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Inflammatory Bowel Disease and Mental Health

Study One: Inflammatory Bowel Disease and Depression and/or Anxiety: Patients' Perspectives

Study Two: An Evaluation of Publicly Available Information on Inflammatory Bowel Disease and Mental Health

Author: Ms Chloe Feeley

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School of Applied Psychology

Supervisors: Prof Samantha Dockray, Dr Kim Keating and Dr Lisa Harpur

April 2026

Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism and intellectual property.

Digital signature of the candidate: Chloé Keeley

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Thesis Abstract

There is a suggested link in the research literature between Inflammatory Bowel Disease (IBD) and mental health, which is understood as a bidirectional relationship and mediated by the gut-brain axis. There is a high prevalence of depression and/or anxiety in young adults with IBD. There is also a recognised biopsychosocial impact of IBD on the lives of patients, which can contribute to changes in self-concept, isolation and difficulties with self-management. The presence of psychological difficulties is associated with poorer health-related outcomes in IBD. The information needs of IBD patients relating to their physical and psychological wellbeing are not currently being met by the resources that are available to them. The existing online information sources relating to mental health are highly variable in quality, credibility and utility, and patients do not feel that they receive adequate information from their healthcare providers. In order to explore these factors, two research studies were conducted.

Study one was concerned with young adults with IBD and cooccurring depression and/or anxiety, and explored their understanding of the relationship between IBD and mental health, their previous experiences of communication of this relationship, and their preferences around information provision in the future. This study employed a qualitative design and data collection consisted of three online focus groups with participants (N=8) aged between 18-25. The data was analysed using reflexive thematic analysis, and three themes and four subthemes were identified. These related to the young people's understanding of the relationship between IBD and mental health, the psychosocial burden of IBD, previous sources of information, a focus on physical symptoms, preferences around information provision, the value of peer perspectives, and fluctuating information needs.

Study two encompassed an evaluation of printable and audiovisual materials that provide information around the relationship between IBD and mental health, which are available to patients and the general public. 153 materials (113 printable, 40 audiovisual) from identified public sources (e.g., healthcare providers, websites, social media) were accessed and screened. The materials were rated independently by two raters on their understandability, actionability, reliability and quality, using the Patient Education Materials Assessment Tool (PEMAT) and DISCERN instrument. Descriptive and correlation statistics were conducted. Interrater reliability was moderate to high for both tools. PEMAT scores on understandability were high for both printable (M=70.70) and audiovisual (M=78.79) formats, however audiovisual materials received higher scores for actionability (M=78.65) compared to printable materials (M=49.85). DISCERN scores indicated that most of the materials were of moderate quality. The source of the material was related to quality, and specialist support agencies obtained the most consistent scores. There was, however, high levels of variation in scores across materials contained within the same source categories. Positive correlations were found between materials' understandability, actionability and overall quality, indicating that if a material presented information more clearly, it was more likely to provide practical guidance and be more reliable.

The findings of this research indicates that young people with IBD and cooccurring depression and/or anxiety report a lived experience of the bidirectional relationship between IBD and mental health, despite reporting a lack of formal knowledge. They report a strong need for accessible, reliable, and practical information that does not heighten anxiety. They indicated a preference for this information to be communicated in person by their healthcare teams. Current resources available to patients are inconsistent in quality and utility, creating a gap that can increase

anxiety and reduced confidence in manging their health, which may impact negatively on both their physical and psychological wellbeing. Patient education materials should be assessed for clarity, practical utility and quality to ensure that they meet the information needs of patients.

Overview of Chapters

Chapter 1: This chapter will provide an extended literature review of the existing literature concerned with Inflammatory Bowel Disease (IBD) and mental health, the prevalence of cooccurring anxiety and depression, the biopsychosocial model, other relevant health psychology theoretical models, and the current landscape of information provision and clinical communication around the relationship between IBD and mental health.

Chapter 2: This chapter contains the manuscript of the qualitative study entitled "Inflammatory Bowel Disease and Depression and/or Anxiety: Patients' Perspectives".

Chapter 3: This chapter contains the manuscript of the research study entitled "An Evaluation of Publicly Available Information on Inflammatory Bowel Disease and Mental Health ".

Chapter 4: This chapter will provide an integrated discussion of the key findings of both research studies, how these findings align with the existing research literature, an overview of the limitations associated with these studies, along with recommendations for clinical practice and future research directions.

Chapter 1: Extended Literature Review

Chapter Overview

This chapter reviews the relationship between inflammatory bowel disease (IBD) and mental health within a biopsychosocial framework, with a focus on young adults. It examines psychosocial impact, the bidirectional IBD and mental health relationship, and limitations in clinical communication and patient information. These gaps underpin the rationale for two studies: a qualitative exploration of patient experience and a systematic audit of patient information.

Inflammatory Bowel Disease – A Biopsychosocial Overview

Inflammatory bowel disease (IBD) is a chronic and lifelong condition often with onset in young adulthood, which can be painful and debilitating (Abdelbadiee et al., 2025; Sarid et al., 2018). IBD is an umbrella term for a group of inflammatory illnesses which impact the gastrointestinal tract, the most common of which are Crohn's Disease (CD) and Ulcerative Colitis (UC) (Jones et al., 2019).

Biopsychosocial Model

The biopsychosocial model (Engel, 1977) can be considered to be an appropriate overarching theoretical framework through which to frame the relationship between IBD and mental health (Dent et al., 2022). The biopsychosocial model conceptualises IBD as arising from interacting biological, psychological, and social factors (Dent et al., 2022; Engel, 1977; Gatchel et al., 2007; Wade & Halligan, 2017). A recent scoping review identified the biopsychosocial approach to be an appropriate model to promote understanding of the psychological and social factors

which also impact on the lived experience of those with IBD (Dent et al., 2022; Zhang et al., 2022). This study demonstrated that there are a large number of biological, psychological and social factors that are interconnected in IBD (Dent et al., 2022). These include quality of life, social supports perceived as positive and negative depending on the quality of the support, distress leading to maladaptive coping which further increases distress and impairments in psychosocial functioning (Dent et al., 2022). Employment can be associated with both adverse and positive outcomes, such as job loss due to lowered productivity and higher absenteeism, and high job satisfaction due to providing distraction and opportunities for social support (Dent et al., 2022).

The biopsychosocial model considers the differences and experiences of patients and can guide research and clinical practice to focus on outcomes and factors related to wellbeing that IBD patients perceive as important and relevant to their experiences (Dent et al., 2022; Wade & Halligan, 2017). Given that the burden of IBD is multifaceted and shaped by the interaction between disease activity, illness perceptions, psychological distress and social factors such as stigma, relationships and functional impairment, this highlights the limitations of solely biomedical models and indicates the need for a biopsychosocial framework to capture the complexity and interaction of these factors (Becker et al., 2015; Brooks et al., 2016, 2019; Halloran et al., 2021; Mikocka-Walus et al., 2021; Polak et al., 2020).

Crohn's Disease

Crohn's Disease (CD) is a chronic inflammatory condition of the gastrointestinal tract that can cause irreversible bowel damage and disability (Dolinger et al., 2024). It most commonly affects the colon and terminal ileum

(Dolinger et al., 2024) and presents with abdominal pain, bloating, chronic diarrhoea, blood in stool, fatigue, and weight loss (Torres et al., 2017). Around half of patients develop complications such as abscesses, fistulas, and strictures (Pariente et al., 2011; Thia et al., 2010). CD is managed with pharmacological therapies (e.g., immunosuppressants), nutritional therapy, and surgery (Torres et al., 2017), and is characterised by relapsing-remitting disease with high recurrence rates (Buisson et al., 2012). Historically, up to half of patients required surgery within 10 years and a third required multiple procedures, sometimes resulting in stoma formation (Cosnes et al., 2012), although biologic therapies have reduced surgical rates overall (Lowe et al., 2021). Despite this, fears of surgery remain common (Roda et al., 2020; Spinelli et al., 2021). Disease progression is frequent, with 40% developing bowel damage within 1 year (Fiorino et al., 2016) and 50% progressing within 10 years (Roda et al., 2020), alongside an increased risk of colorectal and small-bowel cancer (Laredo et al., 2023; Roda et al., 2020). CD is also associated with significant physical, psychological, and social burden (Touma et al., 2023), including pain, bowel urgency, impaired daily functioning, disrupted work and education, strained relationships, and identity challenges, particularly in young adults (Engel et al., 2021; Kitchen et al., 2020; Touma et al., 2023; Touma & Baeza-Velasco, 2025). This contributes to higher rates of anxiety and depression compared with the general population (Loftus et al., 2011), highlighting CD as a condition marked by chronic inflammation, unpredictability, and substantial long-term physical and psychological burden.

Ulcerative Colitis

Ulcerative Colitis (UC) is a chronic inflammatory disease of the colon characterised by continuous mucosal inflammation that begins in the rectum and extends

proximally (Feuerstein & Cheifetz, 2014). Patients typically experience abdominal cramping, chronic bloody diarrhoea, urgency, frequency, faecal incontinence, and fatigue (Feuerstein & Cheifetz, 2014; Gros & Kaplan, 2023; Segal et al., 2021). UC is managed with pharmacological therapies such as 5-aminosalicylic acids, corticosteroids, and biologics, although some patients require surgery including colectomy or ileoanal pouch formation (Segal et al., 2021). Treatment response rates are estimated at 30–60%, with around one-fifth requiring hospitalisation within five years (Gros & Kaplan, 2023; Turner et al., 2021). Ongoing monitoring with biomarkers and colonoscopy is required (Gros & Kaplan, 2023), due to increased colorectal cancer risk (Ullman & Itzkowitz, 2011). UC follows a relapsing-remitting course requiring long-term management to control symptoms, prevent complications, and maintain quality of life (Gros & Kaplan, 2023; Turner et al., 2021).

Beyond physical symptoms, UC has a substantial psychosocial impact, particularly in young adults (Newton et al., 2019). Symptom unpredictability contributes to emotional distress and reduced participation in work, education, and social activities (López-Sanromán et al., 2017; Newton et al., 2019). Many young people report social withdrawal due to embarrassment or fear of symptoms, alongside feelings of difference from peers (López-Sanromán et al., 2017; Savard & Woodgate, 2009). Elevated anxiety, depression, and emotional dysregulation are common and associated with reduced self-efficacy and poorer disease management, contributing to worse health outcomes (Ishaq & Sultan, 2020; Newton et al., 2019).

Overall, UC is a relapsing inflammatory condition with significant physical, psychological, and social burden, particularly during young adulthood.

Psycho-Social Impact of IBD in Young Adults

Disease Burden in the Transition to Adulthood.

Emerging adulthood represents a particularly vulnerable developmental stage for individuals with IBD, as it is a critical developmental period (Arnett, 2000, 2023; Touma et al., 2023) typically marked by personal growth, risk-taking, increasing independence and self-management, exploration of intimate relationships, and progress towards further education and career development, creating a foundation for a person's adult life (Arnett, 2000; Becker et al., 2015; Brooks et al., 2016, 2019). Patients with IBD are most often diagnosed during the period of emerging adulthood (Kamp et al., 2020), and in the last twenty-five years, prevalence rates of IBD in individuals under the age of 18 have doubled (Abdelbadiee et al., 2025; Ashton & Beattie, 2024). Successfully navigating the transition from paediatric and parent-led to adult services can introduce a further challenge, as young adults must acquire supplementary skills related to disease management, navigation of healthcare systems, and disease-related knowledge (Gumidyala et al., 2017; Szigethy et al., 2011). The acquisition of disease related knowledge and management skills during this transitional period can contribute to greater self-management, enhanced coping skills, and improved health outcomes (Gumidyala et al., 2017). These overlapping developmental and illness-related demands can create a heightened vulnerability to disruption in daily functioning, particularly in relation to social participation and relationship development.

Social and Functional Impact.

In addition to the physical and emotional demands that are placed on patients with IBD through frequent and intense medical management and oversight, there is

also a significant impact on the social development and lifestyle of patients (Le Berre et al., 2020; van der Have et al., 2014). The overarching social impact of IBD on patients can result in perceived isolation, missed social milestones and reduced opportunities to engage in activities which support psycho-social functioning (Ross et al., 2024). Sexual functioning, family planning and fertility are also impacted in patients, and concerns about reproductive dysfunction can be an additional stressor in relationships (Becker et al., 2015). Dietary restrictions and gastrointestinal symptoms can also limit the amount of social opportunities that are available to those with IBD (Varma et al., 2022). Fears about being treated differently, delayed physiological development, reduced endurance during physical activity, physical symptoms, medical treatment and toilet use contribute to the burden of disease in IBD, and can negatively impact upon attendance at education and social outings (Halloran et al., 2021; Loftus et al., 2011).

Difficulties with impaired sleep and fatigue throughout the day, coupled with the unpredictable nature of clinical recurrence of symptoms, can also contribute to missing work and education, and extended periods of active disease can subsequently raise concerns about financial security if a patient is unable to maintain employment during this time (Becker et al., 2015; Sarid et al., 2018; Varma et al., 2022). The unpredictability associated with frequency and urgency can lead to fear around access to bathrooms and possible faecal incontinence, which can often lead to significant social withdrawal (Becker et al., 2015; Larsson et al., 2017). This evidence highlights that the social burden of IBD is not just a consequence of physical symptoms, but reflects a broader disruption to social participation, independence and life progression, with implications that can encompass relational, occupational and developmental domains.

Identity Development Disruption and Evolving Coping Strategies.

IBD can disrupt identity development during emerging adulthood, a stage characterised by self-exploration and increasing autonomy (Allemang et al., 2024; Arnett et al., 2014; Peters & Brown, 2022; Touma et al., 2023; Touma & Baeza-Velasco, 2025). Young people must integrate illness into an evolving sense of self (Muse et al., 2021), often leading to tension between maintaining a "normal" identity and managing symptoms (Touma et al., 2023; Touma & Baeza-Velasco, 2025). Early coping strategies such as concealment (Allemang et al., 2024; Gelech et al., 2021) may provide short-term relief but can delay adjustment (Steinberg, 2020; Zhang et al., 2026). Over time, individuals may shift towards more adaptive strategies (Gelech et al., 2021; Zhang et al., 2026), although this process is dynamic and influenced by disease activity, stigma, and social context (Allemang et al., 2024; Steinberg, 2020).

Emerging adulthood is marked by a strong cultural emphasis on independence, productivity and physical capability (Arnett et al., 2014; Steinberg, 2020). IBD directly conflicts with these expectations, creating tension between the desire for "normal" adulthood and the reality of dependence on support systems, treatment and symptom management (Arnett et al., 2014; Steinberg, 2020; Zhang et al., 2026). This misalignment can create a perception of not meeting socially expected timelines, reduced autonomy and emotional strain (Zhang et al., 2026). Additionally, identity is socially mediated, whereby validation from others can facilitate integration, whereas lack of understanding or stigma can reinforce distancing from IBD (Allemang et al., 2024; Steinberg, 2020). Identity development in young adults with IBD reflects an ongoing tension between personal experiences, social context and developmental expectations.

Stigma.

IBD is consistently identified as a highly stigmatised condition, often more so than other chronic illnesses, partly due to low public understanding and the socially sensitive nature of its symptoms (Groshek et al., 2017; Saunders, 2014). This stigma functions at interpersonal and internalised levels, characterised by shame and anticipation of negative evaluations from others (Saunders, 2014). This is significant for young adults, whose developmental stage places particular emphasis on peer acceptance (Arnett, 2000, 2023; Arnett et al., 2014). Concerns about being perceived as different, unreliable, or lacking bodily control can frequently lead to concealment or minimising of symptoms (Saunders, 2014). While these strategies may protect against immediate social threat, they can subsequently reinforce isolation and misunderstanding, particularly due to others' misinterpretation of social withdrawal (Gamwell et al., 2018). Stigma can extend beyond social discomfort to shape wider psychosocial outcomes (Dattilo et al., 2022), such as reduced social connectedness, difficulties in peer relationships, and diminished sense of belonging, all which can be related to increased risk of depressive symptoms (Gamwell et al., 2018).

Stigma can also contribute to illness-related uncertainty, particularly regarding symptom unpredictability and future health outcomes, which in turn can exacerbate emotional distress (Gamwell et al., 2020; Roberts et al., 2021). This highlights stigma as a social, cognitive and emotional process that may influence how individuals interpret and respond to their illness (Dattilo et al., 2022; Roberts et al., 2021). Consistent with other chronic illness populations, stigma and illness intrusiveness on daily life is associated with increased health anxiety and psychological distress (Dattilo et al., 2022). The impact of stigma is context

dependent, varying across social environments, requiring individuals to continually adjust how they present their illness (Saunders, 2014). Overall, the literature suggests that stigma is a mechanism through which social, psychological and functional aspects of IBD are interconnected (Gamwell et al., 2018).

Psychological Distress.

The emotionally challenging and intrusive nature of IBD can negatively affect quality of life and contribute to higher levels of psychological distress (Becker et al., 2015; Halloran et al., 2021). Young people with IBD can experience a substantial psychosocial burden and reduced quality of life compared to both healthy peers and other chronic populations (Halloran et al., 2021; Loftus et al., 2011). Anxiety and depression are common in young people with IBD and are strongly associated with a range of clinical and contextual factors, including higher disease activity, corticosteroid use, lower socio-economic status and parental stress (Brooks et al., 2016). In addition, illness perceptions, reduced perceived control, and limited social support have been identified as key contributors to poorer mental health outcomes in this population (Halloran et al., 2021; Polak et al., 2020; Qualter et al., 2021). Epidemiological evidence further highlights the extent of this burden, with young adults with IBD significantly more likely to develop anxiety and depression, alongside other psychiatric disorders, than the general population, and at an earlier stage (Cooney et al., 2024; Knowles et al., 2015; Thavamani et al., 2019). For example, a recent UK population-based cohort study determined that a higher incidence of mental health conditions in young adults with IBD, including anxiety and depression, when compared to healthy peers (Cooney et al., 2024). Additionally, a prospective cohort study concluded that 55% of young people with IBD had elevated anxiety/depression, and 83% reported reduced quality of life, indicating that

psychological distress is driven by interacting clinical and psychosocial factors (Brooks et al., 2019). This reinforces the need for an integrated understanding of IBD that extends beyond physical symptom management alone.

Psychological distress also contributes to further adverse outcomes, as it is associated with poorer treatment adherence, increased symptom burden, and disrupted sleep (Brooks et al., 2016, 2019). Periods of disease flare are associated with increased psychological distress, further reinforcing this interaction (Azevedo et al., 2025; Byron et al., 2020). Young people with IBD may commonly experience uncertainty, unpredictability, diminished control and a sense of vulnerability, alongside efforts to manage or conceal emotional responses (Brooks et al., 2015; Nicholas et al., 2007). These experiences vary however, as patients with elevated negative illness perceptions can tend to report poorer psychological adjustment (Polak et al., 2020). Overall, this evidence supports a bidirectional relationship between psychological distress and IBD, in which emotional responses can both arise from and contribute to ongoing disease burden.

The IBD-Mental Health Relationship

The Association and Prevalence of IBD and Mental Health Difficulties

There is a suggested link in the literature between IBD and mental health difficulties, particularly anxiety and depression, which are more prevalent in IBD than in the general population (Roderburg et al., 2024; Tribbick et al., 2017). Recent systematic reviews and meta-analyses demonstrated that the prevalence of anxiety in individuals with IBD is between 32-35%, and depression is between 22-25%, with higher rates of both observed in women than men (Barberio et al., 2021; Kok et al.,

2023; Neuendorf et al., 2016). Recent general population-level estimates suggest that approximately 18% of adults report anxiety symptoms, and 21% report symptoms of depression, however these figures are based on symptom level prevalence rather than diagnosed disorders, so comparisons with clinical populations should be made cautiously (Terlizzi & Zablotsky, 2024). With regard to young adults with IBD specifically, population based prevalence data show rates of 17% for anxiety and 20% for depression by the age of 25, which are higher than those observed in healthy peers (i.e., approximately 14% and 15% for anxiety and depression respectively) (Cooney et al., 2024). A recent systematic review and meta-analysis reported prevalence rates of approximately 19% for anxiety and 14% for depression among children, adolescents and young people with life limiting conditions, suggesting a similarly high psychological burden across chronic conditions, although differences in condition classification and age grouping limit direct comparison (Barker et al., 2019). The prevalence rates of anxiety and depression in patients with IBD are some of the highest in comparison to other chronic disorders (e.g., colorectal cancer, rheumatoid arthritis, coeliac disease, congenital disorders, gastro-oesophageal reflux disease, and food allergy) (Daré et al., 2019; Gomez et al., 2023; Knowles et al., 2015; Mikocka-Walus et al., 2016). Overall, evidence consistently indicates elevated anxiety and depression in IBD compared with both the general population and other chronic conditions, suggesting a disproportionate psychological burden.

Fluctuations in disease activity are related to psychological outcomes in IBD. CD and UC are characterised by alternating active and inactive periods (Torres et al., 2017). The systematic review by Barberio et al. (2021) found higher rates of anxiety and depression in individuals experiencing active disease states (Barberio et al., 2021). During periods of active disease, over half of IBD patients meet criteria for

anxiety disorders, while approximately a third of IBD patients meet criteria for depression (Barberio et al., 2021; Neuendorf et al., 2016). The prevalence of symptoms of anxiety and depression are more likely (OR 1.2) to occur in patients with CD compared to those with UC (Barberio et al., 2021), which aligns with the findings of another study that indicated rates of depression (OR 3.2), anxiety (OR 2.8) and stressful life events (OR 3) were higher in CD than UC, and quality of life was higher in UC patients (OR 0.27) (Bernabeu et al., 2022). Overall, disease activity and subtype influence psychological burden, demonstrating variability in mental health outcomes in IBD.

In addition, IBD can be associated with higher rates of other psychiatric disorders increasing overall disease burden (e.g., bipolar disorder, schizophrenia, post-traumatic stress disorder) (Bernstein et al., 2019; García-Alanís et al., 2021; Gomez et al., 2023). IBD can also be associated with psychological distress, functional impairment (Greywoode et al., 2022), deliberate self-harm, insomnia (Umar et al., 2022), pain (Sweeney et al., 2020), and reduced quality of life (García-Alanís et al., 2021). A retrospective cohort study indicated that the presentation of mental illnesses during the first year post diagnosis have also been reported to be particularly high in the IBD population, with depression (IRR 1.62) having a higher incidence rate than anxiety (IRR 1.28) (Umar et al., 2022). The co-occurrence of mental health difficulties and IBD can result in a higher demand on healthcare services, a greater cost of medical care (Greywoode et al., 2022; Irving et al., 2021).Individuals with co-occuring mental health difficulties can also experience higher rates of disease relapse (Bitton et al., 2008; Byrne et al., 2017), surgery (Ananthakrishnan et al., 2013), pharmacological treatment (e.g., immunomodulators, psychotropic medications) (Irving et al., 2021) and medical investigations (i.e.,

colonoscopies) (Ananthakrishnan et al., 2013; Bernstein, 2018). Individuals with IBD and mental health difficulties such as depression and anxiety can also experience poorer response to treatment (Mittermaier et al., 2004), lower adherence to medication (Regueiro et al., 2017), and more absences from employment and education (Irving et al., 2021). Psychological distress can reduce self-efficacy and self-management, contributing to poorer health outcomes (Abdelbadiee et al., 2025; Fairbrass et al., 2022; Keefer, 2021a, 2021b; Nikolova et al., 2022; Plevinsky et al., 2016). Overall, these patterns support a bidirectional link between psychological health and IBD, whereby the presence of mental health difficulties can exacerbate disease outcomes and functional impairment across multiple domains.

The association between IBD and symptoms of anxiety and depression has been widely reported in the literature (Abdelbadiee et al., 2025; Barberio et al., 2021; Fairbrass et al., 2022; Gracie et al., 2018; Irving et al., 2021). This relationship has been conceptualised as bidirectional in nature and mediated by the gut-brain axis, inflammatory responses, and gut microbiome (Abdelbadiee et al., 2025; Fairbrass et al., 2022; Keefer, 2021a; Yuan et al., 2021). The presence of depression has been observed as a predisposing factor to the onset of IBD, even when this has been present as much as five to ten years prior to IBD diagnosis (Abdelbadiee et al., 2025; Bisgaard et al., 2023; Nikolova et al., 2022; Piovani et al., 2024). Psychological distress can exacerbate the physical symptoms of IBD through interactions along the gut-brain axis (Abdelbadiee et al., 2025; Fairbrass et al., 2022; Hu et al., 2021; Mikocka-Walus & Andrews, 2018).It is also associated with increased severity of disease (Burisch et al., 2013; van den Brink et al., 2016), frequency of disease flares and escalation of treatment (e.g., surgery) (Fairbrass et al., 2022; Hinnant et al., 2025;). The presence of cooccurring depression and anxiety

can also reduce a patient's quality of life (Burisch et al., 2013; Fairbrass et al., 2022; Hu et al., 2021; Kok et al., 2023) and ability to engage in effective self-management (Keefer, 2021a; Kok et al., 2023). Together, these factors may contribute to poorer disease related outcomes (Fairbrass et al., 2022; van den Brink et al., 2016). IBD at baseline has been associated with an increased risk of future anxiety and depression (Bisgaard et al., 2023; Fairbrass et al., 2022; Hinnant et al., 2025). This association may reflect the pervasive impact of the disease on quality of life including pain, fatigue, stigma, reduced social functioning and uncertainty (Hu et al., 2021; Keefer, 2021b; Kok et al., 2023). Overall, this bidirectional relationship highlights the importance of addressing mental health within IBD care, given its association with both physical and psychological outcomes.

Conceptual Mechanisms regarding Directionality

Psychosomatic Model.

The psychosomatic model, which historically proposed that psychological distress had a causal relationship to IBD's onset or progression through the experience of physical symptoms as manifestations of emotional distress, is a perspective that has been challenged and is now considered to be outdated (Shah et al., 2014; Van Oudenhove et al., 2010). The primary criticism of this model was the attribution of blame that it placed on the patient's psychological state and their ability to cope, instead of acknowledging that the pathophysiology of IBD is moderated by the immune system and is underpinned by biological mechanisms, rather than exclusively psychological factors (Abdelbadiee et al., 2025; Lastretti et al., 2025; Sajadinejad et al., 2012; Shah et al., 2014). This model lacked empirical evidence and carried the risk of perpetuating stigma and non-disclosure of mental

health problems from patients, due to the misattribution of implicit blame towards patients for their physical difficulties (Aronowitz & Spiro, 1988). The psychosomatic model can however, continue to appear in the context of clinical discussions, in instances whereby a patient's mental health concerns may be dismissed or minimised as a causal factor in their illness, highlighting the importance of non-blaming, non-stigmatising and accurate clinical explanations (Saunders, 2014). While psychological distress is not a direct cause of IBD, it can be a mediating factor in relation to perceived symptom severity and coping behaviours (Sajadinejad et al., 2012).

Bidirectional Gut-Brain Axis Model.

The relationship between IBD and mental health can be conceptualised as a self-perpetuating cycle whereby interactions through the gut-brain axis influence disease onset, progression and prognosis. This bidirectional model links inflammatory disease processes and symptoms (e.g., pain, fatigue, urgency) with increased anxiety, depression, stress and psychosocial burden (Abdelbadiee et al., 2025; Fairbrass et al., 2022; Gracie et al., 2018). Preexisting anxiety and depression can serve as a predisposing contributary factor to the development of IBD, and can increase the risk of flares and disease severity (Burisch et al., 2013; Fairbrass et al., 2022; Gracie et al., 2018; Mikocka-Walus & Andrews, 2018). Evidence suggests pre-existing depression approximately doubles IBD risk, with increased risk also reported for Crohn's disease and ulcerative colitis (Piovani et al., 2024). Depression may also precede the onset of IBD by several years (Bernstein et al., 2019; Bisgaard et al., 2023; Piovani et al., 2024).

The difference between the psychosomatic and the gut-brain axis models is that psychological distress is not viewed as a causal mechanism, but rather as part of a bidirectional interaction in which IBD and mental health mutually influence one another (Abdelbadiee et al., 2025; Fairbrass et al., 2022; Hu et al., 2021; Keefer & Kane, 2017). Enduring mental health difficulties can also have a negative impact on the overall course of the disease, precipitate relapse to active disease states and hinder both response and adherence to treatment (Kok et al., 2023). Symptoms of IBD can significantly contribute to psychological distress and impair progress towards personal, social and employment goals (Jones et al., 2019; Kok et al., 2023). This framework emphasises IBD as a condition in which psychological and physiological processes are dynamically interconnected, supporting the need for integrated care addressing both domains.

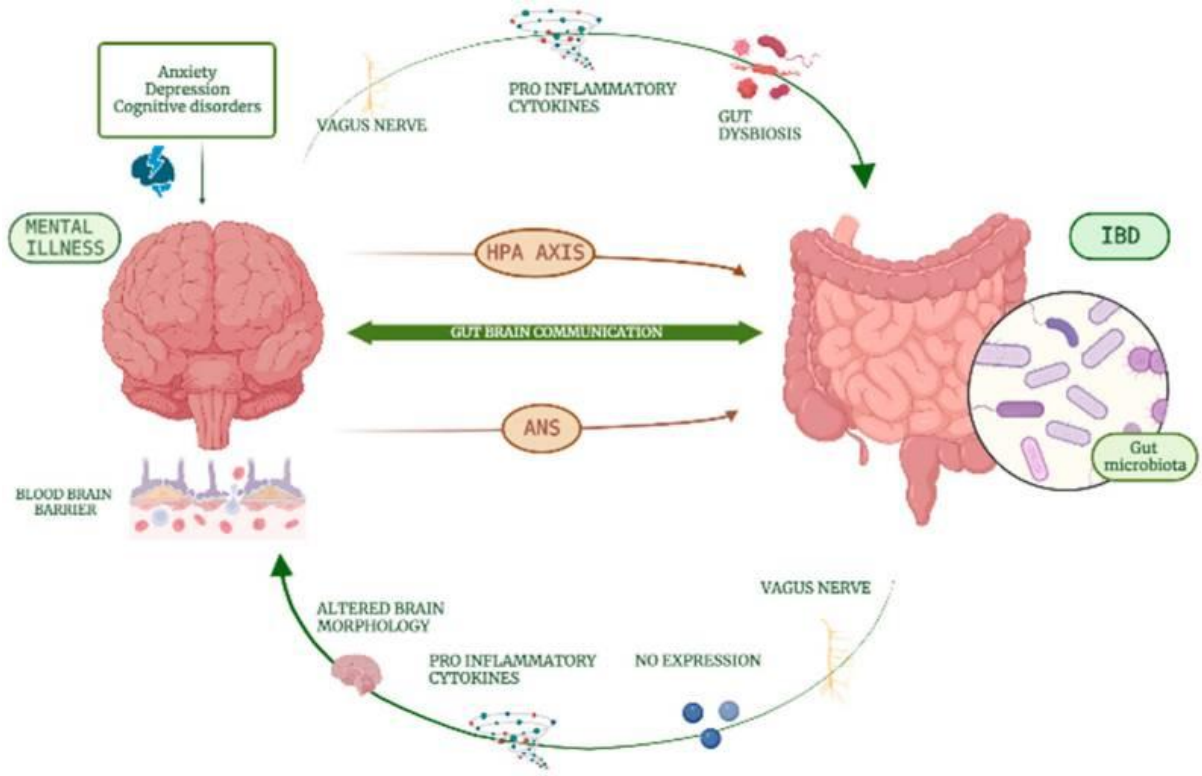
Biologically, this relationship is thought to be mediated by the gut-brain axis, involving connections between the enteric nervous system and the central nervous system (Sajadinejad et al., 2012). This includes communication between neuroendocrine pathways and the hypothalamic-pituitary-adrenal axis (HPA axis), and the autonomic, peripheral and central nervous systems (Fairbrass et al., 2022). Psychiatric comorbidity risk in IBD patients may be increased due to signalling between the central nervous system and the gastrointestinal system (Bisgaard et al., 2023). Mechanisms include changes in the gut microbiome, pro-inflammatory cytokine activity leading to sickness behaviour (i.e., fatigue, loss of appetite and changes in executive functioning, in order to preserve energy and promote recovery), (Dantzer, 2023) and neurological signalling through the vagal nerve (Bisgaard et al., 2023; Dantzer et al., 2008). However, less is known about how patients understand and experience this interaction in daily life.

Previous research suggests that the functional and social limitations associated with IBD symptoms can negatively impact psychological wellbeing (Byron et al., 2020; Hu et al., 2021; Mikocka-Walus et al., 2021; Norton et al., 2012). These limitations may also reduce self-management capacity (Iizawa et al., 2023; Plevinsky et al., 2016), which is associated with poorer physical and mental health outcomes (Hu et al., 2021; Mikocka-Walus et al., 2021). This suggests that patients with IBD likely experience this bidirectional relationship in daily life, but there is limited understanding of their knowledge of this process (Berenblum Tobi et al., 2024; Byron et al., 2020; Mikocka-Walus et al., 2021).

Figure 1.

The Biological Mechanism of the Bidirectional Nature of IBD and Mental Health

(Bartocci et al., 2023)



Clinical Communication and Patients' Perspectives

Clinical Communication Gap Consequences

There is a reported need in the literature that patients with IBD require more comprehensive information on self-management and behavioural strategies to support their wellbeing (Iizawa et al., 2023; Norouzkhani et al., 2023; Plevinsky et al., 2016).Implementing a stepped care approach to psychological support may be beneficial in facilitating patients to access useful resources and supports, and in guiding healthcare providers around appropriate interventions (Hinnant et al., 2025;

Kok et al., 2023). Their information needs are highest at the time of diagnosis and during active disease (Borgaonkar et al., 2002; Fourie et al., 2018; Khan et al., 2016) and after long periods of living with IBD when their information needs were not initially met (Hawkins & Bull, 2024; Plevinsky et al., 2016). Young adults with IBD have a reported preference to receive more information regarding mental health through integrated conversations with their healthcare teams, concurrent to treatment for their physical symptoms (Allemang et al., 2025; Berenblum Tobi et al., 2024; Nicholas et al., 2007; Qualter et al., 2021). Delivering this information in a patient-centred, evidence-based, and accessible format can improve health-related quality of life and mitigate the uncertainty often exacerbated by unguided online searching (Jones et al., 2019). However, existing patient education materials primarily address physical disease management, and may offer little guidance on mental health risks associated with IBD (Hawkins & Bull, 2024; Karimi et al., 2021; Kok et al., 2023). Providing education around the IBD and mental health relationship, alongside lifestyle advice may be considered a universal intervention, which acknowledges the biopsychosocial impact of IBD (Hinnant et al., 2025; Kok et al., 2023; Mikocka-Walus et al., 2021). Initiating conversations around stress, wellbeing and self-management strategies may reduce perceived stigma and normalise mental health discussions in IBD care (Berenblum Tobi et al., 2024; Hinnant et al., 2025; Mikocka-Walus et al., 2021). Such conversations may promote later discussions in relation to any emotional symptoms a patient may experience, and the recommendation of appropriate psychological intervention for such (Byron et al., 2020, 2023; Kok et al., 2023; Norton et al., 2012). This has implications relating to information provision, as greater disease knowledge has previously been linked to better adjustment outcomes, including increased adaptability to illness-related

stressors and improved quality of life (Hinnant et al., 2025; Jordan et al., 2016; Kok et al., 2023; Mercuri et al., 2025; Munson et al., 2009). Increased knowledge can be a facilitator of behaviour change (Kelly et al., 2016; Screti et al., 2024), and may also be associated with reduced levels of perceived stigma and increased health literacy skills (Berenblum Tobi et al., 2024; Groshek et al., 2017; Mercuri et al., 2025; Qualter et al., 2021; Roberts et al., 2021). Individualised and tailored information should consider disease stage and personal coping styles, such as the tendency to seek information ("monitoring") or avoid it ("blunting") under stress (Lesnovska et al., 2014). Developing clear recommendations for information on the IBD and mental health link may guide patients towards positive behavioural changes, support their overall wellbeing, and raise awareness among healthcare providers. This may also improve clinicians' recognition of mental health comorbidities in IBD and increase their confidence in managing this aspect of care (Kok et al., 2023). This evidence highlights the importance of integrating biopsychosocial education within IBD care, recognising that information provision can be an important mechanism associated with improved psychological and physical outcomes (Kok et al., 2023).

The Role of Reliable Information and Health Literacy

Access to accurate information and education around IBD has been highlighted as an important part of the treatment process for patients (Borgaonkar et al., 2002; Plevinsky et al., 2016). However many patients reportfeeling insufficiently informed and express a preference for receiving more information from their healthcare providers (Becker et al., 2015; Fourie et al., 2018; Hawkins & Bull, 2024; Khan et al., 2016). Alongside general self-management information, patients have a reported desire for more education and integration of information around the psychosocial impact of IBD (Berenblum Tobi et al., 2024; Hawkins & Bull, 2024; Mikocka-Walus & Andrews, 2018; Qualter et al., 2021).However if busy gastroenterology teams feel underinformed or do not have access to training or onsite specialist psychological support, they may feel under resourced or lacking in confidence to implement this (Hawkins & Bull, 2024; Hinnant et al., 2025; Kok et al., 2023). As information needs in this population fluctuate and may be higher at different times over the disease course, teams may not have pre-existing stepped care pathways in place in relation to tailored resources or interventions in order to meet these evolving needs (Hinnant et al., 2025; Kok et al., 2023). This may create a disconnect between patient's needs and expectations, and what is available to them from healthcare providers (Hinnant et al., 2025; Khan et al., 2016; Kok et al., 2023; Vegni et al., 2019). Having a lack of reliable disease related information can negatively impact upon patients' quality of life, as when formal clinical communication is lacking patients can seek information elsewhere such as the internet, and this can lead to reduced levels of certainty and increases in anxiety (Jones et al., 2019; McMullan et al., 2019; Niv et al., 2017). With regard to models of health literacy, improving the quality and communication of health related

information, particularly when presented by health professionals, can support patients to develop skills related to the retrieval, comprehension, and application of this information, with implications for engagement, self-management and overarching health outcomes (Nutbeam & Lloyd, 2021). This has been contextualised within IBD by a recent systematic review conducted by Mercuri et al. (2025), indicating that health literacy is associated with treatment adherence, self-management, disease activity, communication with healthcare professionals, psychological wellbeing and quality of life. Identified barriers to the development of health literacy skills encompass a lack of individualised information, inadequate communication, cultural and general literacy challenges, and difficulties relating to accessing, evaluating and applying digital health information (Mercuri et al., 2025). This indicates that the provision of relevant, clear and applicable health information, alongside supporting patients in developing health literacy skills, may promote more effective self-management (Mercuri et al., 2025). Subsequently, this may contribute to improved wellbeing and disease outcomes, supporting the promotion of patient care that is centred on biopsychosocial well-being (Dent et al., 2022). This highlights that limitations in the provision and communication within IBD care are not neutral, but may actively impact the development of health literacy, perpetuate uncertainty and limit patients' capacity to effectively engage in self-management.

Existing research examining patient perspectives highlights ongoing gaps in the accessibility, relevance and adequacy of information available to individuals with IBD. A study conducted by Becker et al. (2015) indicated that 66% of participants reported a strong interest in further information pertaining to the impact of IBD on mental health, but 33% had difficulty accessing this information. The need for up to date and comprehensive information regarding IBD was also emphasised, alongside

the central role of healthcare professionals and the multidisciplinary team in delivering information to patients (Becker et al., 2015; Lee et al., 2018). While the internet and resources such as support agency websites are common sources of information for IBD patients, the most sought-after information is often either lacking or perceived as inadequate (Becker et al., 2015). Similarly, another study concluded that patients preferred to receive disease related information from their medical specialists, that only approximately a third of patients felt that they had gotten the correct information from the internet, and that only a small number of patients felt that they had sufficient information (Wong et al., 2012). These findings suggested a persistent unmet need for reliable, understandable and patient-centred information on IBD, including its complex relationship with mental health. This highlights a gap in both the availability and quality of information, the specific content and utility of which regarding the link between IBD and mental health remains insufficiently understood.

Integrated Psychological Care Models

Due to the associated psychological cooccurrence with IBD (Feng et al., 2024), the use of psychological therapies may be considered as a way to improve mood, coping and quality of life, and manage anxiety and stress (Gracie et al., 2017). However, many gastroenterology services do not have access to a departmental psychology service, or input from a psychology on their Multidisciplinary Teams (MDTs), which is recommended in the literature (Fiorino et al., 2019, 2019; Hinnant et al., 2025). Developing a database of appropriate external services and resources, alongside stepped care interventions that other healthcare professionals can deliver, may support teams that do not have an onsite psychology service (Hinnant et al., 2025; Kok et al., 2023; Menichetti et al., 2018). The primary intervention needs for

IBD patients have been indicated as anxiety, worries and concerns in the context of IBD, and impairments in social functioning (Miehsler et al., 2008). Evidence from systematic reviews and randomised control trials suggests that psychological therapies, particularly Cognitive Behaviour Therapy (CBT), may improve short-term outcomes in mental health and quality of life in IBD (Chen et al., 2021; Li et al., 2019; McCombie et al., 2016; Mikocka-Walus, Andrews, et al., 2016). However, effects are often not sustained, with limitations in the current research evidence relating to study quality, adherence, and the need for more personalised approaches (Emerson et al., 2021; Gracie et al., 2017; Mikocka-Walus et al., 2017; Riggott et al., 2023). Acceptance and Commitment Therapy (ACT), which targets psychological flexibility through mindfulness and acceptance-based strategies, has previously demonstrated significant improvements in stress, anxiety, pain and quality of life in IBD (Ferreira et al., 2024; Marchese et al., 2024; Romano et al., 2024; Wynne et al., 2019). Emerging evidence also suggests good adherence, acceptability and potential advantages over other therapeutic approaches (Naude et al., 2025; Taghvaeinia et al., 2024). Other interventions, including gut directed hypnotherapy (Gomez et al., 2023; Hoekman et al., 2021; Mpakogiannis et al., 2024; von Wietersheim & Kessler, 2006) and psychotherapy (Lores et al., 2023; McCombie et al., 2013; Paulides et al., 2021), show mixed efficacy for psychological outcomes in IBD. Conversely, mindfulness-based approaches (Ewais et al., 2019; Goren et al., 2022; Jedel et al., 2014) and eHealth interventions (Jackson et al., 2016; Keefer & Stiles-Shields, 2015; Naude et al., 2023) demonstrate benefits for stress, quality of life and disease management. Overall, the implementation of the ACT model, mindfulness-based interventions and an individualised therapeutic approach when providing psychological therapies to IBD patients may be the most efficacious for the improvement of health related

quality of life, and reduction of psychological distress. Within the context of the bidirectional gut-brain axis, these interventions may also have subsequent effects on physical disease outcomes, including perceived symptom severity, treatment adherence and overall disease management, highlighting their potential role within integrated models of care (Gomez et al., 2023; Menichetti et al., 2018).

Patient Health Information

Patient Information-Seeking Behaviours

Drivers of Information Seeking.

Information seeking in IBD patients is shaped by an interaction between disease-related, emotional and contextual factors, alongside the characteristics of the information itself. Disease activity, stage, symptom severity, duration of symptoms, anxiety, uncertainty and emotional distress have been associated with information acquisition behaviours among people with IBD (Byron et al., 2023; Kok et al., 2023; Ni et al., 2024; Restall et al., 2017; Vegni et al., 2019). However, these influences are bidirectional, as disease-related anxiety and fear can both motivate active information seeking or contribute to avoidance, depending on how patients respond emotionally when they encounter information (Ni et al., 2024). If information is perceived as overwhelming, time-consuming or emotionally difficult to engage with, this may reduce motivation and influence the sources which are chosen, highlighting the role of emotional processes in moderating engagement (Ni et al., 2024; Vegni et al., 2019).

Information needs fluctuate over time in line with disease activity and levels of distress. Periods of increased disease activity often create a sense of urgency,

prompting patients to seek out practical knowledge related to self-management and sources of support (Byron et al., 2023; Reich et al., 2019; Vegni et al., 2019). In contrast, periods of inactive disease or remission are typically associated with a focus on information around the long-term evolution of IBD, maintenance of wellbeing and research developments (Ni et al., 2024; Vegni et al., 2019). However, this pattern is not consistent across all contexts as patients may either avoid information due to difficulties integrating their illness with their identity or engage in intensive searching driven by anxiety and uncertainty (Ni et al., 2024; Pittet et al., 2016; Zhang et al., 2026). This process can be mediated through individual and evolving coping styles related to active and avoidant coping (Allemang et al., 2024; Gelech et al., 2021; Lesnovska et al., 2014; Zhang et al., 2026). This variability suggests that information seeking is also influenced by emotional regulation alongside clinical needs.

Recent reviews show that IBD patients have ongoing information needs relating to daily self-management, mental health, basic disease knowledge, and shared decision-making (Al Khoury et al., 2022; Ni et al., 2024). Engagement with information is influenced by perceived trustworthiness and usefulness, perceived risks and benefits, emotional responses, health literacy, and social and economic factors (Ni et al., 2024; Restall et al., 2017). Demographic and clinical differences also shape engagement (Ni et al., 2024), as CD patients often report higher knowledge and greater information needs than those with UC (Yoo et al., 2015). This suggests that greater knowledge does not necessarily indicate adequate information, but may reflect awareness of disease complexity, driving continued information seeking (McMullan et al., 2019; Selinger et al., 2017). Overall, informational needs in IBD are heterogeneous and evolve over time, indicating that

standardised approaches may be insufficient (Barberio et al., 2021; Bernabeu et al., 2022). Needs also vary across the lifespan, with practical concerns changing by developmental stage while psychological and social needs remain stable (Norouzkhani et al., 2023; Volpato et al., 2021). Collectively, this suggests that information needs are shaped by changing clinical, psychological, and contextual factors, and that misalignment between patient needs and available resources may persist unless support is tailored and responsive to how patients seek and engage with health information.

The quality of information can also mediate the information seeking response, as good quality, clear, accessible and trustworthy information can promote further engagement, support health literacy and self-management, and reduce uncertainty and stigma (Fisher et al., 2003; Groshek et al., 2017; Mercuri et al., 2025; Nutbeam & Lloyd, 2021). Conversely, a lack of information or accessing information which is of poor quality or negatively perceived can lead to increases in uncertainty, stress and avoidance, delay detection of symptoms, and poorer psychological adjustment to IBD (Ni et al., 2024; Pittet et al., 2016; Polak et al., 2020). It may also contribute to excessive searching, misrepresentation of symptoms and catastrophising, which may negatively impact upon overall health outcomes (Mercuri et al., 2025; McMullan et al., 2019; Nutbeam & Lloyd, 2021; Pittet et al., 2016; Plevinsky et al., 2016). This evidence suggests that information seeking in IBD is a multifaceted process, which requires access to information alongside consideration of its quality, timing and psychological impact.

Where Patients Search for Information.

IBD patients reportedly engage with information sources in distinct ways depending on whether they are institutional or socially mediated. Institutional sources and in-person communication with healthcare professionals are reportedly preferred by patients for obtaining evidence-based information (Cima et al., 2007; Hinnant et al., 2025; Khan et al., 2016; Kok et al., 2023; Ni et al., 2024). This may reflect a wider reported tendency among individuals with chronic conditions to value direct and clinically validated information (Merati-Fashi et al., 2022). However, reliance on institutional sources alone may not always be sufficient, as many patients report unmet information needs regarding the biopsychosocial impact of IBD, leading them to seek out and access alternative resources (Fourie et al., 2018; Hawkins & Bull, 2024; Karimi et al., 2021; Khan et al., 2016; Plevinsky et al., 2016). Over half of IBD patients indicated that they use the internet for disease-specific information, frequently in the months following diagnosis, and when they are lacking valuable information about their disease, treatment and self-management (Bernstein et al., 2011; Catalán-Serra et al., 2015). This is reinforced by evidence that 27% of patients are dissatisfied with the level of information that they received when they first began to experience symptoms of IBD (Pittet et al., 2016). Patterns of engagement can also vary by age, as 47% of young people with IBD access medical websites, suggesting that online institutional resources may play a role in early-stage information seeking (Szeto et al., 2018). This highlights that limited institutional information may reinforce accessing of less regulated and reliable sources, with implications for self-management and health-related decision making.

In contrast, social media and other online peer-based platforms may be more commonly used for experiential and emotional purposes (Adeyemi et al., 2025;

Goren et al., 2022; O'Leary et al., 2020), and to access advice on coping with the daily challenges associated with IBD (Kuehn, 2011; Ni et al., 2024; Szeto et al., 2018). Engagement with these sources may be driven by factors such as perceived stigma, difficulties with health literacy and barriers to accessing traditional care (Adeyemi et al., 2025; Goren et al., 2022; Groshek et al., 2017; Reich et al., 2019). Adults are reportedly more likely to use social media for health-related information compared to young adults, even though young people use the internet to seek IBD related information more frequently (Catalán-Serra et al., 2015; Pittet et al., 2016; Szeto et al., 2018). This highlights a functional difference, as institutional sources are primarily used for authoritative, evidence-based knowledge, while social media addresses social, emotional and experiential needs (Karadag et al., 2022).

Spectrum of Sources and The Need for Critical Appraisal

A spectrum of online information sources are available to IBD patients online, including specialist support organisations and institutions (e.g., Crohn's and Colitis Ireland), national healthcare organisations (e.g., HSE, NHS), clinician and educator content, commercial and pharmaceutical websites, and peer generated content on social media and forums. Some institutional websites were previously rated as higher quality sources of IBD information (e.g. Crohn's and Colitis Foundation of America, HealthCentral) (Promislow et al., 2010). However, less than half of online IBD resources were previously rated as high quality, with alternative medicine sites performing worst compared to institutional and pharmaceutical websites (van der Marel et al., 2009). Systematic reviews indicate that online IBD information regarding CD and UC is of highly variable quality, often lacks clarity and does not meet patient's information needs (Bernard et al., 2007; Langille et al., 2010). Online materials can range from high-quality and evidence-based information to substandard resources, suggesting that a substantial proportion of resources accessed by patients may lack credibility (Bernard et al., 2007; Fortinsky et al., 2012; Langille et al., 2010; Promislow et al., 2010). As patients frequently rely on online sources to support their understanding and management of IBD, exposure to lower-quality information may contribute to misunderstanding, increased uncertainty and less effective self-management (Bernard et al., 2007; Nutbeam & Lloyd, 2021; Promislow et al., 2010). The aforementioned evaluations did not consider understandability or actionability of materials, and they did not examine content relating specifically to the psychological aspects of IBD. Therefore, it remains unclear whether available resources not only provide accurate information, but also present it in a way that is meaningful, useable and supportive of behaviour change,

particularly in relation to the IBD and mental health relationship. Given the rapid changes in online content, and that existing investigations are dated, updated evaluations are needed.

IBD patients can often use social media sources of information (Adeyemi et al., 2025; Groshek et al., 2017; O'Leary et al., 2020; Reich et al., 2019), however, they can often have large amounts of peer generated content, typically promoting non-evidence based health and self-care advice, and links to commercial websites marketing unregulated remedies (Fortinsky et al., 2012). Alongside formal healthcare communication, social media platforms are a key information tool for IBD patients and healthcare professionals, and can provide accessibility, reassurance and peer support (Adeyemi et al., 2025; Goren et al., 2022; Reich et al., 2019). However concerns remain around privacy, confidentiality and the credibility of the information portrayed on these networks, as they can blur the boundaries between lived experience, opinion and evidence, making it difficult for users to appraise credibility and clinical validity (Adeyemi et al., 2025; Goren et al., 2022; Reich et al., 2019). The variable quality and lack of reliable evidence on social media creates a tension between emotional resonance and informational accuracy, particularly for young adults with IBD, where content perceived as relatable or supportive may not align with the evidence base. This may have important implications for misinformation, trust in credible sources, and self-management behaviours.

Summary of Key Points

This review identifies a key gap in understanding and managing the relationship between IBD and mental health. It characterises IBD as a

biopsychosocial condition, particularly affecting young adults during a critical developmental stage, where it may significantly impact identity, social functioning, mental health, and quality of life. Evidence also supports a bidirectional link between IBD and anxiety/depression, mediated by gut-brain axis mechanisms involving neuroendocrine, immune, neurological, and psychological pathways. While psychological interventions such as ACT show promise, access and integration into routine IBD care may remain inconsistent, highlighting the potential of psychoeducation as an early stepped-care intervention to improve illness perceptions, coping, and self-management.

Despite this, many patients report receiving insufficient information from healthcare providers, particularly regarding the gut-brain connection and mental health self-management strategies. These unmet information needs may lead patients to seek online information, where quality is highly variable and includes peer, commercial, and institutional sources, with limited evaluation of IBD and mental health content specifically. Overall, the literature highlights that there remains a dual gap in both understanding young adults' experiences of co-occurring IBD and mental health conditions and in assessing the quality of information they access.

Rationale

While the association between IBD and mental health has been previously evaluated, there is limited understanding of how young adults perceive this relationship and their related information needs (Cho et al., 2018; Gumidyala et al., 2017). There is also limited evidence regarding the quality and utility of available information that influences patients' awareness of this relationship and self-

management of their symptoms. Although IBD patients have a reported need for more disease related information to support self-directed behavioural change and self-management (Borgaonkar et al., 2002; Lesnovska et al., 2014), existing literature predominantly focuses on biomedical aspects such as the disease mechanisms, treatment, symptoms, and lifestyle factors (Fourie et al., 2018; Hawkins & Bull, 2024; Keefer, 2021b; Kok et al., 2023). As a result, comparatively less attention has been given to communication and patient understanding of the bidirectional relationship between IBD and mental health, and how patients make sense of this in the context of their condition (Cho et al., 2018; Kok et al., 2023; Mikocka-Walus et al., 2021). External to clinical settings, young adults have high rates of accessing health related information through online resources and social media, which can provide valuable support and a sense of shared experience, but may also influence their perceptions of their experiences through exposure to both unreliable information and non-evidence based guidance (Byron et al., 2013; Naslund et al., 2016; Wilson et al., 2011). Despite this, little is known about how young adults interpret, evaluate and apply this information in the context of IBD and mental health. This is further compounded by substantial variability in the quality and reliability of available information (Bernard et al., 2007; Langille et al., 2010; Mercuri et al., 2025; Promislow et al., 2010; van der Marel et al., 2009), which may contribute to a wider gap between patient needs and the current information landscape (Catalán-Serra et al., 2015; Fortinsky et al., 2012; Keefer et al., 2018; Mercuri et al., 2025; Mikocka-Walus, Knowles, et al., 2016). This discrepancy has important implications for health literacy, self-management and psychological wellbeing, including increased uncertainty, anxiety and reduced self-efficacy

regarding the management of their condition (Groshek et al., 2017; McMullan et al., 2019; Mercuri et al., 2025; Nutbeam & Lloyd, 2021; Selinger et al., 2017).

Developing an understanding of what young adults know about the relationship between IBD and mental health, and how they would like to receive this information, and the extent to which existing resources are able to meet these needs is of high importance. This may partly reflect persistent gaps in psychosocial information provision, variability in the quality of available materials, and limited integration of mental health content within clinical IBD care (Fourie et al., 2018; Hawkins & Bull, 2024; Keefer, 2021b; Khan et al., 2016; Mikocka-Walus et al., 2021). Addressing this may require both an understanding of patients' lived experiences of information seeking and needs, and an evaluation of the quality and useability of the resources they are likely to encounter (Becker et al., 2015; Brooks et al., 2016, 2019; Cho et al., 2018; Touma et al., 2023). This may provide clinicians with an evidence base to inform the development of psychoeducational resources and to support MDTs in delivering consistent, psychologically informed communication that better aligns with patient needs and reduces reliance on potentially inconsistent external resources (Hinnant et al., 2025; Kok et al., 2023).

To address the aforementioned gaps in the literature, the present thesis employs a two-pronged approach:

Study one aims to use a qualitative design to explore the firsthand perspectives of young adults (aged 18-25) with IBD and co-occurring anxiety and/or depression. It aims to investigate their understanding of the relationship between IBD and mental health, their experiences of health-related information seeking, and their preferences around information provision on IBD and mental health. This study

will address the identified gaps concerning the subjective, lived experience of the bidirectional relationship and the specific information desires of this developmental group (Becker et al., 2015; Brooks et al., 2016, 2019; Cho et al., 2018; Kok et al., 2023; Touma et al., 2023).

Study two aims to conduct a systematic audit of publicly available information (from websites, specialist services, social media, and video platforms) on the relationship between IBD and mental health. Using standardised and validated tools, it will critically assess the understandability and actionability of these materials using the Patient Materials Assessment Tool (PEMAT) (Shoemaker et al., 2014), and quality and reliability using the DISCERN instrument (Charnock et al., 1999). This study will address the need to evaluate the quality of the information resources concerned with the link between IBD and mental health, which is currently unknown (Bernard et al., 2007; Jones et al., 2019; van der Marel et al., 2009).

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Chapter 2:

Inflammatory Bowel Disease and Depression and/or Anxiety: Patients' Perspectives

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I declare that the content of this assignment is all my own work. It has not been submitted in respect of any other course/module. Where I have used the work of others, it is acknowledged and referenced accordingly.

Abstract

Background and Aims: Young adults with Inflammatory Bowel Disease (IBD) often experience comorbid anxiety and depression, reflecting the complex interplay between physical and psychological health. While existing research has explored lived experience of IBD, less is known about how young adults interpret the relationship between IBD and mental health, and how they seek, evaluate, and use information about this connection. This is particularly important during emerging adulthood, a developmental stage characterised by increasing independence and evolving health literacy. This study aimed to explore young adults' perceptions of the relationship between IBD and depression and/or anxiety, and preferences around information provision.

Methods: A qualitative design was employed and three online focus groups were conducted with participants aged between 18-25 (M=22.13) with a diagnosis of IBD and cooccurring depression and/or anxiety. Three males and five females took part (N=8). Data was analysed using Reflexive Thematic Analysis.

Results: Three main themes and four subthemes were identified, related to participants' understanding of IBD and mental health, psychological burden of IBD, patterns of information seeking, a focus on physical symptoms despite recognition of the psychological impact of IBD, preferences and fluctuating needs around information provision, and the value participants placed on shared understanding.

Conclusions: This study highlights the importance of continued integrated mental health discussions within IBD care, emphasising the value of peer support and individualised information. Young adults value in person communication and

contextually appropriate and trustworthy resources to support their understanding and management of the bidirectional IBD and mental health relationship.

Keywords: Quality of Life, socio-economical and psychological end points

Introduction

Inflammatory Bowel Disease (IBD), which includes Crohn's Disease (CD), Ulcerative Colitis (UC) and IBD-unclassified (IBD-U) (when a distinction between CD and UC cannot be made), is a chronic gastrointestinal condition characterised by relapsing and remitting inflammation of the digestive tract, usually diagnosed during adolescence and young adulthood [1–6]. IBD creates significant physical burden for patients, including chronic pain, fatigue, faecal incontinence, rectal bleeding, and unpredictable disease flares [7,8]. Beyond the physiological manifestations of IBD, there is developing recognition in the research literature of the cooccurring psychological impact of this condition, particularly anxiety and depression [9–11]. Young adults with IBD have a higher risk of developing clinically significant anxiety and depression than the general population, and they can also experience low self-esteem, psychological distress and poorer perceived quality of life [1,3,12–16]. A prospective cohort study concluded that 55% of young people with IBD had elevated anxiety/depression, and 83% reported reduced quality of life, with IBD's emotional burden and active disease predicting psychological difficulties [17]. IBD and mental health have been conceptualised in the literature as bidirectionally linked, whereby emotional distress may exacerbate and increase severity of IBD symptoms during periods of active illness [18,19]. This may be mediated through dysregulation of the gut-brain axis and inflammatory responses [2,18,20–22]. The chronic and unpredictable nature of IBD can also contribute to psychological distress, due to disease burden, isolation, social stigma and concerns about the future [23].

Young adulthood is a significant developmental stage, usually defined as the period between ages 18-25, characterised by increasing independence, identity formation and key life transitions [24,25]. For IBD patients, this transitionary period can

be further burdened by the demands of managing a chronic illness [6]. Research suggests that young adults with IBD are faced with particular psychosocial challenges including disruption to educational and employment opportunities, independence, difficulties with social relationships, and heightened perceptions of stigma [26–28]. Beyond elevated rates of anxiety and depression, the psychological burden of IBD may have associated implications for young adults' identity formation, social participation, and everyday functioning [23]. The unpredictable nature of disease flares, alongside concerns related to stigma and disclosure, can disrupt educational engagement, employment trajectories, and the development of independence during a critical life stage [26,27,29].

The way information concerning IBD and mental health is communicated may play an important role in shaping patients' understanding and coping strategies [30,31]. Healthcare professionals are a primary source of information, however research evidence has highlighted that discussions around mental health within the context of IBD care are often limited or inconsistent [10]. Patients have previously reported that the psychological aspects of their presentation are under-addressed, and that a more significant emphasis is placed on the management of physical symptoms [32]. Effective communication about the IBD and mental health relationship may be important for the promotion of self-management, encouraging help-seeking behaviours and improving outcomes relating to overall wellbeing [33]. External to clinical settings, young adults are reported to commonly access health information and peer support online, however while social media and patient forums provide shared experiences and validation, they may also promote misinformation and non-evidence based guidance [34–36]. Despite this, little is known about how young adults interpret and evaluate this information. The relevance, clarity and accessibility of sources of

information are of particular importance for young adults, as they may navigate complex health information of varying quality alongside managing other significant life transitions [37].

Existing literature indicates that while improved health literacy is linked to better outcomes in IBD, it remains largely symptom-focused and has only partially captured how young people understand and engage with the relationship between IBD and mental health. A recent systematic review concluded that improved illness related knowledge and health literacy reduce the psychological burden of IBD, enhance self-management behaviours, quality of life and treatment adherence, whilst barriers to health literacy include lack of tailored patient-centred information, inadequate communication and cultural differences[38]. Qualitative explorations of young people's perception of living with IBD highlighted that they experience IBD as part of their identity, with the gut-brain connection understood through lived experiences of the bidirectionality of psychological distress and symptom flares [39,40]. Evidence also highlights perceptions that mental health is under-addressed within routine care, alongside a desire for more holistic and biopsychosocial approaches to treatment, and a greater recognition by healthcare professionals of the personal meaning of their illness [27,39]. Much of the research evidence to date has focused on the management of physiological symptoms of IBD and quantitative assessments of psychological symptoms [41]. Existing studies explored lived experience broadly [26,29,42–49], but few examine how young adults specifically understand, interpret, and seek information about the IBD and mental health relationship [50]. Crucially, little is known about how young adults with IBD actively interpret and evaluate information about the relationship between IBD and mental health, despite their reportedly high reliance on both clinical and online sources.

Young people with IBD have previously expressed a need for individualised and developmentally appropriate information that reflects their identity formation and evolving capacity for self-management, highlighting that their information needs and coping styles may change over time [31,51–54]. This cohort reportedly desire mental health discussions to embedded in IBD care and clear information on its relationship with IBD, reflecting a view of mental and physical health as integrated aspects of health [39,40,50]. Existing literature has recommended the facilitation of these discussions by gastroenterology teams and developed guidelines around the implementation of biopsychosocial IBD care within services [55–57]. The value of peer-led support has also been reported in the literature as having a high level of perceived value for these patients, despite accompanying concerns about privacy [58]. However, how these preferences translate into real-world information-seeking remains unclear. Previous research suggests the need for further qualitative work to explore how young adults with IBD understand the relationship between mental health and IBD, how they prefer this information to be communicated, and whether perspectives on integrating mental health within IBD care vary across patients [50]. Qualitative approaches may also aid to address gaps in understanding how patients experience and manage everyday challenges, and perceive support from healthcare professionals, which may inform more personalised and responsive psychological communication within IBD care [47]. Overall, there is a need to better understand how young adults with IBD translate information and support preferences into engagement with both clinical and peer-based resources.

The Current Study

The purpose of this study was to qualitatively explore young adults' perceptions of the relationship between IBD and depression and/or anxiety, and how information about that relationship is communicated to young adults aged 18-25. This study collected data through focus groups. Participants were asked to reflect on and discuss topics related to IBD and depression/anxiety, and the way in which information is presented about the relationship between these.

Key Research Questions:

1. What are the perceptions of individuals with IBD and anxiety and/or depression of the relationship between these conditions?
2. What aspects of information sharing do individuals with IBD, and anxiety and/or depression consider to be important when presenting information about the mental health related risk factors which are associated with IBD?

Materials and Methods

Design

This study was qualitative and cross sectional in nature. A qualitative design was chosen for this study as the research questions were exploratory in nature, and aimed to develop an understanding of individual's subjective perspectives on the topic, making it particularly appropriate for examining processes of subjective meaning making. Ethical approval was sought and obtained from University College Cork Clinical Psychology Research Ethics Committee (CPREC) and the Hospital Research Ethics Committee.

Participants

This study sought to recruit young adults aged between 18-25 with experience of IBD and cooccurring depression and/or anxiety. A purposive sampling technique was employed, as all participants were recruited from a hospital outpatient gastroenterology department in an urban centre in Ireland. Patients were eligible to take part in this study if they were aged between 18-25, had a diagnosis of IBD, a self-reported diagnosis of depression and/or anxiety from a health professional, experienced symptoms of depression and/or anxiety in the previous 12 months, and had reasonable fluency in the English language. Patients were excluded if they did not meet the age or diagnostic criteria (IBD or depression/anxiety) and were not currently experiencing symptoms of depression and/or anxiety. Consultation with an expert (Consultant Gastroenterologist) highlighted that several physical health conditions commonly cooccur with IBD and are recognised in clinical practice and the research literature as related to IBD. These include musculoskeletal, metabolic, cardiovascular, respiratory and immune-mediated conditions [59–61]. Patients with

these commonly cooccurring illnesses were not excluded from the sample. Patients who had a diagnosis of an acute illness which is not commonly co-occurring with IBD were excluded from eligibility for the sample. Patients with severe and enduring mental illness or suicidal ideation were also excluded due to their vulnerability as a population, and to mitigate the level of risk of harm resulting from participation in this research.

Patients were identified and recruited to the study during routine patient contacts by Consultant Gastroenterologists, IBD nurses, and the IBD Clinical Psychologist. Patients identified as suitable were provided with information about the study. The lead researcher individually contacted patients who had indicated an interest in taking part and who had consented to follow up. Patients were contacted via email, and provided with a participant information leaflet. Eligibility screening, informed consent, and demographic data collection were completed through an online Qualtrics form, with consent obtained prior to participation. The lead researcher was available via email to address any queries.

The final sample consisted of N=8. The sample consisted of 3 males (37.5%) and 5 females (62.5%), aged between 18-25 (M=22.13). 50% of participants (N=4) had a diagnosis of Crohn's Disease, three participants had a diagnosis of Ulcerative Colitis (37.5%) and one participant indicated that their diagnosis was classified as IBD-U (12.5%). Age of initial IBD diagnosis ranged from 8-19 years (M=14.88). Regarding prevalence of mental health difficulties within the sample, N=5 participants reported a diagnosis of anxiety (62.5%), N=1 indicated a diagnosis of depression (12.5%), and N=2 had both anxiety and depression (25.0%). Participant pseudonyms and demographic information are presented in Table 1.

Table 1. Participants' Gender and Age

Pseudonym	Gender	Age
Ella	Female	18
Christine	Female	18
Monique	Female	22
Roisin	Female	22
Jack	Male	23
James	Male	24
Sophie	Female	25
Henry	Male	25

Procedure

During recruitment, participants could choose to attend focus groups in person or online via MS Teams. Three online focus groups (2–3 participants each) were conducted, each lasting approximately 60–90 minutes and guided by a pre-developed interview schedule. Online focus groups were considered appropriate due to their accessibility and ability to foster a comfortable, private environment that may facilitate open discussion of sensitive issues. The lead researcher acted as the moderator of the focus group, while one of the co-authors was present as an observer. The observer was a qualified Clinical Psychologist who was independent of both the participant group and the hospital from which the participants were recruited. The observer was present to support participant wellbeing by managing any potential or actual distress that arose during the focus groups, although this was not required. As data collection took place outside of standard business hours and

involved discussion of potentially sensitive topics, the observer also supported post-group debriefing with the lead researcher. The observer provided minimal input during the focus groups to minimise their influence on the discussions. Their contribution was limited to occasional facilitation where appropriate, for example, during the first focus group, they briefly redirected the discussion back to the research question when it had moved off topic. The participants were sent a follow up email following the conclusion of each focus group detailing relevant resources and support services. Data was collected by recording the focus groups on MS Teams, which were then automatically transcribed. These transcripts were corrected and pseudonymised by the lead researcher prior to qualitative data analysis.

Data Analysis: Reflexive Thematic Analysis

Research Positioning

This study was framed using an experiential critical realism perspective, which aligns itself with the concept that there is an existing objective reality, but it acknowledges that there may be different perspectives on reality which are valid and shaped by individual and social contexts [62–64]. An inductive analytic approach was taken to the data, whereby the interpretation was driven by and grounded in the content of the data [62,65].

The lead researcher led the analysis, with an approach that reflected their individual perspective and professional knowledge. The lead researcher is a Trainee Clinical Psychologist and doctoral researcher. They have a strong interest in the interplay between physical and mental health, partly driven by their own personal experience of living with a chronic inflammatory condition. They have a deeply held sense of respect and compassion for individuals who are navigating chronic illness

and mental health difficulties, and can relate in part to the impact on quality of life that living with an illness can have. The researcher's positioning provided a reflexive, accommodating and compassionate approach to data collection and analysis, which prioritised the voice of the participant. A primarily semantic development of themes and codes was employed, whereby the meaning attributed to the data was based on what was explicitly stated by participants [65]. This was informed by the researcher's awareness of their own potential empathy with some of the experiences discussed by participants, and was employed as a strategy to minimise interpretative bias. Maintaining a reflective journal alongside regular conversations with the co-authors in the context of supervision aided reflection around how the researcher's personal experiences, professional knowledge and dual position as a researcher and practitioner in training may have influenced their approach to data collection and interpretation.

The co-author that participated as an observer during the focus groups is a Chartered Clinical Psychologist with professional experience of working with young people with co-occuring and interacting physical and mental health needs. This background provided a particular lens through which they experienced the focus groups, characterised by an awareness of the interaction between physical and mental health and the complexities of young people's experiences. This was acknowledged throughout the research process through discussion with the research team as part of ongoing reflexive practice.

Results

A brief description of the results is presented in Table 2.

Table 2. Overview of Themes and Subthemes

Theme	Description
1: Understanding of IBD and Mental Health Relationship	Young adults with IBD and depression and/or anxiety have lived experience of the relationship between IBD and mental health.
1A: The Psychological Burden of IBD	The psychosocial impact of IBD perpetuates distress.
1B: Sources of Information	Young adults value information provided by their healthcare team, and use the internet to source experiential information from peers.
2: Acknowledgement of Mental Health Impact but Focus is on Physical Symptoms	There is a focus on practical advice for managing physical symptoms of IBD and a hesitancy to discuss mental health difficulties.
3: Preferences relating to Information Provision	Young people value individualised and applicable information, and benefit from discussions with their healthcare providers around the psychosocial impact of IBD.
3A: Peer Perspectives are Valuable	Information provided by others with lived experience of IBD is perceived as most relevant and relatable.
3B: Fluctuating Information Needs	Young adults' information seeking tendencies are mediated by disease activity and uncertainty.

Theme 1: Understanding of IBD and Mental Health Relationship

The participants reported limited formal knowledge of this relationship when asked, however they expressed a desire to better understand the psychobiological link between IBD and mental health: "*in regards to the link between the two … my knowledge would be quite limited … it's an intrigue for me to see the like biological kind of connection maybe that there is with the gut and the brain"* [James]. They expressed a perception that information and resources relating to their mental health in the context of IBD were mostly gained through online sources, and that it is something that they would like to receive more information about through their healthcare providers:*"as a patient, I feel like it's not communicated as much as it should be"* [Sophie]. Henry also expressed *"I think most of what I learned, especially about colitis and its relationship with anxiety and depression, was online … when I had my flare … at the time I joined, you know, a few Facebook support groups or whatnot and it was just crazy to see … how this is affecting people".* Christine also indicated *"I tried to look at TikTok and stuff to sort of see how it affected other people as well. I think probably a lot of those sources weren't the best for giving actual information on how those are linked though".* Despite reporting a lack of formal knowledge, the young people described an experiential understanding of the connection between their IBD symptoms and their mental health, through their experiences of escalation in anxiety and depression both preceding and following the onset of disease flares: *"I noticed it just from existing. And the correlation between … situational anxiety and situational depression and how that would, translate into physical health and flares"* [Roisin]. Ella also noted *"I find anxiety and stress, anything like that, a massive trigger to my disease. I definitely find that when I am stressed that my symptoms do get worse … definitely for me, there is like a massive*

link between the two". There was a shared consensus of the presence of situational anxiety which arose in the context of navigating day-to-day challenges associated with having IBD, and that the additional planning that was required in order to engage in social, educational, employment and leisure activities was a significant source of stress: *"a few situations that can be tricky and that can cause a lot of kind of anxiety, worry, even, maybe some depression … just that anxiety of the different situations in flare ups of having to try and combat these day-to-day struggles that someone with IBD would have"* [James].

Subtheme 1A: The Psychological Burden of IBD

The young people expressed that there were a number of factors associated with having IBD which perpetuated their psychological distress. Perceived isolation during flares, compounded by home confinement, treatment demands and missed peer interactions, was exacerbated by feeling misunderstood by others: *"you often find yourself with very few people to talk to about it. And then because it is an awkward topic, you know, you don't want to announce to anyone that, oh can't go out tonight because I'm just bleeding on the toilet … it's very isolating and it often feels like you've no one to talk to about this"* [Henry]. The participants also named an internalised sense of shame around their illness and a perceived personal responsibility for being sick, which was compounded when they followed unsolicited advice given to them by others, which did not lead to any relief: *"I hold a lot of shame around my illness … I just have an aversion to talking about it with people"* [Christine]. Henry also described *"a lot of people mean well, but it is a bit overwhelming because often it makes you just feel like you're doing something wrong … and I think that's something you often feel with these conditions … sometimes you feel like you've done it to yourself somehow".* The young people also reported

perceiving that some prescribed medications negatively affected their mental health, creating a dichotomy in which physical symptom relief was accompanied by increased psychological distress: *"when you're at your worst physically with this condition, your mental health suffers tremendously and that's without even mentioning any of the medications, because it seems like a lot of the medications for this condition have a nasty effect on your mental health"* [Henry].

Subtheme 1B: Sources of Information

The participants expressed that they were able to gain some insight into the link between mental health and IBD from attending individual therapy with the IBD Psychologist, and some conversations with their medical team when outwardly presenting with symptoms of psychological distress: *"resources by the nurses ... the psychologist, the doctors"* [Jack]. Roisin also reported *"I'm linked in with the psychological services in [hospital] as well, so that made it very clear to me what the link was".* The lived experiences of others within the IBD community, accessed through social media platforms such as TikTok, Instagram, Facebook and Reddit, also provided experiential information around the impact of IBD on wellbeing: *"I would look to TikTok or I also sometimes saw Reddit stories ... and I think I saw a few Instagram posts as well"* [Christine]. Ella also expressed *"I'd also kind of go on TikTok and just even Google. I'd say on TikTok it was more just seeing other people's stories and kind of their daily experiences, and I'd find that to be relatable".*

Theme 2: Acknowledgement of Mental Health Impact but Focus is on Physical Symptoms

The young people described that there were mainly physical health specific information sources and resources online, and that advice given to them from their social support networks generally focused on strategies to improve physical wellbeing, such as diet and supplements: *"the stuff that's said to me is usually diet and it's like a lot of homoeopathic sort of medicines and … have you tried Slippery Elm and all this sort of stuff? It's a lot of herbalism, and articles - top 10 things to do*" [Roisin]. They expressed that they also tend to seek out practical resources relating to managing their physical symptoms or around navigating psychosocial stressors: *"mainly I would be looking for stuff to help with my physical symptoms because I felt that my mental health was just a reaction to my physical health, but that might not be true"* [Christine]. James also expressed *"when you're unwell, you really want to sort your body and your physical symptoms".* The participants named a hesitancy to speak about their mental health difficulties, and that it was easier to discuss their physical symptoms with others: *"sometimes with physical health, it's easier to describe to other people because you can give some points of comparison, whereas mental health, if people haven't gone through similar things, then it's harder to explain how you're actually feeling with it"* [Sophie]. Ella also reported *"you talk about so much about the physical aspect, but not so much the mental".* This was partly associated with the perception of feeling like a burden to others, due to being unwell so often, and the sense that their outward identity to others was that of a person with a disease: *"I think there's a big thing of feeling like you're a burden … if you're someone who's sick commonly, you very often feel like you're annoying people, or you're letting people down, and I think as well that must be part of finding*

it easier to tell people, oh, I'm in bits instead of, I'm in bits, and also there's a whole lot going on in my mind right now" [Roisin]. Ella also described *"I hate feeling like I'm just reduced to my disease, sometimes I get that reaction off of other people. It's like all they can relate to when they think of me is my disease. Like, oh, you're the one with the disease".*

The perception that others external to the IBD community do not understand the significance of the impact of their symptoms on their wellbeing therefore meant that they were less likely to disclose further difficulties associated with their mental health: *"a lot of the conversations are around the physical side of the disease, I don't think I've ever really had a conversation where it's about like mental health and how you're actually feeling, because you might be really sore or fatigued or just your stomach is really at you, but you also could be really sad, but you're less likely to talk about that"* [James]. The participants' long-term goals centred around achieving remission in the first instance, in order to facilitate progress towards managing their emotional wellbeing and reducing anxiety: *"nowadays I'll be trying to find ways to, how do I get a bit of peace of mind from this anxiety? And I suppose just trying to find ways to stay in remission … either by looking at supplements or therapies or whatnot in conjunction with your medication"* [Henry]. Monique also expressed *"I guess when I was feeling bad, what I needed was medical help and then later psychological help".* The young people also expressed a perception that their mental health difficulties had to escalate substantially prior to being recognised and support offered: *"I think it is kind of isolating … because it takes so long for a lot of people, even family included, and it takes for you to be at your absolute weakest, then to for them to kind of take it seriously"* [Henry]. The participants acknowledged that although their physical symptoms are addressed by their healthcare team, they felt

that there was a limited focus given to discussions around their psychological wellbeing: *"so important to kind of make sure that these healthcare professionals are really kind of considering the mental health aspect to things ... a lot of the time, what's harder for the patient might not just be the physical aspect, but dealing with it mentally can be a lot more difficult for some people"* [Ella].

Theme 3: Preferences relating to Information Provision

The young people in this study indicated that they would like to receive information regarding the relationship between IBD and mental health from trusted sources, such as their multidisciplinary team, alongside practical advice on actions and lifestyle changes that they can employ to support their emotional wellbeing when they are feeling physically unwell: *"I would prefer just kind of going through what your life with IBD is going to be like, with someone in person. And I think for me it would be really important that yes, they're kind of pointing out the facts and they're telling you ... this is how you're probably going to feel, and it's going to suck basically. It's not really going to be a great experience, but there are ways to improve"* [Ella]. The participants also named a desire for the psychobiological risks associated with IBD to be introduced at an early stage in their treatment: *"I wish that someone had explained to me that you're going to feel very awful about yourself for the next year or two, and it's gonna be a struggle. But here's some resources and you're always free to call up one of the nurses and have a chat with them"* [Henry]. They also desired information to be communicated through an in-person format, followed by written resources to refer back to, to aid understanding, retention and provide a facility to clarify information: *"I find reading ... articles or things, very*

cold and if you have any questions you know they can't be answered right then and there you have to contact someone and that's a whole palaver" [Christine]. Sophie also reported *"it's nice to have resources to look back on, to read in my own time and kind of refer back to".* The participants expressed a preference to receive individualised information through discussions with their healthcare providers, which considers their physical disease state, their mental health symptoms and psychosocial functioning: *"I think all our experiences are quite different. I feel like maybe there should be advice a bit more attributed to our own experiences"* [Jack]. They described a preference for conversations around mental health and psychosocial factors to be initiated and followed up on by health professionals, in order to mitigate the barriers to bringing up these topics themselves, which are largely fuelled by an internalised sense of shame: *"if the doctor initiates such a conversation, it just makes a huge difference because you're trying to build up the courage and you're going into the appointment and be like, just say it first thing you go in and then ultimately you don't say it"* [James].

A hesitancy was reported in relation to searching for online resources for disease related facts and treatment advice relating to both physical and psychological symptoms, naming a preference for this to be integrated into discussions with their healthcare providers. This was converse to the participant's use of social media platforms for validation and shared peer experiences: *"I am wary of the Internet with, especially with the anxiety element of illness. Just in case, if you're looking up something small to do with your illness and then it might send you down a whole other track of, well, this might also be this. It's kind of not good for me to look at those things 'cause I might start spiralling"* [Roisin]. For some participants this was aided by using a tangible resource such as the "IBD Disk" [66] to facilitate

conversations in clinic, which encompasses physical, psychological, and social functioning: *"I think those disks are invaluable because … there's different mental health issues linked there that the doctor can bring up … I think a lot of patients are feeling very, very anxious going in because they feel uncomfortable maybe bringing up topics, if there was a tool that maybe combines with the disk that the doctor could … potentially bring these topics up, I think it would be very helpful for patients"* [James].

Subtheme 3A: Peer Perspectives are Valuable

The participants reported that peer perspectives are perceived as the most valuable sources of information due to lived experience of IBD: *"there's maybe unspoken things that you mightn't read, that a patient or a person with IBD would fully understand because I guess it's the lived experience that you mightn't get from reading about the disease or you know, everyday little things, little situations, little worries which are a big worry for a person with IBD, whether it's within a flare up or out of a flare up"* [James]. Monique also reported *"I think for me at least it'd be easier to hear from other people that are going through the same experiences rather than people that think this is how you should handle it"*. Having others that are perceived to understand what they are going through and recommend things that have helped them previously was seen as a valuable resource: *"coming from someone who has experienced it … it's such a great way of feeling less isolated and it's very relatable"* [Chrisine]. James also described *"it makes you feel a bit better because you're thinking … there's other people going through these experiences"*. They also indicated a desire for peer connection to obtain useful information and support: *"I think I would have loved to have chatted with someone who had experienced some form of IBD and I think it would have helped me navigate this and*

just giving you a sense of hope. You know, because I think when you're flaring, you just feel completely hopeless and you just feel like nothing's ever going to get better" [Henry].

Subtheme 3B: Fluctuating Information Needs

The young people expressed that the level of information that they required fluctuated depending on their disease activity and levels of anxiety: *"there's more sense of urgency when you're in a flare up because there's so many different things happening … like physical symptoms … your anxiety is definitely heightened and you kind of want to relieve that as well as taking the drugs to relieve your own symptoms. So, you're kind of trying to grab every resource you can, whether it's … therapy or even online resources to see if there's any way to help your anxiety in that time"* [James]. They reported a tendency to avoid information and reminders of IBD when they are well, and to seek information and resources when they are unwell: *"when I'm in remission, I'd try and avoid anything relating to my disease and try to kind of forget about it … I hate thinking about it … when things do start getting worse, that's kind of when I turn to all these resources and try to get help, even off of my nurses, and that's when I start talking about it again"* [Ella]. Christine also reported *"I think when you're feeling good again, you sort of just forget what it was like when you were sick. Just because it's that one bit of calm that you can finally relax in, the calm before the storm you could say"*.

Discussion

These findings suggest that young adults with IBD experience and understand a bidirectional relationship between disease activity and psychological wellbeing, grounded in lived experience rather than formal clinical explanation, and that their preferences for information provision are shaped by fluctuating needs, a desire for holistic and clinician-led mental health discussions. This may highlights how psychosocial burden, stigma and communication gaps influence both understanding and information engagement. Participants reported feeling underinformed about the relationship between IBD and mental health, despite demonstrating experiential understanding of the interaction between psychological and physical symptoms in their daily lives [40], consistent with quantitative evidence linking disease activity with anxiety and depression [17,18] and the gut-brain axis theoretical framework [2,20–22]. The present study extends this literature by highlighting how this relationship is actively interpreted by young adults in their daily lives. This interplay between their physical and mental health corresponds with the findings in the existing qualitative literature, which reports that IBD patients notice that increases in disease activity and severity lead to increases in psychological distress and vice versa [29,39,40,47,50]. Participants reported a negative impact of some of the medical treatments for IBD on their psychological functioning, which is consistent with previous literature on the impact of corticosteroids on mood and cognition [67]. Due to the participants' reported impact of their physiological disease state on psychological well-being, alongside the psychosocial factors which increase disease related burden and further perpetuate levels of distress, the biopsychosocial model may be an appropriate theoretical framework to understand this relationship [21,68,69]. This model takes a holistic approach to recognising the interplay between biological

and genetic factors, psychological concepts such as experiences, behaviour and self-concept, and social influences such as relationships and socioeconomic status [68–70]. The current participants desired individualised care, consistent with studies advocating the integration of patient preferences, characteristics and experiences across physical, psychological and social domains, to capture the multifaceted daily challenges of IBD [40,44,46,47,51].

These findings suggest that perceived social misrecognition of IBD can contribute to identity constriction and reduced disclosure of distress, which may subsequently limit opportunities for social support and help-seeking. Participants in this study also reported high levels of internalised shame, which may be understood as a socially mediated response linked to stigma, the invisibility of their symptoms and difficulties in communicating illness burden [28]. The psychosocial burden of IBD, encompassing shame and stigma [28,42,43], isolation and reduced social participation [40,43,47,49], disrupted educational and employment [29,44,45,48], and high levels of uncertainty and unpredictability relating to disease activity [40,45,47,54], has also been highlighted in the existing qualitative literature. Participants perceived being seen by others as an extension of their condition, and the narrative that their social network do not understand what they are going through, may lead them to minimise their distress and may disrupt identity formation processes, which is a key consideration for their developmental stage [16,39]. This perspective was also reflected in a recent qualitative synthesis, which identified a felt sense among patients that their self-identity has been shaped by their condition and that they have a strong desire to be understood by others, however this resides in the backdrop of feeling misjudged and a need to hide their true experiences [43]. This may contribute to reduced social connectedness and increase experiences of otherness, which are associated with

feelings of isolation and perceived stigma [39,40,42,43,47]. These experiences may impact negatively on patients' psychosocial wellbeing and reduce opportunities for effective support seeking[40,47,48,51].

Participants reported a hesitancy to explore online information due to anxiety and concerns regarding validity, alongside a preference to receive information from healthcare providers in order to ensure relevance and applicability, as reflected in the literature [38,45,50,71]. This can be understood in the context of theoretical models of health literacy, whereby improving the structure and quality of health communication, particularly from healthcare professionals, can enable patients to develop skills in retrieving, understanding and implementing information [38,72]. The young adults in this study felt that a holistic approach to information provision and in person conversations initiated by their healthcare providers around the psychosocial impact of IBD would be beneficial in allowing them to feel more supported and reduce barriers to disclosure of the impact on their psychological functioning[26,38,40,50,51,57]. This finding aligns with literature suggesting that post-diagnosis education on IBD's biopsychosocial impact and follow up discussions of factors affecting wellbeing may facilitate health literacy, support help-seeking and contribute to more effective self-management[38,40,47,50,71,72].

Participants in the current study described prioritising the management of physical symptoms of IBD, often seeking practical guidance and treatment-related information as a pathway to improving broader psychosocial functioning. This emphasis reflects evidence from meta-syntheses indicating that physical symptom burden is a central challenge in IBD and is closely linked to reduced psychological wellbeing, social functioning, and quality of life [47]. However, a tension emerged in current participants' reports, whereby they expressed a need for more information

and support around mental health, which they perceived as limited, while simultaneously prioritising their own physical health in their engagement with resources and discussion with others. This suggests a disconnect between their recognised needs and help-seeking behaviours. This focus on their physiological functioning may be partly driven by perceived stigma, feeling misunderstood by others, the burden of IBD, alongside more defined medical treatment pathways, which may reinforce the perception that it is easier to disclose and seek support for physical symptoms than for psychological distress [29,44,47]. The young adults' fluctuating use of resources, which was driven by seeking support during periods of active disease and avoiding reminders during remission, may also reflect a cyclical avoidance engagement pattern linked to symptom fluctuation and emotional regulation [52–54]. The disengagement and avoidance reported by participants during remission may serve as a strategy to reduce cognitive and emotional burden, maintain emotional wellbeing, and preserve a sense of normality and autonomy through separation from an illness identity [31,39,53,54]. This finding reflects the changeable nature of information needs and coping style identified in the literature, highlighting the importance of time sensitive and appropriate communication [27,30,31,41]. The participants' emphasis on the value of shared understanding and peer-led support reflects prior literature highlighting the importance of experiential and peer-based information in shaping young people's illness perceptions, adjustment and coping strategies [32,35,39,43,44,71].

Strengths and Limitations

The use of a qualitative focus group design enabled an in-depth exploration of the young adults' lived experiences, which identified nuanced insights into the perceived relationship between IBD and mental health, which may not have been accessible through quantitative measures alone [6,33]. The shared peer experience within the focus groups was reported by participants as particularly valuable, providing a supportive environment in which they could openly discuss sensitive topics and feel validated in their experiences. By recruiting participants aged 18-25, this study focused on a developmental stage which is characterised by identity formation, increasing independence and transitional life and healthcare experiences, which improves the relevance of the findings for this cohort [11,23]. This research integrates participants' perspectives on both information and peer support, highlighting the mechanisms by which young adults navigate healthcare, self-management and social support networks [32,38,39]. The identification of themes grounded in participant experiences provides a framework that can inform clinical practice, psychoeducation and future intervention development, ensuring that the findings are both actionable and transferable within similar healthcare contexts.

There were several limitations associated with this study that should be considered when interpreting the findings. Although the small focus groups generated rich qualitative data and participants reported value in shared experiences, the limited sample size, due to recruitment from a single hospital and the time-constrained nature of the study, may have reduced the diversity of perspectives and limited the generalisability of the findings to other regions or healthcare settings. This may have also reduced confidence that the identified themes fully represent the wider population of young adults with IBD and cooccurring depression and/or

anxiety. The study did not specifically explore cultural or socioeconomic factors, which may also influence experiences of IBD, mental health and health literacy, potentially limiting the range of experiences and perspectives, and transferability of the findings to broader populations. The cross-sectional design limits insight into how experiences, information needs and coping strategies may evolve over time, constraining the development of more nuanced and longer-term understanding. Reliance on self-reported experiences which may be influenced by recall bias, or social desirability can affect the accuracy of reported experiences and may reduce confidence in the validity of some themes. Additionally, as the study only reflects patient views, it may not present a full account of current clinical practice, and differing perspectives from service providers could challenge or contextualise the findings, particularly regarding the perceived implementation of mental health supports. Recruitment was affected by delays and participant attrition, which may reflect the practical challenges of engaging young adults with IBD and cooccurring anxiety and/or depression, as they are a population often balancing chronic illness management with education, employment and social demands. However, this may have also introduced sampling bias, indicating that the findings may reflect the experiences of those more able or willing to take part, rather than the wider patient group.

Clinical Implications and Recommendations

The recommendations arising from this research are aimed at addressing the information needs of young adults with IBD.. Routine psychological screening for anxiety and depression could be considered to identify unmet psychological support needs and inform information provision and discussions around mental health, which has also been suggested in the previous research literature [14,20,40,50,55]. In addition,

continued use of a biopsychosocial approach to communication and psychoeducation [68–70], framed within the broader context of the individual's life, experiences and development [17,27,47,48,51], may support patients' understanding and application of health information [38,71]. The initiation of conversations about mental health could be considered by healthcare professionals [33,39,40,50], in order to integrate discussions around anxiety, depression and stress [29,40,45], to reduce the shame, stigma and hesitancy often reported by young adults [26,29,44,48]. This may be supported by a practical resource such as the "IBD Disk" [40,50,66]. The content of information provided could be tailored to reflect the young person's disease state and developmental stage, while also being sensitive to fluctuating needs during periods of disease flare and remission [26,27,29,38,45,49]. The development of a database of local psychological support services and evidence-based resources which provide practical guidance, could be implemented by services which do not have access to a departmental psychology service [55,56]. Interventions relating to education and lifestyle could also be implemented by all clinicians as a universal resource for patients [55,56]. Therapeutic interventions and conversations regarding IBD and mental health may be led by asking patients to generate lived experience of this relationship, and from integrating problem-solving around emotional, social, and functional challenges, alongside traditional evidence-based models [55,56]. The participants' fluctuating engagement with resources suggests the need for psychologists and other healthcare professionals to support health literacy and adaptive coping strategies, enabling young adults to navigate both physical and psychological aspects of IBD effectively during periods of both active and inactive disease [26,27,38].

With regard to future service development, as young adults with IBD perceive their mental health as inexplicably connected with their disease activity, this

highlights the need for psychological assessment, psychoeducation and support to be a part of routine IBD care [2,20–22,33]. Given the transitional developmental stage of young adults, clinicians may consider tailoring interventions to acknowledge identity formation, increasing independence and evolving self-management capabilities [11,23,26]. Psychological interventions can also consider bidirectionality in order to address both the emotional consequences of IBD flares and the role of psychological distress in exacerbating symptoms, alongside how this can be integrated into accessible sources of psychoeducation [18]. Peer-led and experiential resources were highly valued by the young adults, suggesting that group-based interventions or peer mentoring programmes could compliment individual therapy. The facilitation of peer support access under clinical supervision may assist young adults to safely engage with online and in-person peer networks [32,39,41,71]. Addressing enduring barriers to engagement, such as physical symptoms, stigma, internalised shame or avoidance of supports during remission may be achieved through check-ins, online programmes or group sessions, in order to normalise mental health discussions, improve accessibility and promote help-seeking behaviours [36,46,47,71]. These recommendations may assist with fostering health literacy and promoting a sense of self-efficacy for young adults navigating the challenges of IBD and mental health [38,48,72].

Conclusion

This study highlights important insights into how young adults construct understanding without formal knowledge, identifies information avoidance cycles, provides evidence for clinician responsibility in initiating mental health conversations, and emphasises the tension between clinical authority and peer-based knowledge. The findings highlight that young adults with IBD feel that they have limited formal knowledge of the link between their condition and psychological wellbeing, but have a deep personal understanding of the bidirectional nature of this relationship and the psychological burden of this disease. The participants highlighted the importance of shared understanding, peer-led support and the integration of mental health discussions into their IBD treatment. Young adults in this study expressed a strong desire for tailored, holistic care and information that is relevant to both their physical presentation and the psychosocial challenges that they face. These insights were consistent with existing literature, reinforcing the need for individualised and applicable patient information in order to support the development of health literacy skills, increase self-efficacy and reduce uncertainty. The study highlights the necessity for further research to explore how best to support this population's biopsychosocial information needs. The recommendations, including the integration of discussions around mental health into IBD management, indicate important areas for supporting psychosocial well-being and increasing access to relevant information.

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Chapter 3:

An Evaluation of Publicly Available Information on Inflammatory Bowel Disease and Mental Health

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I declare that the content of this assignment is all my own work. It has not been submitted in respect of any other course/module. Where I have used the work of others, it is acknowledged and referenced accordingly.

Abstract

Background: To systematically evaluate the quality, understandability and actionability of publicly available patient information materials concerning the relationship between Inflammatory Bowel Disease (IBD) and mental health.

Methods: A cross-sectional evaluation was conducted. 153 materials (113 printable, 40 audiovisual) from identified public sources (e.g., healthcare providers, websites, social media) were systematically retrieved and assessed. Each material was independently scored by two raters using two validated tools: the Patient Education Materials Assessment Tool (PEMAT) for understandability and actionability, and the DISCERN instrument for information quality and reliability. Descriptive statistics and Pearson correlations were calculated.

Results: Inter-rater reliability was substantial for PEMAT items (Cohen's $\kappa = 0.664$; 79% agreement), moderate for DISCERN items (weighted $\kappa = 0.554$), and good for total scores using ICC (PEMAT-P = 0.828, PEMAT-AV = 0.886, DISCERN = 0.787). While mean PEMAT scores for understandability were high for both printable (M=70.70) and audiovisual (M=78.79) formats, actionability scores were higher for audiovisual (M=78.65) compared to printable materials (M=49.85). DISCERN scores indicated most materials were of moderate quality. The source of information was related to quality; materials from specialist support agencies scored highest. Positive correlations were found between materials' understandability, actionability and their perceived quality.

Conclusions: Publicly available information on IBD and mental health is of variable quality and utility, even from reputable sources. A gap exists between materials being understandable and providing actionable self-management steps. However, if a

material presented information more clearly, it was more likely to provide practical guidance and be more reliable. To mitigate potential patient harm, clinicians must guide patients to high-quality sources. Development of future resources should integrate patient feedback and apply stricter quality criteria to improve actionability and reliability.

Key Words: Inflammatory Bowel Disease (IBD), Mental Health, Patient Information Quality, Understandability, Actionability

Key Messages

- **What is already known?**

Patients with IBD may prefer more information but may frequently encounter challenges in accessing it. Considerable variations in information and resource quality may increase uncertainty and limit effective self-management.

- **What is new here?**

A novel systematic evaluation of the quality, understandability, actionability and reliability of IBD and mental health information, revealing clear gaps between comprehension, practical guidance and clinical usefulness across sources and formats.

- **How can this study help patient care?**

Clinicians should direct patients to specialist-developed, evidence-based resources, emphasising materials with clear, actionable steps. Integrating quality and utility criteria into evaluation of resources may improve safety, engagement and outcomes.

Introduction

Inflammatory Bowel Disease (IBD) is an umbrella term for a group of inflammatory gastrointestinal conditions, including Ulcerative Colitis (UC) and Crohn's Disease (CD). When active, these conditions can be painful and debilitating, are often chronic and can have a systemic impact on physical health, emotional wellbeing and quality of life [1]. There is a previously reported link between IBD and mental health, namely mood disorders, anxiety, and psychological stress [1,2]. Anxiety and mood disorders are more prevalent in people with IBD than in the general population, with over 32% of people with IBD experiencing symptoms of anxiety and 25% experiencing depressive symptoms [3,4]. The relationship between IBD and mental health is suggested as bidirectional in nature, and may be mediated by the gut-brain axis [5]. In this psychobiological model, preexisting anxiety and depression may be a predisposing factor to the development of IBD, and enduring mental health difficulties can have a negative impact on the overall course of the disease, precipitate relapse to active disease states and hinder both response and adherence to treatment [2]. Symptoms of IBD may also contribute to psychological distress and impair progress towards personal, social and employment goals [2,6]. While the relationship between IBD and mental health has been previously investigated, less attention has been paid to how this information is communicated to patients and the public.

Individuals with IBD have a reported need for information that can support them to improve their ability and confidence in self-management and self-directed behavioural modifications, to enhance their physical and emotional well-being [7,8]. Providing evidence-based, patient-centred, concise and well-structured information to these individuals may have a positive impact on reducing levels of uncertainty and

promoting health-related quality of life [6,9]. Patients who have a higher level of disease related knowledge have been associated with having more positive adjustment related outcomes [10], such as higher levels of adaptability to the stressors associated with living with IBD [11]. Seeking health and disease-related information from online sources can exacerbate feelings of uncertainty in IBD patients, suggesting that not all sources of information are beneficial for patients' understanding and management of their condition [9]. While the internet can provide some useful information regarding symptoms, complications and treatment for IBD, there are identified gaps in the content relating to prognosis, risks and self-management [12]. A good quality resource is defined as reliable, evidence-based, unbiased, promotes informed decision making and presents a range of treatment choices, including the potential outcomes of each and highlights any areas of uncertainty [13,14]. The quality of information available online to IBD patients varies significantly in quality and reliability, with very few sources reportedly producing high quality materials that adequately explain treatment options [15]. A number of previous studies have sought to evaluate the quality and accessibility of online resources for patients with IBD. They present a narrative that whilst there is a vast collection of information available both through reputable sources (e.g., medical websites) and unverified forums (e.g., social media, blogs), the accuracy and reliability of the information provided is varied, and these resources are often not patient-centred and do not promote shared decision-making [12,15–18]. However, much of this research is outdated, focuses on general IBD content, and is not concerned with evaluation of information specifically addressing the IBD mental health relationship. Patients have a reported need for health information but may frequently

encounter challenges in accessing and understanding it, resulting in a gap between the evidence base and patients' real-world knowledge.

The information needs of IBD patients can fluctuate across the lifespan and throughout their disease course [7,19], and young adults, patients with higher levels of education, and those with increased severity of symptoms are reported to be more likely to seek out information online [16,20,21]. Whilst many patients may revert to their gastroenterology team for information regarding their disease, the next most commonly consulted resource is the internet, followed by general practitioners [20]. Over half of IBD patients reportedly feel that their general IBD information needs are not met, highlighting the need for an increased level of accessible and reliable information sources for patients [20]. Limited or lack of knowledge, lack of understanding of presented information, and misinterpretation of health-related messages have previously been identified as barriers to health-related behaviour change, whilst an increase in knowledge has been identified as a facilitator to positive behaviour change [22]. It is also important to consider individual knowledge patient needs, as this can vary depending on what disease stage they may be at (i.e., newly diagnosed, remission) and their coping style [7]. Patients' coping styles can range from active to avoidant in relation to information and help-seeking, which can be mediated by disease stage and activity, psychosocial experiences, affective processes, health literacy and information quality [7,23–26]. Higher levels of information seeking in IBD patients can be associated with increases in disease activity, worsening physical symptoms, anxiety and uncertainty [9,21,27,28]. Increased general practitioner use, accessing alternative health websites and sources that provide unverified health information are also associated with higher levels of anxiety in IBD patients [29]. Health anxiety also can drive excessive searching for health-related

information and reassurance seeking, which in turn may further exacerbate levels of health anxiety [28]. Poor quality health information may therefore contribute to misunderstanding of the gut-brain relationship, increased levels of anxiety and uncertainty, and reduced confidence in managing their condition, which can result in poorer self-management, reduced adherence to evidence-based recommendations and delayed help-seeking [23,28,30–33].

Much of the previous literature on information provision to patients with IBD focuses on general factors such as the disease course, physical symptomology and self-management of lifestyle factors (e.g., diet), and may not provide guidance around the bidirectional nature of the relationship between IBD and mental health [2]. To date, there has been no systematic evaluation of the quality, clarity, and actionability of information specifically addressing the psychobiological relationship between IBD and mental health.

Rationale

In a population that often experiences isolation and whose vulnerability to the development of mental health issues is strongly associated with their physical disease, it is vital that they have access to high quality and reliable resources [34,35]. Having access to reliable and useful information may reduce the need for continuous searching and levels of uncertainty and anxiety [6,9]. Accessibility for those with varying levels of health literacy and sources that provide strategies for self-management in order to support their health related quality of life are important considerations for this population [20,34,35]. Information that is evidence-based and communicated in an accessible format may support the development of health literacy skills [36], which subsequently may promote more positive health outcomes,

through the development of self-efficacy and facilitating communication with healthcare providers [24]. As IBD is a disease marked by uncertainty, unpredictability, and multifaceted biopsychosocial challenges, patients may require sources of applicable, reliable and relevant health related information that do not further perpetuate their psychological distress by increasing anxiety [6,12,20,28,37,38]. Improving the quality of available information may support the development of more accurate illness perceptions, reduce anxiety, and enhance self-management in individuals with IBD [2,34].

The Current Study

This study will examine both printed and audiovisual materials that provide information on the topic of IBD and the associated risk factors for mental health difficulties. The materials which will be evaluated will include hospital leaflets and resource packs, publicly available information from health authorities and specialist agencies, information available on social media and any other online source (e.g., websites, blogs or support group web pages not affiliated to or run by health authorities). The materials will be assessed for understandability and actionability using the Patient Education Materials Assessment Tool (PEMAT) [39] and for quality using the DISCERN instrument [13].

Key Research Questions

1. How understandable are the information sources regarding the psychobiological relationship between IBD and mental health which are available to patients and the general public?

2. How actionable are the information sources regarding the psychobiological relationship between IBD and mental health which are available to patients and the general public?
3. What is the quality of information sources regarding the psychobiological relationship between IBD and mental health which are available to patients and the general public?

Methods

Search Methodology

This study included a search protocol for retrieving materials, which included a search of defined websites of hospitals, national public health organisations, and specific support agencies (i.e., hospital in an urban centre in Ireland, Health Service Executive, National Health Service, Crohn's and Colitis Ireland). It also included a "Google" search using keywords (e.g., "IBD and mental health", "Inflammatory Bowel Disease and mental health", "Crohn's and mental health" "Colitis and mental health") which included the first 5 pages of search results and a social media search (i.e., Instagram, YouTube, TikTok) using hashtags (e.g., #IBD, #Crohns, #Colitis, #IBDMentalHealth) which also included the first 5 pages of results. It also included a search of artificial intelligence platforms (e.g., ChatGPT, CoPilot, DeepSeek) using keywords (e.g., "IBD and mental health", "Inflammatory Bowel Disease and mental health"). Retrieval of materials was completed by the lead researcher on five dates, between 27th August 2025 – 02nd September 2025. Webpages and social media posts were downloaded from the search engine, in order to control for site owners potentially changing the information during the analysis period. Any webpage which contained an additional downloadable resource was categorised as a separate material, and any website/domain which contained multiple pages with reference to IBD and mental health were also included as separate materials. Searches were completed using guest or "private" browsing windows in order to ensure that previous searches did not impact on the results that were displayed, with previous search history deleted.

Material Selection

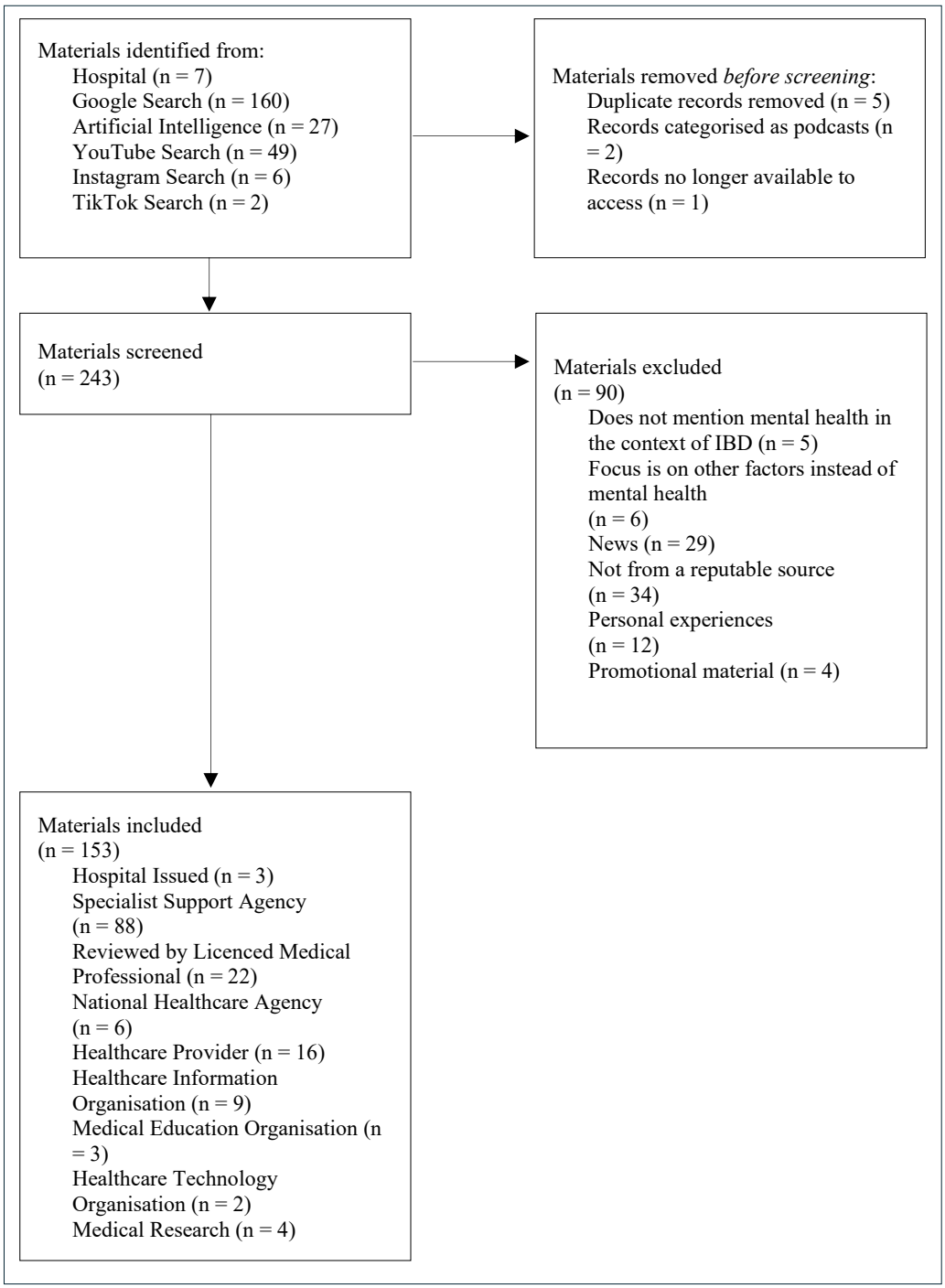
Inclusion Criteria

The inclusion criteria for materials in this study indicated that they must refer to IBD and mental health, they must be free for the public to access, and they must be written in English.

Exclusion Criteria

The exclusion criteria for this study included academic journal articles, news articles, inaccessibility due to a paywall, podcasts, not from a reputable source, the perspective of solely personal experiences, promotional material, or a sole focus on the physical health effects of IBD. Figure 1 displays the process of material screening and selection.

Figure 1. Flowchart of Material Inclusion



Procedure

Duplicates (N = 5) were removed from the dataset prior to screening against the inclusion and exclusion criteria. The materials were screened for suitability (i.e., meeting inclusion or exclusion criteria) by the lead researcher initially, and subsequently by another member of the research team. Included materials were categorised by source (e.g., "healthcare provider", "specialist support agency", "hospital issued", etc.,) prior to analysis. The included materials were scored using either the PEMAT-P or PEMAT-A/V depending on the format of the material, followed by the DISCERN. The rationale for dually employing the PEMAT and DISCERN was to assess how information was presented relating to clarity and practical utility (PEMAT) and what was presented regarding the reliability and quality of information (DISCERN) [14]. The first and second authors independently scored each material using the PEMAT and DISCERN, and the average of the scores for each material was used as the value for analysis [40]. Any significant differences in scoring between raters was resolved through discussion.

Assessment Tools

Patient Education Materials Assessment Tool (PEMAT) [39]

The PEMAT is a validated and systematic instrument which was designed to assess the utility of patient-facing health information, which has previously demonstrated high levels of inter-rater reliability [41]. The PEMAT can be used with both printed (PEMAT-P) and audiovisual (PEMAT-A/V) materials and assesses two domains, understandability (subsections: content, word choice and style, use of numbers, organisation, layout and design, use of visual aids) and actionability. The PEMAT defines a material as understandable when individuals with differing levels

of health literacy and diverse backgrounds can "process and explain key messages", and as actionable when individuals with differing levels of health literacy and diverse backgrounds can "identify what they can do based on the information presented" [39]. PEMAT Total Understandability and Actionability scores were qualitatively described as "High" (100%-70%), Moderate (69%-40%) and Low (39%-0%).

DISCERN Instrument [13]

The DISCERN is a widely used standardised instrument that can be used to assess the quality of public health-related information that is available to patients, which has previously been shown to have a high level of inter-rater reliability and internal consistency [13,42,43]. Although the DISCERN was originally designed for the purpose of evaluating written information, a number of studies have successfully used it with audiovisual materials and have used it alongside the PEMAT [44–53]. The DISCERN consists of three sections, assessing the reliability of the material, the quality of the information relating to treatment choices (including self-care), and an overall rating of the quality of the material [14]. DISCERN provides a total score for each material (reliability and treatment options) out of 75, and an overall quality score out of 5 [54]. DISCERN Total scores were rated as Excellent (75-63), Good (62-51), Average (50-39), Poor (38-28) and Very Poor (<27) [54], while DISCERN Quality scores were rated High (5-4), Moderate (3-2) and Low (1) [13,14].

Researcher Positioning

The lead researcher is a Trainee Clinical Psychologist and doctoral researcher with clinical experience working with adults, young people and children across a range of settings and clinical presentations. Their professional background informed

the rationale for this study and contributed to an understanding of the importance of reliable, understandable and actionable health information for populations with chronic physical health conditions. The researcher acknowledges that their clinical experience and interest in the interaction between physical and mental health may have influenced decisions made throughout the research process, including the focus of the evaluation and interpretation of findings. To support methodological rigour and reduce the influence of individual judgement when assessing information materials, standardised assessment tools (PEMAT and DISCERN) were used, ratings were independently completed by two raters, and inter-rater reliability was examined.

Results

Data analysis was completed using IBM SPSS to produce descriptive statistics and Person Correlation Coefficients. The inter-rater reliability of the PEMAT and DISCERN using multiple raters was also calculated.

Inter-rater Reliability

PEMAT - Cohen's Kappa

Interrater reliability for the PEMAT items was calculated using Cohen's Kappa (κ) to account for chance agreement. This analysis was conducted across all items, rather than separately for understandability and actionability. The results showed substantial agreement between the two raters, $\kappa = .664$ ($p < .001$), with an overall percent agreement of 79%.

Interrater reliability for the overall PEMAT-P scores was evaluated using the Intraclass Correlation Coefficient (ICC). A two-way mixed-effects model with absolute agreement was employed. Based on single-measure values, the analysis showed good agreement between the two raters, ICC = .828 (95% CI [.760, .879];). These results indicate that the PEMAT-P total scores are reliable and consistent across different evaluators for printed materials in this study.

Interrater reliability for the overall PEMAT-AV scores was assessed using the Intraclass Correlation Coefficient (ICC). A two-way mixed-effects model with absolute agreement was utilized. Based on single-measure values, the analysis showed good agreement between the two raters, ICC = .886 (95% CI [.794, .938];). This indicates that the PEMAT-AV provides a relatively higher consistent measure of understandability and actionability across different raters for the materials included in this study.

DISCERN – Weighted Kappa

Interrater reliability for the DISCERN tool was evaluated using a linearly weighted Cohen's Kappa to account for the ordinal nature of the 5-point Likert scale. This analysis was conducted across all items rather than just overall scores or the final quality item. It revealed moderate agreement between the two raters, $\kappa w = .554$ ($p < .001$).

Interrater reliability for the total DISCERN scores was assessed using the Intraclass Correlation Coefficient (ICC). A two-way mixed-effects model with absolute agreement was utilised. Based on single-measure values, the analysis showed good agreement between the two raters, ICC = .787 (95% CI [.629, .869]; $p<.001$). This indicates a high level of consistency in the quality and reliability ratings assigned to the materials.

Descriptive Statistics

Descriptive statistics were calculated for PEMAT and DISCERN scores by type of material: Printable (P) and Audiovisual (AV). For the P materials ($N = 113$), the mean PEMAT understandability score was high, 70.70 ($SD = 11.30$), and the mean actionability score was moderate, 49.85 ($SD = 23.04$). The mean DISCERN total score for this group was average, 46.56 ($SD = 11.15$), with a moderate mean quality rating of 2.70 ($SD = 0.93$). For the AV materials ($N = 40$), mean PEMAT understandability and actionability scores were both high, 78.79 ($SD = 13.80$) and 78.65 ($SD = 30.88$), respectively. The mean DISCERN total score in the AV group was average, 48.81 ($SD = 11.25$), and the mean quality rating was moderate, 2.68 ($SD = 0.89$).

Table 1 presents descriptive statistics (M, SD) for continuous variables (PEMAT and DISCERN scores) by material source. For PEMAT-P Understandability, the total mean scores of 5 source categories were in the “High” range (Specialist Support Agency, Reviewed by Licenced Medical Professional, National Healthcare Agency, Medical Education Organisation, Healthcare Technology Organisation), whilst 4 source categories fell in the “Moderate” range (Hospital Issued, Healthcare Provider, Healthcare Information Organisation, Medical Research). With regard to total mean scores for PEMAT-P Actionability, 1 source was rated "High” (Medical Education Organisation), while 6 sources were rated “Moderate” (Hospital Issued, Specialist Support Agency, Reviewed by Licenced Medical Professional, National Healthcare Agency, Healthcare Provider, Healthcare Technology Organisation), and 2 sources were in the “Low” range (Healthcare Information Organisation, Medical Research).

For PEMAT-AV Understandability, the total mean scores of 3 sources were in the “High” range (Specialist Support Agency, Healthcare Provider, Medical Research), and 1 source was categorised as “Moderate” (Medical Education Organisation). Regarding PEMAT-AV Actionability total mean scores, 2 sources were in the “High” range (Specialist Support Agency, Medical Research), 1 source was rated as “Moderate” (Healthcare Provider), and 1 source was in the “Low” range (Medical Education Organisation).

With regard to total mean scores for DISCERN Total, 3 sources were in the “Good” range (Reviewed by Licenced Medical Professional, Healthcare Information Organisation, Medical Education Organisation), while the majority of sources were in the “Average” range (Specialist Support Agency, National Healthcare Agency, Healthcare Provider, Healthcare Technology Organisation, Medical Research), and 1

source was rated as “Poor” (Hospital Issued). For DISCERN Quality total mean scores, all source categories were in the “Moderate” range.

Table 1. Descriptive Statistics by Source

Source	**PEMAT-P**		**PEMAT-AV**		**DISCERN**	
	Understandability	**Actionability**	**Understandability**	**Actionability**	**Total**	**Quality**
Hospital Issued (P=3, AV=0)	M=65.95, SD=7.29	M=67.62, SD=22.42	-	-	M=35.33, SD=9.50	M=2.17, SD=1.04
Specialist Support Agency (P=56, AV=32)	M=71.25, SD=12.00	M=48.72, SD=26.05	M=80.73, SD=13.58	M=84.77, SD=25.54	M=44.48, SD=11.78	M=2.46, SD=0.95
Reviewed by Licenced Medical Professional (P=22, AV=0)	M=73.16, SD=8.34	M=53.64, SD=13.64	-	-	M=57.27, SD=6.97	M=3.36, SD=0.58
National Healthcare Agency (P=6, AV=0)	M=75.43, SD=7.31	M=40.00, SD=31.62	-	-	M=50.08, SD=6.71	M=3.25, SD=0.94
Healthcare Provider (P=12, AV=4)	M=68.82, SD=10.06	M=56.94, SD=10.87	M=70.38, SD=13.17	M=58.33, SD=16.67	M=45.00, SD=5.65	M=2.91, SD=0.49
Healthcare Information Organisation (P=9, AV=0)	M=62.28, SD=12.78	M=38.89, SD=24.21	-	-	M=53.56, SD=9.48	M=3.06, SD=0.77

Medical Education Organisation (P=1, AV=2)	M=85.29, SD -	M=75, SD -	M=67.15, SD=0.68	M=0.00, SD=0.00	M=51.33, SD=6.21	M=2.50, SD=1.32
Healthcare Technology Organisation (P=2, AV=0)	M=81.37, SD=2.77	M=61.67, SD=2.36	-	-	M=45.00, SD=2.83	M=2.25, SD=0.35
Medical Research (P=2, AV=2)	M=52.65, SD=2.05	M=25.00, SD=21.21	M=76.11, SD=22.46	M=100.00, SD=0.00	M=46.88, SD=10.90	M=2.38, SD=1.11

Person Correlation Coefficient

Table 2 presents Person Correlation Coefficients (*r*) which were calculated to examine the relationships between the scores of patient education materials from different sources, as measured by the PEMAT (Understandability, Actionability) and DISCERN (Total, Quality) instruments. Only coefficients for groups with a sample size greater than 10 ($N > 10$) were interpreted to ensure reliability. Moderate to strong positive correlations were observed between PEMAT and DISCERN scores across included materials, indicating consistency between measures of understandability, actionability and overall quality. Within the Specialist Support Agencies source category, understandability was moderately to strongly associated with actionability ($r = 0.47$ for printable; $r = 0.60$ for audiovisual) and with overall quality ($r = 0.57$ for printable; $r = 0.38$ for audiovisual), suggesting that clearer materials also tend to be more actionable and higher quality. Actionability was strongly associated with quality in printable materials reviewed by a licenced medical professional ($r = 0.61$). A very strong correlation between understandability and overall quality was observed in printable Healthcare Provider materials ($r = 0.81$), however this finding should be interpreted with caution due to the small sample size ($N = 12$).

Table 2. Correlations by Source (>*N*=10)

Source	Type	PEMAT/DISCERN	PEMAT		DISCERN	
			Understandability	Actionability	Total	Quality
Specialist Support Agency (P=56, AV=32)	P	PEMAT Understandability	-	0.47**	0.45**	0.57**
		PEMAT Actionability	0.47**	-	0.32*	0.48**
		DISCERN Total	0.45**	0.32*	-	0.93**
		DISCERN Quality	0.57**	0.48**	0.93**	-
	AV	PEMAT Understandability	-	0.60**	0.42*	0.38*
		PEMAT Actionability	0.60**	-	0.35*	0.35*
		DISCERN Total	0.42*	0.35*	-	0.93*
		DISCERN Quality	0.38*	0.35*	0.93*	-
Reviewed by Licenced Medical Professional (P=22, AV=0)	P	PEMAT Understandability	-	0.38	0.27	0.31
		PEMAT Actionability	0.38	-	0.47*	0.61**
		DISCERN Total	0.27	0.47*	-	0.82**
		DISCERN Quality	0.31	0.61**	0.82**	-

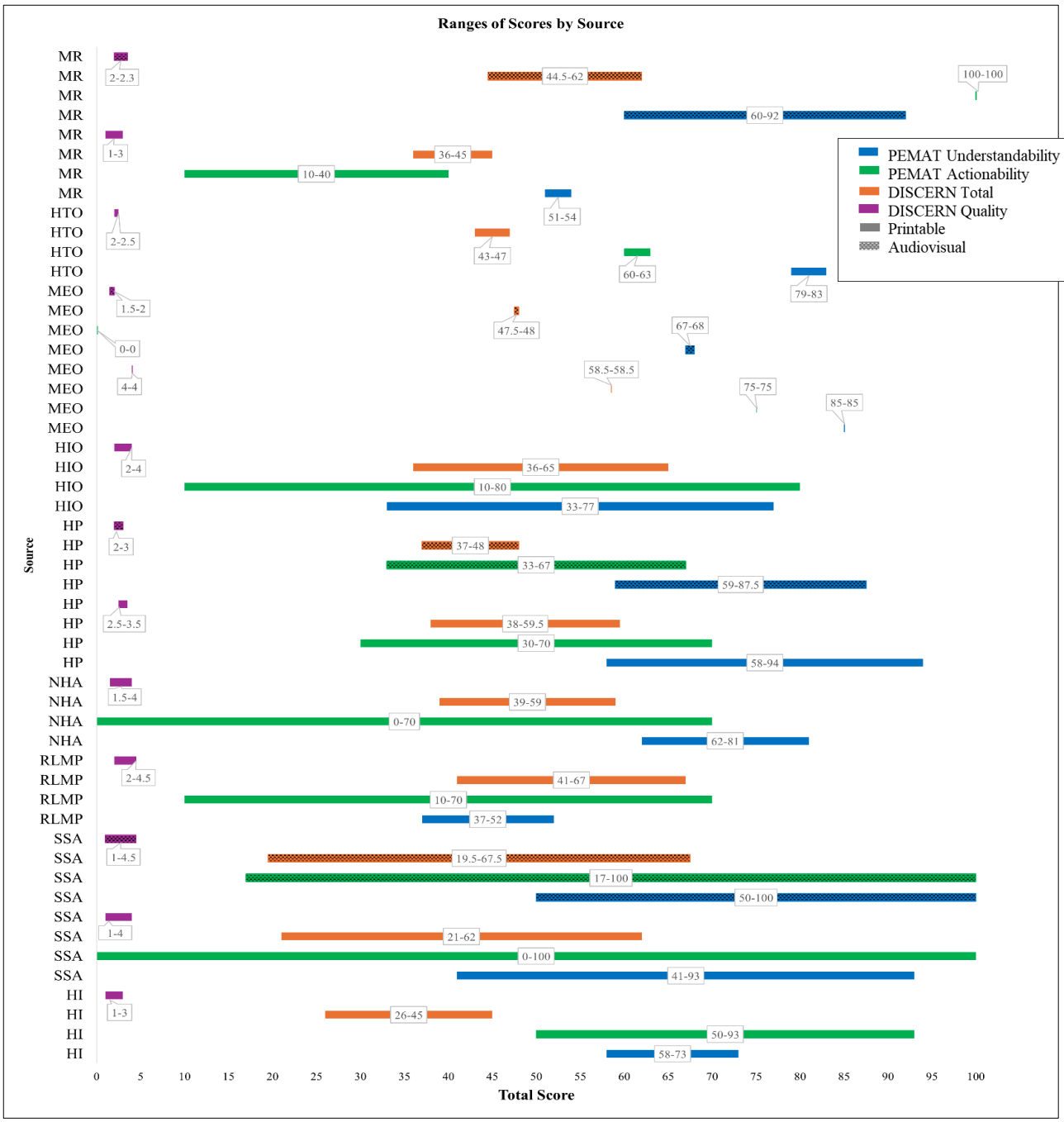
Healthcare Provider (P=12, AV=4)	P	PEMAT Understandability	-	0.39	0.81**	0.44
		PEMAT Actionability	0.39	-	0.00	0.17
		DISCERN Total	0.81**	0.00	-	0.73**
		DISCERN Quality	0.44	0.17	0.73**	-

Note. **Correlation is significant at the 0.01 level (2-tailed), * Correlation is significant at the 0.05 level (2-tailed)

Ranges of Scores

Figure 2 displays the variability in the scores of materials, as measured by the PEMAT (Understandability and Actionability) and DISCERN (Total and Quality) tools, organised by the material's source of origin. The scores for each source (e.g., Hospital Issued (HI), Specialist Support Agency (SSA)) are displayed on the horizontal (x) axis representing the total score. This figure provides a direct comparison of score distributions across different material source types. The key differentiates between the four scales and the two material formats (Printable and Audiovisual). The highest total score for PEMAT Understandability and Actionability is 100, while the highest total score for DISCERN Total is 75 and Quality is 5.

Figure 2. Ranges of Scores by Source



Note. HI = Hospital Issued, SSA = Specialist Support Agency, RLMP = Reviewed by Licenced Medical Professional, NHA = National Healthcare Agency, HP = Healthcare Provider, HIO = Healthcare Information Organisation, MEO = Medical Education Organisation, HTO = Healthcare Technology Organisation, MR = Medical Research.

Discussion

The present study evaluated the understandability, actionability, reliability and quality of information available to patients and the public regarding the psychobiological relationship between IBD and mental health. The majority of materials demonstrated high levels of understandability, but ratings varied in relation to actionability, indicating that they presented information in a clear and accessible way, but they were less effective in providing explicit practical guidance [12]. Assessment using the DISCERN tool indicated that the overall quality of information was moderate, and reliability was average, with very few materials achieving a rating of good. Some materials were rated as high in quality, but they did not provide information that was clearly explained or actionable, indicating that information perceived as reliable may not always mean practical or helpful [15]. Specialist Support Agencies, particularly audiovisual materials from this source, alongside materials Reviewed by Licenced Medical Professionals were the strongest in relation to understandability, actionability and quality, whilst hospital issued materials were the weakest overall source category. No single source achieved high ratings across all domains, and there was substantial variability in ratings within all categories as indicated by the large standard deviations, demonstrating that some materials were very good and others were very poor, even within the same source category. The results of this study are consistent with previous research highlighting the variability in resource quality for IBD patients, indicting a gap in effective sources of information for this population [9,12,15–18]. As the quality and utility of health related information may impact upon engagement, emotional responses and help-seeking [29,30,33], and facilitate the development of health literacy skills and self-efficacy around self-management [11,24,32], encountering a landscape of resources

which are variable in reliability and usefulness [12,15,17,18] may have implications for health outcomes and influence future information and help-seeking [19,28,55].

While most printable materials, especially from professional sources, obtained high scores for understandability, their actionability scores were predominantly moderate, indicating a demonstrated limitation in translating clear information into concrete, actionable steps patients can use for self-management [7,8,12]. In relation to existing models of information acquisition, the Planned Risk Information Seeking Model (PRISM) indicates that the factors which drive information seeking relate to perceived risk, emotional response, gaps in knowledge, beliefs about whether searching is useful, social pressure and self-efficacy [56]. As patients experiencing anxiety and increased severity of symptoms are more likely to seek information, when the information that they access is not fully actionable or of high quality, this may influence feelings of uncertainty and further searching [16,19,20,23,29,57].

The Information-Motivation-Behavioural Skills Model describes meaningful behavioural change as occurring due to acquisition of knowledge and motivation for change, leading to the development of behavioural skills, which subsequently facilitate changes in health related behaviours [57]. Information that is not reliable, understandable or does not provide clear guidance regarding actions may impact the development of behavioural skills, therefore patients may understand what they access but without clear instructions on what to do with the information, behavioural change is unlikely [22]. The Information Response Model suggests that promoting health related behavioural change is reliant on cognitive processes relating to perceived risk and efficacy, emotional reactions to material, and instrumental processes in relation to how useful patients perceive information to be in guiding

action [58]. Perceived trustworthiness in the source of the information increases how useful they perceive that information to be, in turn affecting how individuals think and feel about their ability to take action [29,58]. While the materials included in this study were often understandable, their limited actionability and moderate quality reduce their practical usefulness, meaning that patients may rely on heuristics or continue searching, particularly when materials fail to guide behaviour.

Audiovisual materials were more effective than printable materials at providing clear information that was more helpful in guiding action, suggesting that the format may influence the perceived accessibility and utility of a resource [34,35]. The correlation analysis demonstrated that if a material was easier to understand, it was more likely to be actionable and of higher quality. This highlights that clarity is intrinsically linked to trustworthiness from a user's perspective, aligning with the concept of trust heuristics, which indicates that people make unconscious judgements based on authority, reputation and appearance in order to determine perceived trustworthiness of information, which doesn't reflect how useful the information may be practically [55,59,60].

This research supports previous reports in the literature that patients are met with an environment of highly variable reliability [9,12,15–18]. The identified gaps in actionability and the average DISCERN scores mean that vulnerable patients may often find information that is difficult to apply or lacks a solid evidence base, which may negatively influence anxiety or contribute to poorer health outcomes due to limited guidance regarding self-management strategies [12,28,29,56]. The finding that audiovisual materials are more consistently understandable and actionable is also supported by previous research, suggesting that this format may be associated with improved comprehension and facilitate the acquisition of practical skills through

visual demonstration, although quality may be variable [39,44,52,57]. The poor performance of some materials from reputable sources (e.g., Hospital Issued) suggests that affiliation alone is not a guarantee of quality [55,59,60], indicating a need for standardised quality control processes, clinician guidance and improved psychoeducation, even within healthcare organisations [34].

Strengths and Limitations

This research provided a novel evaluation of the quality of information materials available to patients in the specific context of the relationship between IBD and mental health. This study also used two well-validated instruments that have previously been used to evaluate medical patient education materials. The DISCERN tool has also been used in a number of previous studies which focused on the quality of information for IBD specifically. The inter-rater reliability reported in this study indicated high levels of agreement between raters on both the DISCERN and the PEMAT, signifying reliable and consistent patterns of scoring between both raters. This study included audiovisual materials alongside printable resources, in order to offer a multi-dimensional evaluation of available information sources. Audiovisual materials represent a proportion of modern information seeking, as they may appeal to different learning styles and mitigate the impact of literacy difficulties on engagement with information, compared to traditional printable resources.

There were also several limitations associated with this study. The study relied on researcher rating of standardised evaluation tools. While tools like PEMAT and DISCERN provide essential, objective measures of understandability and quality, they cannot fully capture the subjective relevance, emotional resonance, and practical utility of information from the patient's perspective. As a result, the

findings may not fully reflect how patients actually perceive or engage with the materials, potentially limiting the validity of conclusions about their real-world usefulness. As the DISCERN was developed in the context of assessing medical patient information, it is possible that it was not able to fully able to capture the nuances associated with information regarding psychological difficulties, and an adapted version for assessment of information from a biopsychosocial model may be more suitable. Consequently, as mental health information often differs in structure and purpose from medical treatment information, the quality of psychological materials may have been underestimated or mischaracterised in the findings. The DISCERN tool's focus on treatment choices may partially explain the low scores for mental health-focused materials, which often discuss coping rather than specific medical treatments. This is an important consideration, as the evaluation criteria may not fully align with the intent of the materials, and as a result, lower scores for mental-health focused resources may reflect tool limitations rather than true deficits in quality. The analysis focused on objective quality items and did not measure the direct impact of these materials on patient behaviour or clinical outcomes. As high quality information does not necessarily translate into meaningful patient benefit, the findings cannot determine the real-world effectiveness of the materials.

The search strategy, including search terms, platforms and algorithms, may have influenced which materials were identified. In applied setting patients may search differently (e.g. using social media, different keywords), and as a result, the sample may not fully represent the information patients actually encounter, potentially leading to over or under estimation of information quality. A suggestion for future evaluations is to use broader, user informed search strategies across multiple platforms. This study focused on materials from “reputable sources” and

excluded materials that contained “personal experiences”, which resulted in the non-inclusion of the majority of social media materials, which may prove to be a source of experiential information for many patients. This may be considered in view of ecological validity and may not reflect patient preferences for shared experiences and peer support. There was substantial variance between the number of materials in each source category (SSA = 88 vs HTO = 2) which limited further statistical analysis and the robustness of statistical comparisons, reducing the ability to draw reliable comparative conclusions across categories. There were also significantly more printable materials than audiovisual materials, which resulted in some source categories containing only printable materials, reducing the level of comparisons that could be conducted. As a result, conclusions about differences between material types are limited. This study used a cross-sectional design, and as online information is frequently updated, removed or replaced, the findings may become outdated and may not reflect the dynamic nature of the current information landscape. Assessing the accessibility with regard to literacy was beyond the scope of this research, however this is an important factor to consider when recommending materials to patients as readability is a key determinant of whether patients can understand and use information. Therefore, the findings do not account for the dimension of accessibility when recommending materials.

Future Directions

A number of recommendations for future directions have originated from this research. Future research should seek to include expert by experience ratings of materials, to ensure that the utility of the information is relevant for IBD patients. Clinicians should endeavour to prescribe resources from sources that have been created in conjunction with specialist agencies and other healthcare professionals.

They should provide guidance to patients about the limitations associated with the quality of evidence portrayed in online sources, advising them to verify information against evidence-based clinician advice. There is an identified need to improve the actionability of all materials in order to support the implementation of self-management strategies. Checklists based on PEMAT and DISCERN criteria should be integrated by healthcare organisations and services into the development process for novel patient-facing materials before release, alongside quality audits of existing suites of materials. Patients can be guided to prioritise materials that provide clear, concrete steps for managing physical and emotional well-being, and to consider the source of a resource as a primary marker for information quality. There is potential in the social media space for licenced healthcare professionals to share reliable information, due to the accessibility of these platforms and the high levels of understandability and actionability associated with audiovisual materials, which may aid to reach and engage patients with literacy difficulties and low levels of health literacy [36]. These recommendations relating to information provision for patients around IBD and mental health may be useful in developing information sources that guide patients towards positive behavioural changes that may support their physical and psychological well-being and quality of life. They may also serve to promote awareness in healthcare providers about the relationship between IBD and mental health, contributing to the recognition and consideration of mental health difficulties associated with IBD in their patients, and improve confidence in their management of this and appropriate help-seeking behaviours [2,34].

Conclusion

This study evaluated the quality of patient information sources concerned with IBD and mental health. The findings from this study indicated that information quality is inconsistent. Printable materials are often clear but lack practical steps, and audiovisual materials tend to be more actionable, and may be perceived as higher quality or more trustworthy as a result. The source of information matters, as materials produced by specialist support agencies are typically of higher quality, whilst materials from hospitals often score poorly. Patients seeking help online often find information that is hard to use or not reliable, which can increase anxiety. Improving the quality of information on the IBD and mental health relationship is essential to support informed, confident, and psychologically supported self-management. To address this, healthcare providers must actively guide patients to understandable and actionable resources, preferably in an audiovisual format. Future materials need to be easy to understand, trustworthy and provide clear guidance. Clinicians can play a key role in developing better resources and educating patients to support them in finding reliable information.

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Chapter 4: Integrated Discussion

Chapter Outline

This chapter will provide an integrated discussion of the key findings of Study one and Study two, how these findings align with the existing research literature, an overview of the limitations associated with these studies, along with recommendations for clinical psychology and future research directions.

Key Findings

Study one qualitatively explored young adults with Inflammatory Bowel Disease (IBD) and depression and/or anxiety experiences and understanding of the link between their physical and mental health, and their experiences of information provision around this relationship. The findings from this study encompassed a number of themes, broadly relating to the part that IBD has to play in the profound impact on their psychosocial functioning, the interpretation of their needs with regard to supporting their physical and mental wellbeing, their experiences surrounding past communication of the psychobiological risk factors associated with IBD, and their future preferences for how this could be improved. There was an emphasis on the importance of shared understanding and peer-led support for this cohort, as they felt that others external to the IBD community had a limited understanding of their difficulties. The suggestion for healthcare professionals to take a holistic stance towards their treatment, integrating mental health care alongside management of physical symptoms, was endorsed by the participants. Even though participants named a desire to receive more information and support regarding their mental health and described that psychological distress is often more

impactful than their physical symptoms, they also described patterns of information and help seeking that prioritised their physiological wellbeing, indicating a mismatch between their reported needs and health related behaviours. Practical advice, accessibility of supports and information communicated in an in-person format were perceived as beneficial. The fluctuating nature of their support and information needs, whereby there was a reported sense of urgency around seeking information when unwell, and subsequently avoiding reminders of the disease when they were in remission, was mediated by disease activity and psychological distress. The personal lived experience of the bidirectional nature of IBD and mental health was highlighted, in contrast to feeling that they did not have formal knowledge of this, alongside the psychosocial impact of IBD and how this contributes to their distress.

Study two evaluated the understandability, actionability, reliability and quality of printable and audiovisual materials which presented information regarding the relationship between IBD and mental health. Both printable and audiovisual material modalities were consistent in achieving average ratings for reliability and moderate ratings for quality, however there were high levels of variability in ratings within material source categories, with none achieving high ratings across all domains. The findings from this study concluded that audiovisual materials outperformed printable materials in relation to actionability, and most of the materials across printable and audiovisual formats were understandable. However, levels of actionability were more variable. Materials from Specialist Support Agencies and those reviewed by medical professionals achieved the best overall category ratings. Correlational analysis indicated that there was a positive relationship between understandability, actionability and quality, indicating that if a material presented information in a clearer and more accessible format, it was more

likely to provide practical guidance on actions and to be more reliable. The young adults in study one indicated that they lacked understanding and require more information around the relationship between IBD and mental health, however study two demonstrated that the information which is available is often of poor quality. This convergence suggests that the limitations in available information may directly contribute to patients' difficulties in understanding and managing the relationship of IBD and mental health.

Interpretation of Results

Experience and Knowledge of the Relationship Between IBD and mental health

The perception of having limited formal understanding of the relationship between IBD and mental health was expressed by the participants, due to a reported lack of communication of this information from their healthcare providers and a reported lack of signposting to relevant and reliable resources. This finding is aligned with previous quantitative and qualitative research around the information needs of IBD patients. There is a reported unmet need in the IBD population around information relating to their illness, and over half of patients feel that they have not received an adequate amount of guidance from their healthcare teams or online resources (Borgaonkar et al., 2002; Catalán-Serra et al., 2015; Hinnant et al., 2025; Kok et al., 2023; Lesnovska et al., 2014; Mikocka-Walus et al., 2021). A recent systematic review indicated that conversations between healthcare professionals and patients are predominantly disease centred, and do not consider the psychosocial impact of living with IBD (Hawkins & Bull, 2024; Karimi et al., 2021). However, evidence from the perspective of health care professionals is that almost three-

quarters of IBD services feel that they employ an integrated model of care which recognises psychosocial factors and supports a multidisciplinary approach to treating IBD (Mikocka-Walus et al., 2014). The potential barriers to the application of an integrated model in practice may be associated with limited confidence in speaking about mental health difficulties associated with a perceived lack of knowledge or training, or a lack of specialist onsite psychological services to provide continuity of care to patients who are experiencing psychological distress (Hinnant et al., 2025; Kok et al., 2023). This suggests that the gap is not simply informational, but also structural, reflecting how care is prioritised and delivered. A personal lived experience of the relationship between IBD and mental health was discussed by the participants, in relation to an acknowledgment that when they noticed an increase in their physiological discomfort, this was generally followed by increases in anxiety and psychological symptoms. Similarly, fluctuations in mood and increases in anxiety were recognised as precipitators to flares of disease activity (Mikocka-Walus et al., 2021). Participants demonstrated an embodied understanding of the relationship, despite not having formal biomedical explanations for what they were experiencing or understanding of what was happening for them. This was also represented in the existing qualitative literature, which reported that IBD patients notice that increases in disease activity and severity are associated with increases in psychological distress and conversely, when symptoms of psychological distress are high, this can be associated with increases in physical symptom severity and duration (Allemang et al., 2024; Berenblum Tobi et al., 2024; Byron et al., 2020; Mikocka-Walus et al., 2021; Qualter et al., 2021). This also reflects previous research regarding the gut-brain axis model and the bidirectional relationship which has been theorised to occur between IBD and mental health (Abdelbadiee et al., 2025;

Bisgaard et al., 2023; Fairbrass et al., 2022; Gracie et al., 2018; Keefer, 2021a). These findings highlight a critical gap between lived experience and formal knowledge, suggesting that patients are left to make sense of this relationship independently.

Focus on Physical Symptoms

There was a notable focus on accessing supports for the physical symptoms of their disease, and the perception that in order to feel psychologically well, participants' disease needed to enter remission, which was reflected in their long-term goals around maintaining overall wellbeing. There is substantial evidence in the literature indicating active disease states are associated with increasing psychological distress and reductions in emotional wellbeing (Abdelbadiee et al., 2025; Fairbrass et al., 2022; Hu et al., 2021), and that these factors may impact on self-management behaviours and treatment adherence, which may contribute to the severity and duration of physical symptoms, and increased healthcare needs ((Mikocka-Walus & Andrews, 2018; Nikolova et al., 2022). In light of this evidence, it may be interpreted that some IBD patients may perceive a reduction in physical symptoms as a way to manage the associated psychological distress (Loftus et al., 2008). This may be particularly relevant if their healthcare treatment has prioritised physical symptom management, reflecting patients' desire to gain back a sense of control, which is often reduced in IBD patients (Brooks et al., 2015; Ilias et al., 2020; Nicholas et al., 2007). However, the psychological symptoms of IBD were reported to further affect the participants' internal narrative, beliefs about themselves and others, and reduced their perception about their ability to cope. This is supported by a qualitative study conducted by Cho et al. (2018) which explored the needs of young adults with IBD, as they identified psychosocial needs as the most commonly reported (Cho et al.,

2018). This is converse to a recent meta synthesis conducted by Byron et al. (2020) which demonstrated that the most significant challenge for IBD patients is their disease state (Byron et al., 2020), and it was concluded in a follow-up study that physical symptoms of their disease were the main precipitating factor which drives help-seeking behaviours (Byron et al., 2023). However, the aforementioned meta-synthesis also acknowledged that the physical manifestations of IBD negatively impact upon psychological and social well-being, and can subsequently impact on to reduced quality of life, reinforcing the interplay between biopsychosocial factors in this condition (Byron et al., 2020). These mixed findings were also reflected in the reports from the participants, whereby they named that their psychological symptoms were often more distressing than their physiological symptoms, and they desired more support around this, but their patterns of information seeking largely prioritised managing their physical health. This disconnect between the participants' reported needs and health related behaviours may reflect the compounded impact of perceived stigma, disease burden, feeling misunderstood and unheard, and a perceived lack of knowledge about the link between their IBD and mental health (Byron et al., 2020; Norton et al., 2012; Qualter et al., 2021).. These factors may create barriers to engagement in help-seeking around their mental health, as they may perceive that it may be easier to speak about and seek support for their physical symptoms.

The perceived prioritisation of the physical manifestations of their disease by professionals was accompanied by reports of limited information given about the risk of heightened psychological distress associated with this illness (Fourie et al., 2018; Hawkins & Bull, 2024; Plevinsky et al., 2016).This may have contributed to internal expectations that they should be able to cope independently, and that they

were at fault if they were not able to maintain their own emotional wellbeing. As they reported their emotional needs were less recognised by personal and professional supports, this may have contributed to increasing severity in distress and overwhelm prior to conversations occurring about how they could be supported (Hawkins & Bull, 2024; Karimi et al., 2021; Mikocka-Walus et al., 2021). From the experiences expressed by this cohort, it appears that although their disease activity precipitates their psychological distress, it may also be perpetuated by the lack of information that they have been provided about the relationship between IBD and mental health, and their reported limited opportunities to access support around the self-management of this.

The Psychosocial Burden of IBD

The psychosocial impact of IBD was readily recognised by participants, whereby the additional stressors created by continuously having to hold their physical symptoms in mind when planning for everyday tasks may contribute to anticipatory anxiety and hypervigilance to bodily sensations (Norton et al., 2012; Zhou et al., 2024). The uncertainty that this cohort expressed around whether they would be well enough to complete educational requirements, be able to leave work to access treatment or have access to their medication when travelling, may reflect a perceived loss of control, contributing to situational anxiety around everyday experiences that would typically be considered low threat by the general population (Norton et al., 2012; Zhou et al., 2024). Delayed social milestones, disrupted routine, limited engagement in rewarding activities, and the additional work that they had to do in order to progress towards their goals, may further contribute to feelings of social disconnection, influencing symptoms of depression, anxiety and loneliness (Norton et al., 2012; Qualter et al., 2021; Roberts et al., 2021). These findings may

be conceptualised within the biopsychosocial model, whereby ongoing cognitive, emotional and behavioural factors interact with disease processes to perpetuate psychological distress.

Previous research evidence has reported that young people with IBD may have a felt sense of being different to others, and that embarrassment and perceived stigma appear to actively shape behaviour, particularly through avoidance of disclosure and reduced help-seeking, negatively impacting their relationships and wellbeing (Mikocka-Walus et al., 2021; Nicholas et al., 2007; Norton et al., 2012; Qualter et al., 2021; Roberts et al., 2021). Having to stay at home for weeks on end, often bedbound, due to pain when in a flare, or needing to be in close proximity to a bathroom at all times, was reported to impact upon their ability to engage with social opportunities and engage in leisure and travel activities (Fourie et al., 2018; Norton et al., 2012; Polak et al., 2020; Roberts et al., 2021). As young adulthood is typically a time of developing independence and exploration around relationships and sexuality (Arnett, 2000, 2023), when opportunities to engage in this are practically restricted due to illness, and psychologically restricted due to anxiety around acceptance and body image, this impacted on their identity formation and contributed to an internal narrative around burdening others, a diminished sense of self-worth and increases in shame (Allemang et al., 2024; Mikocka-Walus et al., 2021). A recent qualitative research synthesis by Muse et al. (2021) indicated that IBD has an impact on the self-identity of patients due to a feeling of otherness, as they have a desire to be understood but also experience a converse drive to hide their true difficulties, due to fears of judgement from their social circle (Bernard et al., 2007; Mikocka-Walus et al., 2021; Muse et al., 2021; Norton et al., 2012). The tension between a desire to be understood and a drive to conceal difficulties may

contribute to reduced help-seeking and limited disclosure of psychological distress, particularly where patients anticipate judgement or minimisation of their experiences. Participants described experiences of invalidation and judgement from family and peers, which contributed to feelings of disconnection and being misunderstood. These experiences may have influenced trust in others' ability to understand their difficulties and created barriers to future help-seeking and engagement with supports, which was particularly relevant when their distress of symptoms were perceived as minimised. Participants described challenges in communicating the full extent of their difficulties beyond physical symptoms, which may have contributed to feelings of isolation and reduced opportunities for their psychological needs to be recognised and supported. This suggests that stigma may operate as both a psychosocial burden and a mediator of behaviour, which influences patterns of help-seeking and engagement with information, potentially maintaining unmet informational needs and reinforcing existing information gaps.

The perception that others external to the IBD community could not understand their difficulties impacted upon help seeking behaviours both in their personal support network and when speaking to their healthcare providers (Fourie et al., 2018; Norton et al., 2012; Qualter et al., 2021; Roberts et al., 2021). As they reported that they anticipated stigma from others, and did not want their sole identity in the eyes of others to just be their illness, this may have contributed to further minimisation of their distress which may have supported a perception that it was shameful (Polak et al., 2020). IBD is a condition which has been reported as heavily stigmatised by the general public when compared to a number of other diseases (e.g., HIV), and levels of public knowledge of the condition have been previously demonstrated as low (Groshek et al., 2017). Fourie et al. (2018) conducted a

qualitative systematic review of the lived experiences of IBD, and they suggested that patients are often reluctant to speak about their condition and difficulties due to perceived stigma around symptoms and lack of public awareness of the disease, leading to an overarching theme of "living in isolation and exclusion" (Fourie et al., 2018).

Experience of Receiving Information and Preferences for Information Provision

This cohort described the sources of information that they have previously encountered that were helpful and unhelpful, and what they would like to be presented with moving forward. There was a shared experience of receiving unsolicited advice from people in their personal lives, and an acknowledgement that this generally centred around the management of their physiological symptoms. These experiences suggest that information environments are not neutral, but actively shape how individuals interpret and make sense of their condition. The importance that others external to the IBD community placed on diet and non-conventional or non-evidence based treatments when advising this cohort appeared to reinforce illness perceptions around personal responsibility and control, which may contribute to self-blame and increased psychological distress. This misinformation was also encountered by participants on social media, which may have influenced their caution about the trustworthiness of online resources (Reich et al., 2019). Previous studies have indicated that negative experiences with online information can be associated with increases in anxiety and contribute to avoidance of further information-seeking, limiting opportunities to access accurate, evidence-based guidance (Karadag et al., 2022; Ni et al., 2024). This avoidance may perpetuate knowledge gaps, reinforce uncertainty and reduce engagement with both information and clinical support, with potential longer term consequences for self-

management and psychological wellbeing. This highlights that variability in information may actively shape illness perceptions, emotional responses and patterns of engagement with information and care.

Existing literature has highlighted that there is a gap between the information currently provided by healthcare professionals and the information needs of patients, particularly for young adults with IBD, whereby the information provided tends to be primarily around the physical state of the disease, with limited acknowledgement of the associated psychosocial impact (Hawkins & Bull, 2024; Karimi et al., 2021; Khan et al., 2016; Qualter et al., 2021; Zhou et al., 2024). This previous finding was supported by the reflections of the young adults in this study. This is converse to what IBD patients reportedly seek in relation to information and the content of their discussions with their healthcare team, which can be a biopsychosocial integration of their experiences, characteristics and functioning, in order to support their development of more effective self-management skills (Allemang et al., 2025; Cho et al., 2018; Kok et al., 2023; Mikocka-Walus et al., 2021; Nicholas et al., 2007). This is particularly important during young adulthood, due to the challenges experienced by this population in relation to identity formation, increasing independence and navigation of social roles (Arnett et al., 2014). There was also a reflection that when psychological symptoms were a topic of discussion, they were perceived as an adjunct that were being driven exclusively by their physical symptoms as the underlying mechanism, with limited acknowledgement of the psychosocial factors associated with their developmental life stage, such as identity development, autonomy and social integration. This may further be associated with a sense of being unheard and misunderstood, which may influence engagement in clinical interactions and limit disclosure of psychological difficulties (Norton et al.,

2012). This reflects the experiences of other IBD patients regarding feeling misunderstood, unheard and a lack of acknowledgement of their emotional needs, which may suggest a systemic misalignment between biomedical care and the biopsychosocial and developmental needs of young adults with IBD.

The sources of information and support that were perceived as helpful shared characteristics such as being accessible, trustworthy, reliable, providing clear practical guidance that facilitated action, complimentary to their medical treatment for physical symptoms and presented in a supportive fashion (Dent et al., 2022; Iizawa et al., 2023; Ni et al., 2024; Norouzkhani et al., 2023). These characteristics closely align with established indicators of high-quality patient education materials, including understandability and actionability as captured by PEMAT, and reliability and quality, as reflected in DISCERN, suggesting that participant perspectives provide an experiential validation of the evaluation criteria used in study two. These sources were named as the service provided by the IBD nurses, specialist support agencies such as Crohn's and Colitis Ireland, and peer led support shaped by a shared understanding of the impact of IBD, whether that be provided in person or through online forums (podcasts, Instagram, TikTok, Reddit, Facebook groups). The relative absence of these characteristics in many publicly available materials may reflect a continued emphasis on information provision over behavioural guidance, alongside the dominance of biomedical models that prioritise factual accuracy over practical applicability and psychosocial relevance (Dent et al., 2022). This indicates that information may be perceived as most useful when it reflects an understanding of the biopsychosocial impact of IBD and is delivered in a way that is both credible and practically applicable, whether from professional or peer-based sources. The convergence between participant preferences and established quality criteria suggests

that the current gaps in actionability and reliability identified in study two are not only methodological observations, but may be reflected in lived patient experience, reinforcing the need for more integrated, patient-centred approaches to information design and delivery.

Previous research examining the utility of social media platforms for supporting the information needs of IBD patients indicates that it is a highly accessed resource for information around the challenges of living with IBD, impact on mental health, the experiences of other patients relating to treatment options and efficacy, and validation of their difficulties (Adeyemi et al., 2025; Goren et al., 2022; Pittet et al., 2016; Reich et al., 2019). As the content portrayed on social media networks can be vast and created by those with varying degrees of knowledge around IBD and evidence-based information, patients may encounter and engage with information that they deem to be relatable and empathetic, but it may not provide reliable advice regarding self-management (Adeyemi et al., 2025; Groshek et al., 2017; Ni et al., 2024; O'Leary et al., 2020; Reich et al., 2019; Szeto et al., 2018). There appears to be a tension between emotional validation and informational accuracy, whereby emotionally validating content may be perceived as more credible through mechanisms such as confirmation bias, which may influence maladaptive beliefs, increase vulnerability to misinformation and delay engagement with evidence-based information and care (Kurowski et al., 2021). This further highlights the potential importance of individual discussions to take place between healthcare providers and patients that encompass the biopsychosocial impact of IBD (Dent et al., 2022; Hawkins & Bull, 2024; Karimi et al., 2021).Without this support, patients may turn to alternative sources in order to gain a sense of being understood, but this may come at the expense of accessing unreliable information to support their

wellbeing, which may impact upon self-management, distress levels and future information seeking (Groshek et al., 2017; Khan et al., 2016; Mukewar et al., 2013; Ni et al., 2024; Pittet et al., 2016). This indicates that improving communication is not just informational, it can be an intervention that shapes engagement, help-seeking, and patient outcomes (Screti et al., 2024).

With regards to the needs and preferences for future communication of information regarding IBD and mental health for this cohort, a holistic approach to their overall care was named as the underlying factor (Hinnant et al., 2025; Kok et al., 2023). Preferences regarding information provision for patients in the existing literature have also highlighted the importance of shared experiences and an integration of a holistic model of care (Allemang et al., 2024; O'Leary et al., 2020). The desire for information around the risk factors and management relating to mental health difficulties alongside the psychosocial impact of IBD to be integrated into in person communications with their healthcare teams was reported, in order to enable them to feel more supported and reduce barriers to speaking more openly about the impact on their psychological functioning (Allemang et al., 2025; Berenblum Tobi et al., 2024; Cho et al., 2018; Mercuri et al., 2025; Mikocka-Walus et al., 2021). With regard to theoretical models of health literacy, improving the delivery, structure and quality of health communication, particularly from healthcare professionals, can facilitate patients to develop skills in finding, understanding and applying information, and promote engagement in populations groups that are socioeconomically disadvantaged and may be affected by low health literacy (Mercuri et al., 2025; Nutbeam & Lloyd, 2021). Supporting the development of health literacy skills through the integration of patient education on the biopsychosocial impact of IBD and the multifaceted factors influencing wellbeing

may encourage patients to seek support and further information, and could facilitate more effective self-management of their difficulties (Allemang et al., 2025; Karadag et al., 2022; Mercuri et al., 2025; Mikocka-Walus et al., 2021; Nutbeam & Lloyd, 2021). This suggests that the integration of biopsychosocial information into routine clinical communication is a key mechanism through which patient engagement, health literacy and self-management are supported. The absence of holistic communication may represent a systemic limitation within the delivery of integrated models of care, potentially reinforcing communication gaps, limiting disclosure of psychological difficulties, and constraining patients' capacity to effectively understand and manage the interplay between their physical and mental health.

This cohort strongly endorsed the early integration of mental health information within clinical care, particularly following diagnosis, to support normalising emotional distress, reducing shame, and establishing a precedent for holistic care (Berenblum Tobi et al., 2024; Hinnant et al., 2025; Kok et al., 2023; Mikocka-Walus et al., 2021). A qualitative study conducted by Zhou et al. (2024) highlighted the importance of healthcare professionals providing information about mental health and the psychosocial impact of IBD to patients following diagnosis and ensuring consistent follow up guidance (Zhou et al., 2024). Early and proactive discussions of psychological symptoms were recognised as a strategy that could be beneficial for reducing levels of perceived stigma and facilitating improved engagement in help-seeking (Adeyemi et al., 2025; Hinnant et al., 2025; Khan et al., 2016; Kok et al., 2023; Screti et al., 2024). These discussions could possibly be supported through the use of a practical biopsychosocial resource such as the "IBD Disk" (Ghosh et al., 2017). The preferred modality for receiving information relating to the mental health impact of IBD was in person conversations, subsequently

followed up with written resources, in order to support patients to ask questions about sensitive topics and refer back to guidance in between medical appointments (Hinnant et al., 2025; Kok et al., 2023). This is reflective of previous recommendations for IBD healthcare professionals in relation to how to communicate with their patients regarding mental health (Hinnant et al., 2025; Kok et al., 2023), alongside preferences indicated by other IBD patients (Berenblum Tobi et al., 2024; Hawkins & Bull, 2024; Karadag et al., 2022; Mikocka-Walus et al., 2021). Improving access to information and support for their mental health may have a positive impact on their management of their psychological distress, which consequently may influence their quality of life and physical symptoms through increased self-management and treatment adherence (Fairbrass et al., 2022; Hu et al., 2021; Keefer, 2021b; Mikocka-Walus & Andrews, 2018). Participants emphasised the importance of individualised and actionable information which reflects their fluctuating support needs, including time sensitive information when they were actively unwell, and information that supports self-maintenance of wellbeing when they are in remission (Allemang et al., 2025; Hawkins & Bull, 2024; Kok et al., 2023; Mercuri et al., 2025; Vegni et al., 2019). Providing such information early in the IBD journey may contribute to enhancing patients' sense of agency and self-efficacy in managing psychological symptoms and communicating their needs (Cho et al., 2018; Fourie et al., 2018; Hinnant et al., 2025; Kok et al., 2023; Zhou et al., 2024). Improved access to reliable, clinician-endorsed information may also potentially reduce uncertainty and reliance on external sources, and may influence anxiety related to information credibility and applicability (Groshek et al., 2017). These findings highlight that time-sensitive, individualised and actionable

communication is a central consideration to supporting psychological adjustment, engagement in care, and effective self-management in IBD patients.

As shared experience is reportedly highly valued by this cohort, the introduction of peer-based support services may potentially reduce perceived isolation and improve access to information that is perceived as reliable and relevant (Karadag et al., 2022; Norton et al., 2012; Reich et al., 2019). As there is a reported tendency for this cohort to actively seek resources when they are unwell and avoid reminders of their illness when they are in remission, pre-emptive information and education may support the consistent management of their symptoms and reduce anxiety around searching for answers (Brooks et al., 2015; Byron et al., 2023; Kok et al., 2023; Vegni et al., 2019). The perception that searching for information and guidance can be influenced by disease state and anxiety (Catalán-Serra et al., 2015; Cima et al., 2007; Fortinsky et al., 2012; McMullan et al., 2019) was also reflected in the previous literature, alongside the concept that accessing resources that are not reliable and applicable can be associated with increases in uncertainty and perpetuate difficulties (Selinger et al., 2017).

The reports presented by this cohort is that they are open to receiving guidance and information, and have a willingness to have discussions around the psychological impact of IBD with their healthcare providers in order to access support, however they perceive they that opportunities for this have been limited (Berenblum Tobi et al., 2024; Fourie et al., 2018; Mikocka-Walus et al., 2021). The reported needs of patients for access to actionable and evidence-based information, whether that is provided by healthcare professionals or additional resources was demonstrated (Catalán-Serra et al., 2015). However as these resources are not consistently perceived as accessible (Mikocka-Walus et al., 2016), patients may

continue to search for information and support, which may increase their exposure to unsuitable information. This may contribute to psychological distress in the context of IBD and impact on their ability to manage this distress (Catalán-Serra et al., 2015; Kahlor, 2010; McMullan et al., 2019). This indicates that there may be a misalignment between patient readiness and the current information landscape. In the absence of accessible and actionable information, patients may engage in a cycle of ongoing information seeking, uncertainty and distress, which may further impact their ability to engage with support and implement effective self-management strategies.

How Understandable, Actionable and Reliable are Patient Education Materials Relating to IBD and Mental Health?

The overall landscape of information that can be accessed by patients and the general public around the relationship between IBD and mental health is one of varying utility and quality, which is a finding that aligns with the previous literature (Bernard et al., 2007; Fortinsky et al., 2012; Langille et al., 2010; Radadiya et al., 2020; Tangri & Chande, 2011; van der Marel et al., 2009). Even though most materials appear to be presented in a clear and understandable format, this does not translate into equivalent levels of quality or practical utility, representing a disconnect between understandability and actionability (Langille et al., 2010; Promislow et al., 2010). This distinction is consistent with Nutbeam's model of health literacy, as without actionable guidance, even clearly presented information may have limited impact on patients' ability to implement self-management strategies, particularly in relation to managing psychological distress in the context of IBD (Al Khoury et al., 2022; Baker et al., 2010; Fisher et al., 2003; Ni et al., 2024; Nutbeam & Lloyd, 2021). As the overall quality of the information contained

within the materials was moderate, there is a risk that patients relying on information from these sources may not be accessing the most up-to-date, accurate or evidence-based information, which may subsequently impact on the efficacy and relevance of any presented advice (Adeyemi et al., 2025; Groshek et al., 2017; Hinnant et al., 2025). Audiovisual materials presented information in a more understandable and actionable format than traditional printable materials, which suggests that this format may facilitate functional health literacy by bridging the gap between understanding information and applying it in practice (Jackson et al., 2016; Keefer & Stiles-Shields, 2015; Keller et al., 2014). However, previous studies assessing the utility of audiovisual sources for IBD patient information concluded that the quality of the information contained in these sources may be poor (Mukewar et al., 2013; Radadiya et al., 2020), highlighting the importance of health professional oversight to ensure the accuracy of the content that is presented (de Jong et al., 2017; Goren et al., 2022; Keller et al., 2014; Ni et al., 2024). This highlights a limitation in current patient-facing resources, indicating that clarity alone is insufficient and without corresponding improvements in quality and actionability, information may fail to support meaningful behavioural change, thereby limiting its potential positive impact on self-management and psychological wellbeing

As there were substantially more printable materials than audiovisual materials (more than double), this appears to be an underutilised resource by certain information and support agencies. There is likely a greater prevalence of printable materials due to their ease of production and the longstanding reliance of health promotion and biomedical models on information-heavy written resources (Kimiecik, 2011; Maskell et al., 2018). However, the most readily available format is not necessarily the most effective, as when experiencing distress or uncertainty,

patients may experience difficulties with engagement with lengthy written materials, whereas more accessible formats such as audiovisual materials may help to facilitate understanding and practical guidance (Galmarini et al., 2024; Loy et al., 2021; Mercuri et al., 2025; Morgado et al., 2024; Nutbeam & Lloyd, 2021; Tang et al., 2025). The source of information materials demonstrated that certain agencies provided more useful guidance than others, indicating that this is something that should be considered when signposting patients to resources. Materials provided by specialist support agencies and those that were reviewed by medical professionals were the most consistent categories in relation to the overall understandability, actionability and quality of the information that they presented (Groshek et al., 2017; Keller et al., 2014; Mercuri et al., 2025; Reich et al., 2019). This indicates that materials provided by those who have an in-depth knowledge of IBD and the underlying bidirectional relationship with mental health could be of greater educational and practical value to patients (Jones et al., 2019; Ni et al., 2024). These findings suggest that both the format and source of information are key determinants of its practical value, with actionable, expert-informed resources more likely to support meaningful understanding, engagement and effective patient self-management.

The trend of materials that presented their information with more clarity being more likely to be of practical utility and higher quality suggests that how information is presented may influence the perception of how useful or reliable the information may be. However, there were large variations in the scores for these both within and between source categories, indicating that evaluation of individual materials is vital prior to recommending overarching sources to patients. Previous studies have highlighted the variability in the quality of information sources

available to patients with IBD, which aligned with the information available to these patients regarding the psychobiological risk factors associated with IBD (Bernard et al., 2007; Fortinsky et al., 2012; Langille et al., 2010; Promislow et al., 2010; van der Marel et al., 2009). Hospital issued materials performed the most poorly across all categories, which suggests that sources that would generally be perceived as reputable may not always provide useful and high quality information. There is a tension between the authority and accessibility of health information, whereby improving accuracy alone is insufficient if not presented in a way that enables patients to access, understand and apply it (Nutbeam & Lloyd, 2021). The overall provision of information relating to the relationship between IBD and mental health appears to be characterised by uncertainty and variability, and no single optimal source was identified for the recommendation of any particular resource which may adequately meet their information needs.

Integration of Findings from Study 1 and 2

The findings from this study indicate that individuals with lived experience of IBD and cooccurring mental health difficulties report a clear need for accessible, relevant and applicable information that does not contribute to their existing levels of anxiety, and this is consistent with previous literature examining the information needs of IBD populations (Catalán-Serra et al., 2015; Fortinsky et al., 2012). These experiential accounts are mirrored in the objective evaluation of available patient education materials in study two, which similarly identified limitations in actionability and variability in the quality of psychosocial content. In the absence of information that addresses these three domains, this may contribute to increased uncertainty, reduced self-efficacy and heightened psychological distress, consistent with previously reported associations between unmet informational needs and poorer health outcomes (McMullan et al., 2019; Selinger et al., 2017). This suggests that the current state of information provision does not adequately meet their needs and may contribute to poorer physical and psychological wellbeing (Keefer et al., 2018; Mercuri et al., 2025). This also highlights the importance of developing information resources that can adequately explain the link between IBD and mental health, while also providing effective and actionable strategies to support self-management, which is consistent with a biopsychosocial model approach to care (Dent et al., 2022; Lee et al., 2018; Wade & Halligan, 2017). This indicates that effective information provision in IBD must extend beyond the delivery of clinical knowledge to include actionable self-management guidance and emotionally validating content, in order to support both psychological wellbeing and adaptive disease management.

These findings are consistent with theoretical models of information acquisition and health behaviour, including the Planned Risk Information Seeking

Model (PRISM) (Kahlor, 2010). PRISM aligns itself well to the methodological approach and findings of this study, as it seeks to explain health information seeking behaviours through a number of psychological, social and emotional factors (Kahlor, 2010). Perceived risk and emotional responses were reflected in the young people's anxiety during disease flares and uncertainty regarding symptom progression, which appeared to drive and sustain information seeking behaviour (Catalán-Serra et al., 2015; Cima et al., 2007; Fortinsky et al., 2012; McMullan et al., 2019; Selinger et al., 2017). Knowledge gaps were evident in the participants' reported limited formal understanding of the relationship between IBD and mental health, particularly given the perceived lack of accessible psychoeducational content (Mikocka-Walus et al., 2021). Social influences were reflected in the impact of advice from peers, family members and online communities, which may have influenced both the direction and content of information seeking (Dattilo et al., 2022; Gamwell et al., 2018, 2020; Roberts et al., 2021). Participants' beliefs about the usefulness of searching were potentially undermined by exposure to inconsistent or low-quality information, contributing to reduced trust and hesitancy around available resources (Ni et al., 2024). Rather than representing a linear process, these findings suggest a more dynamic pattern of engagement, whereby negative information experiences may lead not only to continued searching, but also to information avoidance or disengagement (Gelech et al., 2021; Groshek et al., 2017; Lesnovska et al., 2014; Ni et al., 2024; Zhang et al., 2026). Consequently, when the information accessed does not provide clear and practical guidance, or lacks credibility, it may disrupt adaptive information seeking processes, contributing to excessive searching or disengagement, both of which may negatively impact self-efficacy and symptom management.

The Information-Motivation-Behavioural-Skills (IMB) model (Fisher et al., 2003) further supports these findings by emphasising that access to information alone is insufficient to facilitate behavioural change, which is distinct to the PRISM model which explains the drivers of information-seeking behaviour (Fisher et al., 2003; Kahlor, 2010). The model highlights the importance of personal and social motivation alongside reliable and understandable information, and the development of behavioural skills through clear guidance and confidence in their ability to act (Fisher et al., 2003). The variability in the quality and actionability of available IBD and mental health resources in this study suggests that these conditions may not be met consistently, impacting the extent to which individuals are able to translate knowledge into effective self-management behaviours (Kelly et al., 2016; Langille et al., 2010; Mercuri et al., 2025; Nutbeam & Lloyd, 2021; van der Marel et al., 2009). Additionally, limited integration of motivational factors, such as normalisation of distress, validation of emotional experiences, and encouragement of help-seeking, may further reduce the likelihood that patients engage with or act upon available information, particularly when patients already experience uncertainty or reduced confidence in managing their psychological wellbeing (Berenblum Tobi et al., 2024; Hawkins & Bull, 2024; Kok et al., 2023; Screti et al., 2024; Steinberg, 2020). This suggests that the limitations may not solely lie in access to information, but in deficits in translating information into actionable behavioural guidance and the limited reinforcement of patients' self-efficacy (Fisher et al., 2003; Ni et al., 2024; Plevinsky et al., 2016; Screti et al., 2024). This aligns with the participants' reports of feeling under resourced in managing the psychological aspects of IBD, despite having an experiential understanding of their condition, alongside the observed gap between understandability and actionability in available materials. Health literacy

further supports this interpretation by emphasising that effective self-management requires more than the ability to access and understand information, but also the skills to evaluate credibility of the information and facilitate the application of knowledge (Mercuri et al., 2025; Nutbeam & Lloyd, 2021). Consequently, when individuals with IBD are exposed to information that is understandable but lacks actionable guidance or motivational support, this may influence patients' ability to evaluate and use this information for effective self-management, which may contribute to increased uncertainty, reduced confidence and poorer health-related decision-making (Mercuri et al., 2025; Nutbeam & Lloyd, 2021).

In the absence of objective indicators of evidence-based and actionable content, some patients may subsequently rely on trust heuristics to make unconscious judgements on the reliability of sources, based on authority, reputation and appearance (Cummings, 2014; Diviani et al., 2015; Petersen et al., 2022). Where materials are easy to understand but lack clear guidance or transparent indicators of evidence base, patients may substitute heuristic judgements of trustworthiness for more critical evaluation of content (Cummings, 2014; Diviani et al., 2015; Petersen et al., 2022). This is particularly significant given that materials produced by agencies with highly perceived levels of authority and reputation (e.g., hospitals), may not be sources of clear, practical and high quality guidance, suggesting a potential misalignment between perceived and actual utility, which may further contribute to uncertainty and reduced confidence in information seeking (Cummings, 2014). The Information Response Model (Wang et al., 2023) provides a useful framework for understanding this process, as it describes that there are multiple pathways from information to action. Heuristic cues may shape cognitive appraisals of trustworthiness, affective responses and perceived utility, which in turn may

influence how information acquisition translates into health related behaviours (Wang et al., 2023). The findings of this study indicate that the perceived reliability and applicability of information are key indicators of its value for patients (Jones et al., 2019; Ni et al., 2024). However, when these perceptions are driven by heuristic cues this may contribute to misplaced trust. Consequently, patients may engage with information that appears credible but offers limited practical guidance or is not evidence-based, potentially reinforcing uncertainty, undermining self-efficacy, and contributing to less effective self-management behaviours. These models suggest a sequenced process whereby PRISM explains the drivers of information seeking, the IMB model identifies why this information often fails to translate into effective self-management, and the Information Response Model highlights that in this gap, patients may rely on heuristic judgements, with important implications for how health information is designed and communicated.

These findings emphasise the importance of access to reliable, accurate, clear and actionable information, to support effective information seeking and facilitate health-related behavioural change in relation to self-management (Catalán-Serra et al., 2015; Mercuri et al., 2025; Nutbeam & Lloyd, 2021). These findings highlight a systems-level gap in the design and delivery of patient-facing information, whereby variability in quality and limited actionability indicate that current information provision is not consistently structured to support health literacy or effective self-management. This suggests a need for more integrated and quality assured approaches to information provision within healthcare systems, in which clinicians, healthcare organisations, and digital platforms work collaboratively to ensure that patient education materials are not only evidence-based, but also accessible, actionable and responsive to real-world information seeking behaviours. Without

such system-level integration, patients may continue to navigate fragmented and inconsistent information landscapes, with potential consequences for engagement, self-efficacy and psychological wellbeing.

Limitations

There were several key limitations associated with these studies. No clinical outcome data in relation to motivation for behaviour change following exposure to the information contained within the materials was collected as this was outside the scope of the current study. However, this may be an important consideration for future research in order to evaluate the efficacy of these materials for outcomes related to self-management. This limits the ability to determine whether higher quality or more actionable materials predict meaningful changes in self-management behaviours, reducing the practical and clinical applicability of the findings. As assessment of the accuracy of the information contained within the materials was also outside of the scope of the study, an effort was made to control for the potential impact of this on quality ratings by focusing on reputable sources, and exclude sources which were based on personal experiences. However, without evaluating accuracy, it is unclear whether highly rated materials are factually correct, which is a consideration for their safety and appropriateness with regard to patient use. Additionally, the exclusion of personal experience-based sources omitted a proportion of widely used and valued sources of peer support and shared understanding, and may not reflect actual patient information-seeking behaviours, which may often include informal sources of information.

Although the PEMAT and DISCERN are effective objective measures of understandability, actionability, reliability and quality, they cannot capture the applicability, relevance, accuracy and emotional resonance of the information for patients with IBD. This limits the ecological validity of the findings, as materials rated highly on objective criteria may subsequently fail to meet patients' needs in clinical practice. Results were also reliant on researcher rating and evaluation, and although methodological strategies were put in place in order to control for bias, this is something that may have had an impact on the objectivity of ratings. Despite attempts to control for bias, subjectivity in ratings may influence the findings, potentially affecting reliability and reproducibility. The intended purpose of the materials was also not assessed by this study, as this research focused on sources of information that are available to both patients and the general public when information seeking, meaning that some of the materials that were evaluated may not have been explicitly designed for patient education, but nonetheless are accessible to patients when searching online. As some materials may not have been designed for patient education, this may have skewed evaluations of reliability and actionability and reduced the consistency of comparisons. As the DISCERN was developed in the context of assessing medical patient information, it is possible that it was not able to fully able to capture the nuances associated with information regarding psychological difficulties. This may result in under or over estimation of the quality of materials related to mental health, limiting the sensitivity of the evaluation. An adapted version for assessment of information from a psychobiological model may be more appropriate. Without such adaptation, important aspects of integrated physical-mental health information may be overlooked. For example, one of the sections in the DISCERN is around treatment choices, which may be less applicable

to materials concerned with strategies for managing psychological distress and increasing wellbeing, which are perceived as valuable for this population. This reduces the appropriateness of the tool for this context and may bias scoring against materials focused on coping strategies rather than medical treatments.

The homogeneity of the sample in study one may impact upon the generalisability of the results, as they were all recruited from one hospital in an urban centre in Ireland. This limits generalisability of the findings to the wider young adult IBD population, particularly those in different healthcare systems or rural settings. Recruiting from a number of different services may have supported diversity in experiences in relation to their healthcare providers, and provided comparison between different urban or rural areas and factors that may be associated with their environment. This study did not specifically explore cultural or socioeconomic factors, which may have an impact on accessibility to healthcare support services and highlight potential barriers to obtaining information from written or online resources. This also omits key determinants of health literacy and information seeking behaviours, reducing the inclusivity and applicability of the findings.

In relation to minor limitations associated with this research, there were small and unequal numbers of participants across the three focus groups, which occurred due to recruitment delays, the time limited nature of the recruitment process, and participant attrition. This may have limited the depth and balance of the discussion within the groups and reduce the applicability of insights to a wider IBD population. A larger sample size in each focus group may have facilitated additional perspectives and a more nuanced discussion between the participants, in order to capture a wider range of experiences. In relation to study two, there was a high level of variance in

sample size within source categories, with some only containing two materials, which limited the type of statistical analysis which could be completed on the data. This reduced reliability of the comparisons between categories, and the reliability of findings within categories with small numbers of materials. Additionally, there was a disproportionate number of printable materials in comparison to audiovisual materials, which limited the number of direct comparisons between source categories and formats, as some did not contain any audiovisual materials. This encompassed a large amount of social media materials, which are platforms that are regularly used by patients to seek out information around experiences of their peers with the same condition, and can be perceived as valuable for the purpose of shared understanding. Assessing the accessibility of the materials from a literacy standpoint was also outside the scope of this study, however this is an important consideration for patients who may have specific learning difficulties or who do not have high levels of education.

Implications and Relevance for Clinical Psychology

These recommendations highlight the role that clinical psychology can take with regard to a public health and integrated care approach. Due to their in depth understanding and implementation of the biopsychosocial model, Clinical Psychologists are well positioned to provide input and guidance to other disciplines around effective management of psychological distress in the context of illness. Previous research has indicated that psychologists can actively collaborate with Gastroenterology teams to ensure that routine assessment of psychological difficulties and referral to appropriate supports are integrated into IBD treatment

(Fiorino et al., 2019; Hinnant et al., 2025; Kok et al., 2023). The development of referral pathways and tiered models of care to guide access to psychological support can be led by psychologists in conjunction with healthcare teams (Kok et al., 2023; Regueiro et al., 2017). As scientist-practitioners, psychologists are well placed to evaluate the efficacy and utility of resources and information that can be provided to patients, and can develop evidence-based guidelines for other disciplines in order to support their evaluation and development of resources. As suggested by previous literature, training and support for teams can be provided by psychologists around how to effectively integrate discussions around mental health into clinics, and to empower other clinicians to feel confident in speaking about and screening for these difficulties (Hinnant et al., 2025; Kok et al., 2023). Clear guidelines can also be developed in order to support other clinicians through these conversations, and outline a pathway for seeking additional specialist support for their patient's mental health if required. By developing accessible resources and empowering other providers, psychologists can extend their impact to a larger population of IBD patients who may not access formal therapy but are actively seeking information online. This can be achieved by integrating psychologically informed support directly into the information systems that patients already navigate.

Psychoeducation can be a form of standalone intervention which can reach patients who are not actively engaging in formal therapy. The development of a suite of psychoeducational materials, workshops and possibly online programmes encompassing the bidirectionality of IBD and mental health and strategies to support wellbeing during active and inactive disease can be distributed to patients as a form of universal or low intensity intervention (de Jong et al., 2017; Iizawa et al., 2023; Jackson et al., 2016;Screti et al., 2024).

Psychologist's training provides them with an awareness of developmental transitionary periods and the fluctuating psychosocial needs of individuals throughout the lifespan. Due to this, they are well positioned to develop resources and provide guidance around appropriate recommendations in accordance with a patient's life stage. Psychologists also possess a theoretical and practical understanding of the factors which influence information seeking and the development of health literacy skills, and they have an awareness of the facilitators and barriers to health-related behaviour change. Psychology can also support other disciplines to have an awareness of health literacy levels in their patients, and adapt their communication and recommendations in accordance with this (Hinnant et al., 2025; Kok et al., 2023; Mercuri et al., 2025; Nutbeam & Lloyd, 2021). The facilitation of group-based interventions or supervision of peer-led programmes can be implemented by psychology departments, due to the perceived value of peer-based and experiential supports to IBD patients (Norouzkhani et al., 2023; Norton et al., 2012). Psychologist's ability to identify and advocate for the needs of patients can support healthcare systems to provide more patient-centred and efficacious holistic care (Allemang et al., 2024, 2025; Hinnant et al., 2025; Kok et al., 2023; O'Leary et al., 2020). Taking into account the bidirectional nature of IBD and psychological symptoms, psychological input for patients around reducing distress and increasing effective coping may have a positive impact on physical symptoms (Fairbrass et al., 2022; Gracie et al., 2018; Mikocka-Walus & Andrews, 2018). As psychologists have an in depth understanding of mechanisms for change and barriers to engagement through their formulation skills, they can provide guidance to teams around the most effective approach to supporting patients' self-management of their physical and mental health (Fiorino et al., 2019; Hinnant et al., 2025; Kok et al.,

2023). This positions clinical psychology to play a dual, preventative role, by equipping other healthcare professionals with the skills and resources to confidently guide their patients' information-seeking around IBD and mental health, and by proactively shaping a more trustworthy information system to promote patient resilience and wellbeing.

Practical Implications

Patient Education, Information Provision and Resource Quality

With regard to practical implications of this research for clinicians and agencies external to the discipline of clinical psychology, there are a number of strategies that may support the information needs of IBD patients (Hinnant et al., 2025; Kok et al., 2023). Employing experts by experience in the development and implementation of guidelines relating to the management of psychological distress in the context of IBD may be helpful, due to their lived experiences and shared understanding of these difficulties. Using experts by experience to assess the relevance, utility and accessibility of resources and information for patients may also serve to increase the value of providing these to patients. Healthcare teams could endeavour to prescribe resources that have been developed by specialist support agencies or in conjunction with medical professionals, whilst also evaluating individual patient materials from other sources prior to recommending them to patients. Healthcare providers should also provide guidance to patients around seeking information online, and the limitations of online sources with regard to the quality and reliability of what is available. The creation of a database or suite of accurate and credible resources could be created in order to signpost patients to,

should services have limited ability to develop their own materials (Hinnant et al., 2025; Kok et al., 2023). The evaluation of novel, pre-existing and external materials should be completed using tools such as PEMAT and DISCERN in order to limit the need for patients to search through an online landscape of resources of varying reliability (Charnock et al., 1999; Shoemaker et al., 2014). Clinicians should endeavour to develop resources that have a strong focus on providing actionable steps and practical guidance for patients in order to support the development of self-management strategies between clinic appointments (Fisher et al., 2003; Mercuri et al., 2025; Nutbeam & Lloyd, 2021). It is also recommended that guidance be given to patients around prioritising online materials that provide clear, concrete steps for managing their emotional and physical wellbeing, and that they look to the source of the material as a rudimentary indicator for reliability (Kahlor, 2010; Wang et al., 2023).

Holistic, Integrated and Psychologically Informed Care

A holistic approach to care is recommended, which considers the biological, psychological and social factors which may be impacting on a patient's wellbeing and level of functioning (Hawkins & Bull, 2024). Providing information around the psychobiological risks of developing mental health difficulties and the acknowledgement of psychosocial stressors (Berenblum Tobi et al., 2024; Hinnant et al., 2025; Kok et al., 2023; Mikocka-Walus et al., 2021) could be introduced to patients early in their treatment and followed up on throughout their subsequent consultations. This may support normalisation around experiencing an impact on their emotional wellbeing during different stages of their disease activity (Berenblum Tobi et al., 2024; Cho et al., 2018; Vegni et al., 2019; Zhou et al., 2024). Providing this information from the outset may support patients to feel more comfortable in

disclosing psychological difficulties, and gain a clearer understanding of the functional impact of IBD, as it has been framed in the context of their illness and as a consideration for their treatment (Berenblum Tobi et al., 2024; Kok et al., 2023; Mikocka-Walus et al., 2021).

Screening, Referral Pathways and Structured Support Systems

The integration of routine screening for depression, anxiety and impacted quality of life could be considered by healthcare professionals in order to support early recognition of psychological distress and facilitate referral or signposting to relevant supports (Kok et al., 2023). The development of clear referral pathways in conjunction with this screening would also support healthcare providers to make clinical decisions regarding what level of psychological support is required on an individual basis (Hinnant et al., 2025). Guidelines for a tiered intensity model of supports could be developed in order to determine access to psychological supports, beginning with universal initiatives such as signposting to information, and detailing low (psychoeducation), medium (group-based) and high intensity (individual therapy) interventions based on needs (Hinnant et al., 2025; Kok et al., 2023; Regueiro et al., 2017).

Tailoring Information and Supporting Health Literacy

The content of information resources provided to patients should take into account their developmental life stage (e.g., young adults) and the psychosocial impact of this, in order to increase applicability to their emotional and physical needs (Allemang et al., 2025; Arnett, 2000, 2023; Nicholas et al., 2007). A consideration should also be given to cultural differences, socioeconomic status and general literacy skills, as these may impact upon accessibility to information and the

development of health literacy skills (Mercuri et al., 2025; Nutbeam & Lloyd, 2021). The acknowledgement of fluctuating support needs relating to disease activity and levels of anxiety in this population is important when seeking to understand barriers and facilitators to help seeking behaviours and motivation for health related behaviour change (Byron et al., 2020, 2023; Fisher et al., 2003; Mercuri et al., 2025; Nutbeam & Lloyd, 2021). The provision of pre-emptive actionable information to support consistent management of psychological and physical difficulties may potentially influence levels of uncertainty and improve self-efficacy during periods of active disease activity (Screti et al., 2024; Zhou et al., 2024).

Future Directions

Future considerations for research should include evaluation of the accessibility of information materials relating to IBD and mental health with regard to levels of literacy. As audiovisual formats have been observed to be more understandable and actionable, and this is the predominant format on social media, further investigation of materials in this format should be conducted to determine their efficacy and suitability for patients whose level of literacy may serve as a barrier to accessing information from traditional printable materials. The impact of information on promoting health related behaviour change and perceived ability to engage in self-management should be evaluated in respect of clinical outcomes, in order to provide a clearer understanding of the value of providing mental health resources to IBD patients. Evaluation tools such as PEMAT and DISCERN should be adapted for use with patient education materials that are from a psychological perspective. Future studies which also assess the accuracy of the information

contained in education materials alongside their purpose will serve to provide stronger recommendations around the utility of these resources. An evaluation of the reliability, understandability and actionability of social media posts by healthcare professionals around IBD and mental health, would provide evidence around whether this could be a valuable resource to develop for patients, due to their tendency to search for information on these platforms. An increase in the number of participants and heterogeneity of the sample relating to socioeconomic factors, cultural differences, healthcare providers and area of residence should be considered for future qualitive explorations of this topic, in order to increase validity of the recommendations. Future research which focuses on healthcare provider perspectives on delivering information around IBD and mental health to patients may be beneficial with regard to the identification of potential barriers for this in clinical practice. An evaluation of peer-based support groups may be valuable to determine their effect on emotional wellbeing. Further research on this topic with different age groups may also be helpful to identify changes in support needs across the life cycle of IBD patients.

Conclusion

This research conducted a novel exploration of information provision relating to IBD and mental health from a dual approach, exploring perceptions of young people with IBD and depression and/or anxiety's perspectives of this relationship and their information experiences and needs, and evaluating the understandability, actionability and quality of existing information materials on this topic. Previous studies have sought to demonstrate the general information needs of IBD patients and evaluate the landscape of patient education materials relating to the condition, and the current research findings align with these, alongside several theoretical models of information acquisition. It was highlighted by these studies that IBD patients have lived experience of the bidirectional IBD and mental health relationship, and that their distress can be associated with a lack of information and support for their emotional wellbeing, alongside psychosocial stressors. It was also determined that most materials provide information in a clear and understandable format, and that audiovisual materials show strengths in providing actionable information. On average, the materials were of moderate quality and information sourced from Specialist Support Agencies were most consistent in their ratings. However, the overall landscape of information materials from different sources that are available to patients regarding IBD and mental health showed high variability in relation to quality and practical utility. Implications for clinical psychology and other disciplines highlighted the importance of the integration of mental health care into routine IBD treatment, alongside the development of applicable resources for this population. Future research should seek to further assess the accuracy and accessibility of information, with particular focus on audiovisual materials, and seek to include wider IBD populations in their studies.

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Appendix A: Clinical Psychology Research Ethics Committee (CPREC) Ethical Approval for Study One

Authorisation – TO BE COMPETED BY THE REVIEWERS

Date when this research was considered by the Ethics Committee of the School of Applied Psychology

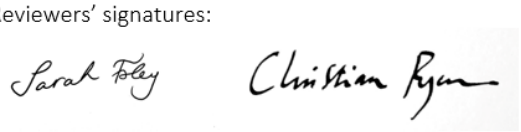
Result (please check one):

Approved	X
Approved with minor comments (resubmission is not required)	
Approved pending clarification (a list of sections and required clarifications must be made below or appended)	
Approved pending approval from external body (the body or bodies from which approval is pending must be specified)	
Not approved	
Referred to Social Research Ethics Committee (SREC)	
Other	

Feedback for the applicant:

There is sufficient information here to outline and justify the amendments, which do not change the ethical rigour of the application.

Reviewers' signatures:



Date: 12-11-24

Appendix B: [redacted] Hospital Research Ethics Committee Ethical Approval for Study One

[redacted]

Appendix C: Clinical Psychology Research Ethics Committee (CPREC) Ethical Approval for Study Two

Authorisation – TO BE COMPETED BY THE REVIEWERS

Date when this research was considered by the Ethics Committee of the School of Applied Psychology

Result (please check one):

Approved	
Approved with minor comments (resubmission is not required)	X
Approved pending clarification (a list of sections and required clarifications must be made below or appended)	
Approved pending approval from external body (the body or bodies from which approval is pending must be specified)	
Not approved	
Referred to Social Research Ethics Committee (SREC)	
Other	

Appendix D: Focus Group Schedule for Study One

Section	Content	Purpose
Welcome	Facilitator introductions Review of informed consent General housekeeping and confidentiality Introduction of topic for discussion	To provide participants with context for what the focus group will involve and to introduce the topic.
Discussion		
Opening Question	What do you know about the link between IBD and mental health?	To gain insight into participant's preexisting knowledge on the topic.
Key Question	Where did you previously receive information about IBD and mental health?	To gain insight into what sources of information have previously been made available to the participants.
Key Question	Did you ever use internet resources or social media to obtain information regarding IBD and mental health, if so what kind of information did you find?	To gain insight into what sources of information participants have sought out of their own accord.
Key Question	What was your experience of using the internet or social media to obtain information? Was it helpful?	To gain insight into participant's perception of what is helpful/unhelpful with regard to information provision.
Key Question	What was your motivation to obtain information from the internet or social media resources? (i.e.,	To gain insight as to whether the internet is perceived as participant's primary source of information.

		perceived lack of information from health provider / own interest?)	
	Key Question	Did any health professional ever speak to you about the link between IBD and mental health?	To gain insight into participant's previous experiences with receiving information from a health professional.
	Key Question	What are important things for health professionals to consider when providing information about the link between IBD and mental health to patients?	To gain insight into what participant's perceptions of the optimal way to receive this information are.
Closing		Closing out discussion Thanking participants for contributions Reminder of confidentiality Signposting to external support services	To close out the discussion for participants in a contained way and provide them with information regarding external supports should they have any concerns.

Appendix E: Publication Guidelines for the *"Journal of Crohn's and Colitis"*

The publication guidelines for the *"Journal of Crohn's and Colitis"* are contained within the table below, these guidelines have been cited from the instructions on the journal's webpage to ensure accuracy. The following permanent link is to this version of the journal instructions as of April 2026: https://web.archive.org/web/20260427111438/https://academic.oup.com/ecco-jcc/pages/manuscript_preparation

Journal of Crohn's and Colitis	
Article Type	Original Article
Word Limit	7,500 (excluding tables, figures and references)
Tables/Figures (number)	The number of figures and tables should be in balance with the length of the manuscript
References (number)	Cited in text by Arabic numerals in superscript. Reference list numbered in order of appearance and double-spaced at the end of the text. Based on American Medical Association (AMA) Manual of Style, (11th Edition).
Abstract (format, length)	250 words maximum. Organised using the following headings: Background and Aims, Methods, Results, and Conclusions.
Main Body Headings	Title Page, Abstract, Introduction, Materials and Methods (including statistical considerations and ethical statement), Results, Discussion,

	Acknowledgements, References, Figure Legends, Tables, Figures.
Reporting Guidance	Written in clear, concise English. Double-spaced (including references, tables, and figure legends). Number pages in upper right-hand corner, beginning in the title page. Number lines continuously, beginning in the title page. Start each section on a separate page.
Additional Guidance	Select between 1 – 3 keywords from the 12 listed below: 1. Basic science, experimental models and pathophysiology 2. Biomarkers 3. Clinical trials 4. Endoscopy 5. Epidemiology 6. Genetics and molecular epidemiology 7. Imaging 8. Microbiology 9. Paediatrics 10. Pathology 11. Quality of Life, socio-economical and psychological end points 12. Surgery

Appendix F: Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT)

Understandability

Item #	Item	Response Options	Rating
	Topic: Content		
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	
	Topic: Word Choice & Style		
3	The material uses common, everyday language.	Disagree=0, Agree=1	
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	
5	The material uses the active voice.	Disagree=0, Agree=1	
	Topic: Organization		
8	The material breaks or “chunks” information into short sections.	Disagree=0, Agree=1, Very short material1=N/A	

9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material*=N/A
10	The material presents information in a logical sequence.	Disagree=0, Agree=1
11	The material provides a summary.	Disagree=0, Agree=1, Very short material*=N/A
Topic: Layout & Design		
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1, Video=N/A
13	Text on the screen is easy to read.	Disagree=0, Agree=1, No text or all text is narrated=N/A
14	The material allows the user to hear the words clearly (e.g., not too fast, not garbled).	Disagree=0, Agree=1, No narration=N/A
Topic: Use of Visual Aids		
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A

19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1, No tables=N/A	

Actionability

Item #	Item	Response Options	Rating
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, diagrams=N/A	

Appendix G: DISCERN: "A questionnaire for judging the quality of written consumer health information" (Charnock, 1998)

Item #	Question	Rating				
		No		Partially		Yes
Section 1: Is the publication reliable?						
1.	Are the aims clear?	1	2	3	4	5
2.	Does it achieve its aims?	1	2	3	4	5
1.	Is it relevant?	1	2	3	4	5
4.	Is it clear what sources of information were used to compile the publication (other than the author or producer)?	1	2	3	4	5
5.	Is it clear when the information used or reported in the publication was produced?	1	2	3	4	5
6.	Is it balanced and unbiased?	1	2	3	4	5
7.	Does it provide details of additional sources of support and information?	1	2	3	4	5
8.	Does it refer to areas of uncertainty?	1	2	3	4	5

Section 2: How good is the quality of information on treatment choices?

9.	Does it describe how each treatment works?	1	2	3	4	5
10.	Does it describe the benefits of each treatment?	1	2	3	4	5
11.	Does it describe the risks of each treatment?	1	2	3	4	5
12.	Does it describe what would happen if no treatment is used?	1	2	3	4	5
13.	Does it describe how the treatment choices affect overall quality of life?	1	2	3	4	5
14.	Is it clear that there may be more than one possible treatment choice?	1	2	3	4	5
15.	Does it provide support for shared decision-making?	1	2	3	4	5

Section 3: Overall rating of the publication

16.	Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices:	Low Serious or extensive shortcomings	Moderate Potentially important but not	High Minimal shortcomings

serious

shortcomings

Appendix H: Publication Guidelines for *"Inflammatory Bowel Diseases"*

The publication guidelines for *"Inflammatory Bowel Diseases"* are contained within the table below, these guidelines have been cited from the instructions on the journal's webpage to ensure accuracy. The following permanent link is to this version of the journal instructions as of April 2026: https://web.archive.org/web/20260427111226/https://academic.oup.com/ibdjournal/pages/General_Instructions

Inflammatory Bowel Diseases	
Article Type	Original Article
Word Limit	7,000 (excluding tables, figures and references)
Tables/Figures (number)	No more than seven (combined)
References (number)	No more than 40. Double-spaced at the end of the text in order of appearance. American Medical Association Manual of Style (11th Edition).
Abstract (format, length)	250 words maximum. Sectioned into: Background, Methods, Results, and Conclusions. Include three to five key words.
Main Body Headings	Abstract and Key Words, Key Messages, Introduction, Materials and Methods, Results, Discussion, Acknowledgments, Ethical Considerations, References, Tables, Figure Legends

Additional Guidance	Include Key Messages after the abstract. No more than one sentence per point. 100 words maximum. • What is already known? • What is new here? • How can this study help patient care?