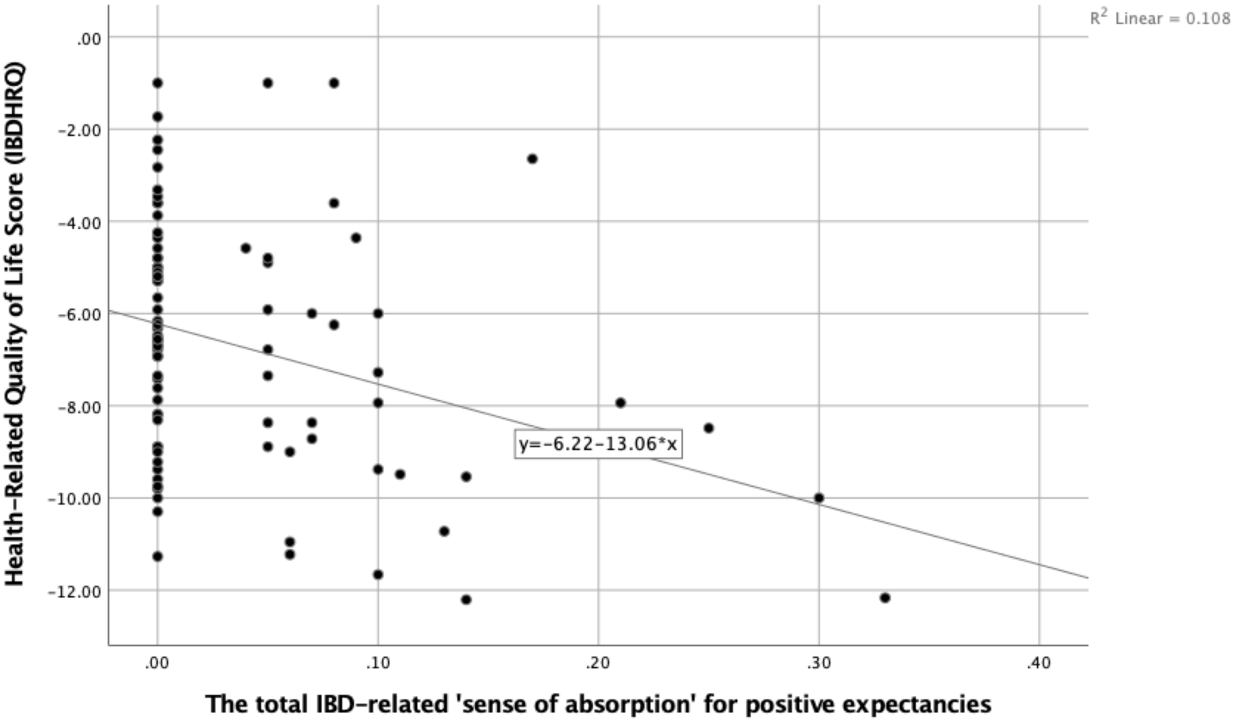
---

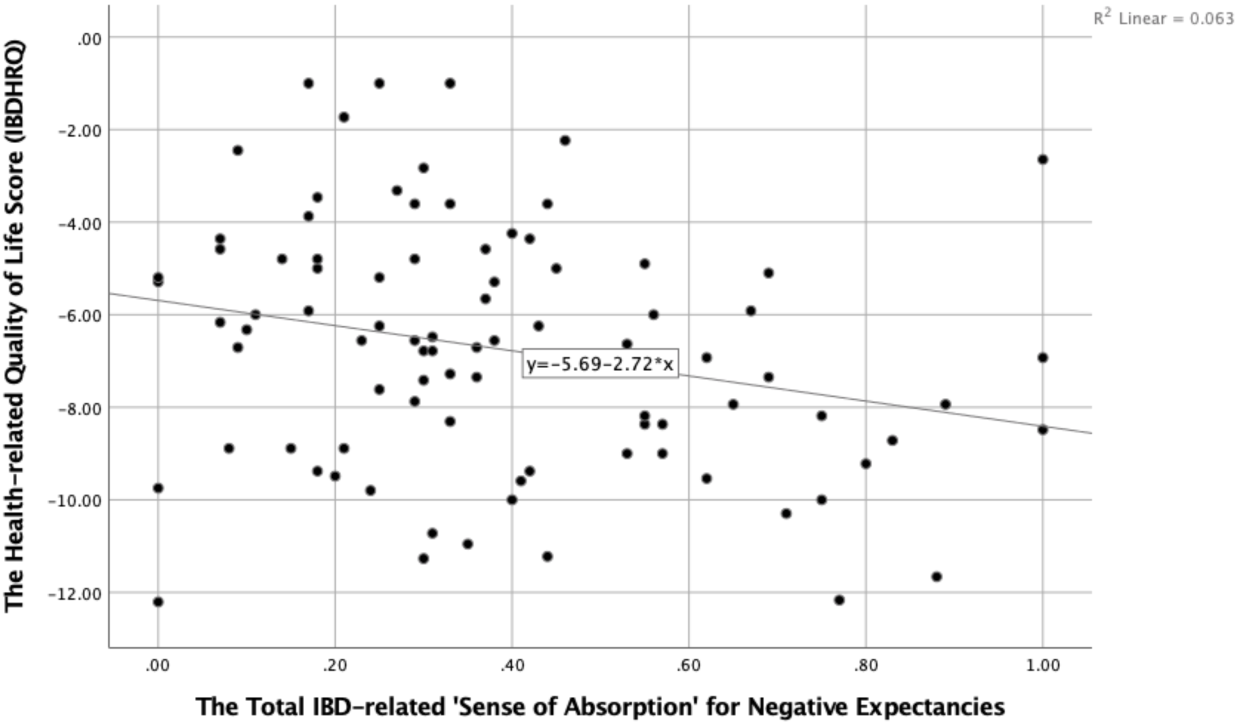
[5] Participants included folic acid, balsalazide, allupurin, allopurinol, budesonide foam enema, B12 injections, intervavenous conrticosteroids, omeprazole, iron tablets, lansoprazole in the ‘other’ category.

Appendix K

Scatterplots visualising the significant relationships between the total IBD-related 'sense of absorption' and psychological wellbeing measures for both positive and negative future expectancies.




R^2 Linear = 0.108
Health-Related Quality of Life Score (IBDHRQ)
.00
-2.00
-4.00
-6.00
-8.00
-10.00
-12.00
y=-6.22-13.06*x
.00
.10
.20
.30
.40
The total IBD-related 'sense of absorption' for positive expectancies


R^2 Linear = 0.063
The Health-related Quality of Life Score (IBDHRQ)
.00
-2.00
-4.00
-6.00
-8.00
-10.00
-12.00
y=-5.69-2.72*x
.00
.20
.40
.60
.80
1.00
The Total IBD-related 'Sense of Absorption' for Negative Expectancies