Patient-led Analysis of Inflammatory Bowel Disease: Defining an Equitable Approach towards Patient-centric IBD care

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Short title: A Patient-led Narrative of Inflammatory Bowel Disease and Wellbeing

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Keywords: IBD, PROs, wellbeing, PPIE, patient involvement

Introduction

This paper explores the role of the ‘patient’ in delivering research related to wellbeing living with Inflammatory Bowel Disease (IBD) beyond clinical results. The following paper has been written from the perspective of people with lived experience of IBD, with edits from clinical researchers.

The traditional doctor-patient relationship has evolved overtime to become more patient-centric and collaborative in relation to care. Particularly with IBD, there has been a shift to understand experience beyond inflammatory markers (bowel frequency, calprotectin tests, and blood samples). Healthcare professionals, and more specifically IBD clinicians, now want to know about fatigue levels, daily stresses, and how a patient personally feels their IBD is being managed. Alongside this, patients are becoming increasingly knowledgeable about their condition often through information online, networking with other IBD patients or joining support groups, and participating in research opportunities. These patient-centric interactions are increasingly being transferred to clinical research, which seeks to combine a more holistic approach to understanding a topic area.

Public Patient Involvement (PPI) groups are often formed to fully inform this more rounded approach to care and research. PPI groups are where patients, members of the public and researchers or clinicians co-produce solutions and outputs to improve services and allow patients to be more involved in decision making and developments related to their care. PPI groups often exist in charitable organisations, such as Crohn’s and Colitis UK (CCUK) and the James-Lind alliance but are now more frequently embedded into research facilities or specific clinical research groups.

PPI groups are routinely asked for their invaluable insights in the design or development stages of clinical research, such as reviewing participation sheets or final research papers, but in analysis and writing up results they often assume a less dominant role. This is primarily due to the technical knowledge that is often required to analyse scientific or specialised information. However, as research continually focuses on and values the patient’s perspective, outputs are no longer restricted to understanding clinical results, such as immune-cell function or biomarkers. Instead, responses from patients, provided in their own words, can be analysed alongside and aid a deeper understanding of clinical results.

To analyse these patient comments, researchers must have a depth of understanding of the key issues faced by their patient group to avoid misinterpretation or researcher bias. Where the researcher does not have direct experience of the topic area, important details may have been removed or diluted in the final output. This is where PPI group members with lived experience can provide invaluable knowledge in the analysis and write-up of the results but are often underutilised. This paper presents the analysis and write-up of one free-text survey question led by members of a PPI group.

This paper will explore a patient-dominant model and approach to research: where patients lead in defining the topic areas, setting the agenda, and communicate information to the target population, firstly, the IBD population and secondly, clinicians and researchers.

The aims of this paper are to:

1. Understand the priorities around research and wellbeing from the perspective of survey respondents and the PPI group.

2. Understand how patients analyse, present and communicate patient reported concerns of wellbeing and experience with IBD.

3. Understand how to make this process more transferrable for future projects (specifically, how to make this appealing to clinical researchers).

Ultimately, this paper seeks to explore the value of the patient voice in understanding and analysing experiences of IBD in relation to Wellbeing.

Methodology

The process for this paper began with the MUSIC IBD study, a clinical study that aimed to look at Mitochondrial DAMPs as mechanistic biomarkers of gut mucosal inflammation in adults and children. This study led to the development of a PPI group, whose role was primarily to review materials for this clinical work to ensure they were accessible to an IBD audience. The role of the PPI group evolved beyond this and began to include discussions with researchers and clinicians on wellbeing and the wide variation of experiences felt by IBD patients, two aspects often difficult to capture in clinical research. From these discussions, it was clear that there were differences in patient's accounts of their own wellbeing in comparison to what their clinical results would report.

The MUSIC IBD clinical team ran a Wellbeing Survey to compare patient-reported outcomes (PROs) of people with IBD to those without this condition. The survey captured information from over 1,375 IBD patients from two time points (January - March and June - September 2023). This study included 40 closed questions, where respondents were asked about bowel habits, fatigue, mental health and general wellbeing. Feedback was incorporated from the PPI group and led to additional questions, for instance about stoma bags and menstruation. At the end of the Wellbeing survey, respondents were asked whether they had 'any further comments that you feel are important and have not been addressed?'. This resulted in 415 free-text comments from respondents with IBD.

Most respondents to the survey answered this question by sharing insights into their experiences of living with IBD to express what was important to them, often providing more detailed context to the closed questions in the survey. As the PPI group, clinicians and researchers discussed a few of the free-text responses, it became evident that the invaluable insight of PPI members with lived experience of IBD was strengthening the interpretation of these comments. **These PPI members were then given the opportunity to lead on the analysis and write-up of the free text responses.**

As well as their experience of IBD, the PPI representatives brought a range of skills from their academic and creative backgrounds. MH has skills in social research and qualitative analysis, so agreed to lead the analysis of the free text comments and the development of this patient-led paper. DD was an undergraduate student studying pharmacology and undertaking an inflammation-based honours project. EP is a musician and a Patient Representative and Crohn's and Colitis UK Research Champion. AT is a PhD student in immunology and inflammation, and a rowing athlete. TK a PhD student in gut health and analytical chemistry as well as a CCUK rep.

The following approach was agreed and carried out by the PPI group:

a) **Analysis:** High-level topic analysis was conducted by MH to draw out main priority topic areas for the survey respondents with IBD using colour coding in Excel. These initial topic areas were then reviewed by other members of the PPI group and used to guide the structure of the paper.

b) **Topic Areas:** An initial meeting was set up for the PPI group to discuss inclusion and exclusion of topic areas. The PPI group agreed that representation of all topics, even those where only a few survey respondents mentioned it’s importance (e.g. age), should be considered to capture the variation of experience with IBD. It was agreed that PPI members would lead on individual topic areas to encourage collective leadership and result in a well-rounded paper informed by multiple perspectives. Each PPI member chose their top 3-5 from the list of topic areas and MH allocated roughly three topics per person to lead on.

c) **Discussion:** It was agreed that the PPI group would discuss each topic area together over regular Teams calls (20 minutes per topic). Originally, it was thought that discussions of topic areas would take place over two or three meetings, however it became apparent that after the first meeting more time would be needed. Seven meetings were held to discuss themes. The discussions would particularly focus on why this topic may have been important for survey respondents and the PPI groups’ similarities and differences in experience to expand on the topic area further. PPI members would explore the free text comments relevant to their topic, select a few that resonated with them or made them reflect differently on their experience, and bring their initial thoughts to the meeting. The lead would then encourage others to share their experiences or thoughts on the topic. The lead would take notes throughout the meeting, which would be used to guide their write up of the topic for the paper.

d) **Writing:** It was agreed that PPI members would write up their own topic for the report. MH shared resources on writing styles but asked the PPI group to explore their topic areas freely to allow the papers narrative to develop naturally. The PPI group worked from a shared google word document. To utilise the wide skill set of the PPI group, PPI members were encouraged to use any additional sources they felt were relevant to develop their topic (e.g., including literature or sources from journals or charities). As the paper developed it became clear that the overall style of writing was academic, reflecting the PPI members who came from a scientific academic background. This presented challenges for PPI members who were less familiar with this style and engaging with scientific journals or jargon. After producing an initial draft, the approach was adjusted and individuals with less familiarity with academic writing took on a more review-oriented role, providing feedback and further input to their sections as they were refined. As the process slowed and fewer contributions were made, MH then reviewed the paper and streamlined the narrative as well as drafting other sections outside of the results. The final version was peer reviewed by the PPI group before being shared and reviewed by the clinical research team.

e) **Reflection**: To understand how this process could be made more transferrable for future projects, the PPI group held a reflection section after writing the first draft. Benefits of the process were discussed, such as the opportunity to lead topic areas, the number and length of meetings to discuss topic areas (although frequency may need to be adapted depending on the groups preferences), the opportunity to learn from other experiences, being able to delve into the complexities of each topic area, and give a voice to the respondents from the survey. Reflections on how to make the process smoother included delegating tasks based on skill sets, creation of a template with resources to guide clear communication, and more focus on the impact of the work earlier on in the process. The group also reflected on being entirely patient led for the discussion and writing process. All members enjoyed that discussions were only attended by the PPI members who had IBD. Some members felt that additional support may have been beneficial during the writing process, however most liked the freedom to initially write without clinical input.

Considerations and Risks

By having multiple contributors involved in the process, the PPI group developed a paper that explores a deeper understanding of certain aspects of IBD and wellbeing as a patient that might not have been possible if interpretation and analysis was conducted by clinical researchers without IBD. However, the 400+ free text comments and the experiences shared by the PPI group highlight that no two experiences of IBD are the same and therefore, the experiences discussed in this paper may not be representative of all people with IBD.

Two potential risks of developing a patient-led paper are that some of the participants may become unwell during the process due to the unpredictable nature of IBD or be unable to attend all discussions due to busy schedules. To mitigate this a number of actions were taken: 1) having MH take notes during every discussion as a back-up copy in case of absences during the writing stage; 2) dividing topics among five PPI members to distribute workload; 3) provide opportunities for PPI members to input their experiences and opinions ‘offline’ via written submissions for missed meetings; and 4) share resources with each other to support wellbeing (as often some topics were sensitive to discuss).

Quotation marks have been used when referring to responses from the survey. For the purposes of anonymity, PPI member’s individual experiences have been labelled as a collective discussion of an issue so that members cannot be specifically identified.

All group members were white women living in the UK and those with other characteristics may have offered a different perspective.

Findings

The following subsections are based on the high-level topic areas produced from the survey responses and further explored by the PPI group. A decision was made early in the process to omit the number of respondents that mentioned each topic area. The complexity and variation in experience of IBD suggests that respondents may have experience of more than one topic, even if they did not mention it in their response to the question. In addition, it was felt that quantifying the experiences distracted from the importance of the topic area, which are all ultimately important areas to consider for further research. Instead, the topics discussed below are ordered by the frequency they were mentioned in the survey results, e.g. the impact of IBD on quality of life was mentioned the most and ageing with IBD was mentioned the least.

Quality of Life

Quality of life (QoL) in IBD patients encompasses physical, emotional, and social wellbeing, which are often affected by the chronic and unpredictable nature of the disease. The QoL of an IBD patient is ultimately determined by how much the disease impacts an individual's life, what is important to them, and how well the disease is managed. The QoL areas detailed here will be further examined throughout this paper however, it is important to explore this theme directly, as respondents spoke about the significant ways in which IBD impacts QoL overall. As one respondent of the survey commented, *"I think it would be important for people to be more aware of how many areas of your life IBD affects".*

Symptom management and the impact this has on daily activities were commonly reported by survey respondents in relation to QoL. Effective symptom management is crucial for minimising pain, complications and reducing risk of future flare ups, and therefore paramount in improving patient's QoL. Physical symptom management may include taking medications, adjustment to daily routines, and dietary and lifestyle modifications. PPI members resonated with one survey response, "*My condition improves if I eat bland food, however that can feel quite limiting and makes life quite boring"* highlighting that symptom management may come at a sacrifice. Due to the wide range of physical symptoms, symptom management can become complicated and require significant planning both for immediate disease management and long-term health outcomes. Respondents commented on feeling as though *"life is ruled by treatment*", having to be "super aware of planning [ahead]", and that "to live a full and happy life on biologicals…takes a lot of planning and is an all day daily task". However, when the right management methods are found the burden of IBD is reduced; "In remission just now and quality of life has improved greatly", and "[due to the right medication, diet and exercise] I don't have to think about my Crohn's because it's not affecting me daily, which really improves my well-being".

The psychological impact of IBD plays a vital role in shaping the QoL for patients. This is predominantly due to the chronicity of disease, the constant threat of flare-ups and the associated isolation, anxiety, distress, and depression. Respondents reported feeling "grief at losing the old me", feeling as though they "can't trust my body [in sexual encounters]", and feeling "so so so alone". Some respondents commented that they feel as though they just must accept their IBD related QoL and just "get on with it". PPI group members agreed that often acceptance is key, but that it is incredibly frustrating as it takes time to come to terms with the person you need to be to live with IBD. The PPI group also spoke about what QoL looks like for them, including the variation of QoL reported by survey respondents, highlighting that it often means something different to different people.

Social considerations impacting the QoL of IBD patients are also significant. The symptoms of IBD can make it more difficult to socialise and partake in different events, and this can lead to withdrawal from interactions and social isolation. Respondents commented on feeling as though they "don't go out at all", "stay in when guts are dodgy", have to cancel plans for fear of being "caught outside, no where near a toilet" and that when "symptoms lessen[-]…[they are able to] go out!". This is compounded by a potential fear of being judged or misunderstood, and feelings of guilt for not being able to take part in events, further diminishing QoL. PPI group members spoke about being labelled as someone who is unreliable, often just due to the unpredictability of the disease, and that this lack of understanding from friends or family impacts social interactions and ultimately can lead to isolation.

Finally, survey respondents reported challenges associated with employer support, particularly around understanding and awareness of IBD. This becomes even more challenging considering the relapsing and remitting nature of the disease and understanding IBD symptoms, from the view of the employer, can be complex. Respondents reported that due to IBD they had to “stop working”, “not feeling able to work as much as you would like to” and feel as though IBD has “restricted [-] career opportunities”. The PPI group spoke about how education poses similar challenges to the employment issues raised by survey respondents. PPI members with experience in education reported difficulties in obtaining extensions for deadlines, having to prove that they are unwell when symptoms are less visible (such as fatigue), and asking for adapted accommodations (such as toilets nearer exam rooms).

Throughout the survey responses, an overarching theme of “surviving, not living” comes through from IBD patients. Overall enjoyment in life and the ability to carry out day-day activities are inhibited by the symptoms and limitations imposed by IBD. While this is specific to an individual, the burden that comes with living with a chronic disease is common to patients.

Cost of and access to care

Cost of and access to care was the second most prominent topic to emerge from the survey with respondents reporting on their experiences interacting with healthcare services and professionals.

Some respondents reported that delayed access to care results in feeling as though they are unable to access care in a timely manner and needed to manage their own IBD. Some respondents from the survey reported that they felt they could no longer access immediate care through appropriate routes and that understaffing in healthcare often resulted in feelings of “neglect[-]” or “stress[-]”. Respondents to the survey commented on times where they haven’t felt listened to by medical professionals, resulting in patients feeling as though they "have to grin and bear it [symptoms]". PPI members resonated with one comment which suggested that patients may delay seeking care as they are "hoping to ride it [a potential flare] out and hope it calms down soon". This may be due to multiple reasons, such as not wanting to burden an already overrun healthcare system or feeling as though the IBD team do not have time or are unable to help.

When accessing care, respondents reported not always understanding the information given to them by healthcare providers or being given insufficient information about the decisions made about their treatment. The PPI group discussed how communication issues are often made worse when transitioning from child to adult services, where the care received in adult services is less intensive, and communication is not as often. The PPI group also discussed how little guidance there is for IBD patients when they are travelling or moving to a new country. Nearly all PPI members felt that they needed extensive knowledge of their medical history to be able to receive care from new healthcare providers who would not have access to their original medical records. This is especially challenging if someone has multiple conditions or must speak to non-specialised healthcare providers about their IBD medication or symptoms. Some PPI members discussed that having background knowledge on IBD through medical science aids a deeper understanding of treatment options or decisions around care but otherwise, the group agreed that information provided online can be overwhelming and is sometimes not massively accessible.

Respondents to the survey also commented on the time and financial cost of navigating access to IBD-related healthcare, where managing multiple medications and interactions with healthcare providers can be challenging. Respondents to the survey touched on how "prescription charges add a burden and worry" and that extra charges are often necessary to accommodate IBD, such as cool bags to carry around medication. The PPI group related to one particular respondent who said, "life at times can feel it's ruled by hospital appointments, regular blood tests, ordering and collecting monthly prescriptions…[etc]". In addition to this, the PPI group discussed the cost and time it takes travel to attend these various appointments and that care in the local community would be a worthwhile consideration.

Respondents to this survey also wished to comment on times where their access to care and treatment has worked for them and expressed gratitude for the services they received. Two responses that particularly stand out are “Having an effective and approachable IBD team has been a lifeline” and “When the doctors put me on the right medication I was able to find the will power to get better and make my life normal again”. The PPI group agreed that public and patient engagement gives a unique insight into IBD beyond the patient perspective and allows them to appreciate the pressures that the NHS are under, as well as gratitude for the work and research that goes on behind the scenes. However, improvements to communication of medical treatments, as well as access to and cost of care should be explored further.

What does 'remission' mean

The concept of being ‘in remission’ varied widely among respondents, with many highlighting the ambiguity and confusion surrounding this term: ‘what [does] it really mean[-] to be ‘in remission’”. The PPI group agreed that the problem with the concept of ‘Remission’ is fundamentally a communication and language problem.

For some respondents, being in remission meant that no active inflammation or symptoms are detected, implying this person has recovered and is well, sometimes called ‘Deep Remission’. For example, one respondent reported being symptom-free for over 13 years, associating remission with a state of full recovery. However, remission, to some respondents, described a state where there may still be some symptoms, although mild and less severe than when they were experiencing an acute flare. This form of remission largely suggests that although they are on their way to recovery, mild symptoms still persist: specific examples include “...finally have a bit of remission I think… if I could just get over feeling the fatigue effects” and “Even though I’m in remission I struggle with fatigue, having a nap most days to alleviate the tiredness.” This understanding of remission suggests a transitional phase, rather than an endpoint where symptoms are not fully resolved.

The most common experience of remission reported by survey respondents challenges the concept of remission as recovery. For many, despite no active inflammation being detected and being declared that they are in ‘clinical remission’, there is still a continuation of symptoms. One respondent encapsulated this, saying “*I am technically in remission, but symptoms, although lesser, persist*” and another reported “in remission according to blood test results. But I have constant aches and open bowels 4/5 a day.” These lingering symptoms create frustration and confusion, as patients find themselves labelled as “well” despite continuing to live with symptoms. One respondent reported having “constant fatigue, aches and pains and mouth ulcers”. Another described their remission as “like it’s just sleeping, grumbling, waiting to wake up and have a flare”.

The PPI group had an experience of all types of remission expressed by the survey respondents. The group discussed that the first definition is usually what most patients understand ‘Remission’ to mean, that they have no active inflammation and, crucially, no symptoms. This is the benchmark that causes the actual experience of remission to become confused and inaccurate. Clinicians may still use the term ‘remission’ even when bowel symptoms or other IBD symptoms, like fatigue and joint pain, persist. This can leave the patient, who still has symptoms, feeling frustrated, hopeless, and potentially let down by their clinician. This mismatch between medical definitions and patient experiences can have broader implications. The clinician may imply or even directly conclude that the remaining symptoms must be caused by another condition altogether, such as IBS or unexplained pain or by stress or lifestyle choices. This can lead the patient to feel as though they are responsible for their continuing symptoms. The PPI group spoke about being unable to know what full remission should feel like and that this ‘deep remission’ or life without IBD symptoms is something that some members haven’t experienced for years. Some PPI members spoke about the ‘diagnosis of remission’ as having implications on support received from social circles. Group members recalled times where they felt they were being perceived as over exaggerating symptoms by family and friends because the doctor said they are in remission, so eventually you end up “just putting up with being in remission” [quote from PPI discussion]. The group agreed that use of the term remission is ‘thrown around’ and should be used with more consideration.

From the survey respondents and PPI group discussions, it was clear there is an interest to explore the differences between what remission means to the person with IBD in comparison to clinical remission. **The PPI group agreed that it would be useful to develop new language to describe these different states of 'wellness', as this is an important factor to consider when assessing patient clinical and self-reported outcomes.** The survey respondents also highlighted that acknowledgement from clinicians is required where a patient is still experiencing symptoms, but they are in remission, and that exploring the reasons for this and providing support is meaningful to the patients.

Mental Health

Many respondents mentioned mental health, particularly stress, anxiety, and depression, in relation to their wellbeing and quality of life with IBD. These were often related to trying to manage the condition outside the home, aftereffects of surgery, and anxiety around the potential or current condition of flaring. As one respondent puts it, "*Often the anxiety associated with IBD can be as troubling as the physical symptoms*".

The unpredictable nature of living with IBD can cause anxiety about being able to do daily activities or be able to work, even in 'remission' symptoms such as fatigue and bowel urgency are common. Respondent examples included, feeling "anxious about going out & doing normal activities", "Need[ing] to plan days around toilet trips", and "the stress and anxiety through driving…'will I make it without stopping' journey'". Ultimately, poor mental health, because of living with IBD, adds unnecessary stress to carrying out normal daily activities. Some PPI members added that this stress and anxiety also has the potential to exacerbate IBD symptoms and for some PPI members, their experience of increased stress and IBD symptoms resulted in a round of steroids or a change in treatment to avoid a prolonged flare. However, the PPI group also felt it was important to note that poor mental health itself may not cause a flare and the onus should not be on the patient to 'relax' or 'manage stress better' as a solution or preventative measure to reduce IBD flares. For some patients, environments that cause stress or poor mental wellbeing cannot be controlled. The PPI group also discussed the side effects of medication to help manage IBD symptoms, such as steroids, can result in mood changes and depression and that where possible some members have even avoided this treatment to reduce the impact on their mental health. It became clear from the respondents and the PPI discussion that the impact of poor mental health and IBD is complex and requires further exploration in research, particularly in cases where the patient cannot control the factors or environments causing additional stress and potentially exacerbating IBD symptoms.

The PPI group related to one response about the anxiety of starting new treatments and wondering whether they will work and what the side effects might be: ""I am now starting over again with new medication. It is the worry that it could take a long time to get back to remission and find one that works for me, this is what puts my life on hold and makes me feel anxious and frustrated". The PPI group discussed the trial-and-error nature of new treatments can result in cycles of getting your hopes up and the crushing disappointment of failed treatments which can often be harder to handle each time. Additionally, the anxiety about visiting hospitals repeatedly and the possible need for invasive treatments, such as endoscopies, and surgery can be huge. PPI members spoke about anxiety around complications of treatments, whether they will be able to tolerate the pain or side effects and have the mental and physical perseverance to take them after already enduring a long period of flaring. They may also be very anxious about changes to their body image and the impact of stoma surgery, both topics discussed in chapters below. However, the PPI group and respondents also shared experiences where clinician's choice in treatment or change in approach after listening to these concerns removed these anxieties and improved general wellbeing in addition to remission.

The PPI group members discussed that most people would find it easy to support others with short-term illnesses, but that it takes a lot of effort to support someone over longer periods of time, especially for unpredictable chronic conditions like IBD. If there is a repeated cycle of failed treatments, some friends and family may struggle to accept that there isn't an easy answer and start to question whether the patient is "making it up, [which] in some ways [-] worse than the physical symptoms and it does lead to negative feelings". The PPI group discussed the mental impact that comes from the difficulty of being able to commit to social events, and that often this can result in a fear of letting people down before the event has even happened. The group agreed that it can be difficult to maintain relationships because you must choose where to spend your energy, which can result in a thinned-out support network as people struggle to understand your experience. Ultimately, this can cause "feel[ing] isolated and alone" and that "no-one understands" unless they have this condition themselves.

The PPI group are aware of some places where appropriate mental health support is accessible and offered as part of IBD treatment, but this is not widespread due to waiting lists and staff shortages. Access to private mental health treatment comes at a cost and may not be an option for some patients. One survey respondent summed this up with, "No emotional or mental health support is offered or taken seriously from my experience", and the PPI group agreed that this is an essential area where change is required.

Extraintestinal Manifestations of IBD symptoms

Respondents mentioned 'non-typical' IBD symptoms that they felt were important to highlight as impacting their experiences and wellbeing with IBD, such as constipation, vomiting, pain and bloating. This topic is based on respondents mentioning symptoms that they believe are explicitly linked to their IBD. The respondents have mentioned these symptoms because they have not been asked about it during the survey, which might indicate that it was not considered a typical IBD symptom when the survey was created.

Non-typical IBD symptoms, with respect to this study, refers to symptoms other than loose stools and blood in stools. As IBD is a systemic disease, extraintestinal manifestations (EIMs) of the disease can occur. Non-typical IBD symptoms can include non-typical IBD gut symptoms like pain and constipation as well as EIMs which are manifestations of IBD related inflammation that occur outside of the gut. Research suggests that up to 50% of patients with IBD experience a minimum of 1 EIM therefore non-typical IBD symptoms are an important aspect of IBD to discuss (Vavricka et al., 2015; Hedin et al., 2019). During the PPI discussions non typical IBD symptoms were discussed and experiences of living with these symptoms were shared.

The non-typical IBD symptom which was mentioned the most was constipation. While IBD is typically associated with diarrhoea, constipation can also occur and constipation is suggested to occur more in inactive UC than CD (Farrokhyar et al., 2006). Several respondents of the survey and some PPI members expressed that they feel the symptom of constipation is overlooked despite being problematic and one respondent shared that “constipation is a problem for them 99% of the time”.

The second most mentioned non-typical IBD symptom was pain generally and the symptom of abdominal pain. Pain is one of the most common symptoms experienced by IBD patients and pain can occur regardless of an IBD patient's current disease activity. Pain has been suggested to contribute to the poor quality of life experienced by some IBD patients (Schirbel et al., 2010). Respondents of this survey described the pain of IBD as “severe” and “unbearable” with one respondent referring to how pain impacts their sleep. During the PPI group discussion, abdominal pain was discussed and how easily this can be dismissed as being related to other things, such as menstruation pain, which is particularly problematic pre-diagnosis. The group also discussed how pain is not comprehensively monitored for IBD despite the symptom being experienced by most patients. The group discussed how it can understandably be difficult to identify whether symptoms like pain is due to IBD or whether it is due to something else, as “it’s not clear whether it’s Crohn’s related or some other condition”. Out with this survey, journals such as the BMJ have recently released a practical guide about chronic abdominal pain, due to the increasing number of studies referring to patients feeling misunderstood by clinicians regarding their pain and the insufficient management of chronic pain in IBD patients (Baillie et al., 2024). While pain and constipation have been discussed in depth the Crohn’s and colitis UK website has information regarding many typical and non-typical IBD symptoms.

IBD is not only restricted to affecting the inside of the gut, but the condition can also affect other areas of the gastrointestinal tract, including the mouth in which lesions and ulcerations can form making it challenging for individuals to eat, as well as areas outside the gut, such as inflammation in the skin and joints (Ribaldone et al., 2020; Crohn’s and colitis UK 2019, 2021). Comments left by respondents of the survey mentioned that treatments are aimed at treating “physical gut symptoms” however EIMs like joint pain “can be just as difficult to live with” and that research regarding EIMs may be worthwhile. Approximately 40-50% of IBD patients suffer from joint pain and some IBD treatments like anti-TNF agents are used to simultaneously reduce IBD symptoms as well as reduce EIMs (Orchard., 2012). The PPI group discussed their knowledge about EIMs, including erythema nodosum (a skin condition which causes tender red nodules usually on the shins), issues with eyes such as dryness, and ectopic Crohn’s disease (Crohn’s located in the vulva).

Some members of the group had not heard of the EIMs mentioned above before and the discussion allowed members of the group to further their understanding of IBD, as well as highlighted the extensive knowledge required to understand IBD. The PPI group agreed there is a need for a multidisciplinary team or stronger communication between teams, for patients to receive the correct care and manage medication effectively.

Impact of Additional Conditions

Many respondents spoke about additional conditions, such as other autoimmune disorders and the impact of surgeries, that they did not link to their IBD but felt that it impacted their life with IBD, such as COVID, arthritis, or fibromyalgia. As one respondent put it “I have multiple conditions so sometimes it’s hard to tell what causes some symptoms”.

This topic highlights the importance of acknowledging other short or long-term conditions that impact their responses to IBD wellbeing or coordination of care. Respondents reporting these additional conditions emphasised the level of knowledge required to ascertain (often guessing) what is and what is not an IBD related issue: “been ill for flu like symptoms… it’s all culminated in a flare blood in stools”. Respondents also highlighted the challenges of having a variety of conditions to manage at the same time, as one respondent summarised “when there are comorbidities things get very challenging.. medications get even more confusing and capacity to focus on healing IBD gets very hard as it’s hard to manage everything all at once”. Patients with comorbidities often deal with many different healthcare professionals across multiple disciplines. The survey responses highlighted the requirement for well-communicated multidisciplinary teams to manage complex treatment plans effectively. The PPI group discussed the benefits and risks of using multiple medications and how these must be carefully balanced. This is particularly crucial as treatment effects of IBD medications are less well known for IBD patients living with other conditions, due to their exclusion in investigative randomised control trials (RCTs) (Román AL et al., 2011). Considering the potential drug interactions, additional side effects, and adherence challenges, this can be an added layer of stress to a patient's treatment journey.

Overall, this topic highlights the importance of acknowledging other short or long-term conditions that introduce unique challenges to the management of IBD. Comprehensive coordination of care, particularly for people with dual pathologies, is essential for addressing challenges and to provide effective IBD management. Ensuring that all aspects of health are considered, alongside communication and knowledge sharing by the correct healthcare professionals for improved decision-making and overall patient reported as well as clinical outcomes.

Awareness and knowledge about IBD

Awareness and knowledge of IBD was mentioned by respondents of the survey and referred to topics including the stigma surrounding IBD, the isolation and lack of sympathy experienced by IBD patients, as well as the need to raise more awareness of IBD especially particularly focused on the invisible illness nature of IBD. During the PPI group discussion members of the group shared their own views and experiences in relation to the topic area.

Several respondents of the survey commented regarding feeling embarrassed about their condition due to the stigma surrounding IBD. One respondent commented that they are very open about their IBD, however they “still find it embarrassing as no one wants to talk about issues” with their bowels”. Another respondent commented “that the disease is debilitating and misunderstood which makes it hard for people to understand which stops you wanting to talk about your illness”. Stigma surrounding IBD has shown to have an impact on a patient’s quality of life (Taft and Keefer., 2016) and that IBD can lead to embarrassment among patients due to the nature of their symptoms, such as bowel incontinence and odours as well as the visible aspects of IBD surgery such as having a stoma (Guo et al., 2020). During the PPI group discussion, members spoke about initially feeling embarrassed and apprehensive when explaining IBD to family and friends. Members discussing IBD among family members found that some of their relatives also had this condition, but due to stigma and embarrassment this wasn’t disclosed. Stigma surrounding IBD may be due to the lack of knowledge regarding the condition which makes raising awareness important (Guo et al., 2020). Without this knowledge, patients often suffer alone.

The invisible nature of IBD can often make it challenging for others to understand an IBD patients' needs or experiences. An IBD patient can appear visually well, but they may be experiencing an IBD flare without noticeable symptoms. Several respondents of the survey referred to the challenges experienced due to the invisible nature of IBD including finding it difficult for others to understand what they are going through and referred to phrases which the PPI group resonated with such as being told “you look fine” and “you don’t look ill”. These phrases can be difficult to respond to and have left many of the survey respondents feeling as though they are “making it up”. Another survey respondent referred to how their partner received more sympathy for a minor finger injury “than when [they] had a severe Crohn's flare”. As IBD is not visible like a minor injury, such as having a cast for a bone fracture, people cannot visually see you are unwell and may contribute to the lack of understanding or support.

Respondents referred to the lack of accommodation by society when living with an invisible illness. Other respondents referred to the lack of understanding in areas like the workplace. PPI members could also resonate with lack of understanding in workplace settings and that it’s difficult for employers to understand, for example, that there may be a toilet down the corridor but during a flare of IBD a toilet much closer is required. However, some respondents and PPI members spoke about the flexibility provided in hybrid or home working and that now employers seem somewhat more understanding about workplace adjustments since the COVID-19 pandemic. Similarly, schools and higher authorities have also been suggested to lack appropriate awareness of IBD, making aspects of life more difficult for IBD patients. Being faced with less understanding members of society, one respondent recalls being told that they “don’t ‘look’ like” they should be using disabled toilets. Comments referred to schools not understanding the urgency of IBD or patient issues/needs despite people with IBD having medical cards. Survey responses also highlighted that authorities may not recognise IBD as a “serious illness”, referring to the lack of support for IBD patients in terms of “benefits and accessible parking”. Efforts have been made by organisations like Crohn’s and colitis UK to raise more awareness of IBD and to emphasise the needs of patients including toilet accessibility, financial support and parking accessibility. However, these survey comments suggest that more needs to be done.

Raising further awareness of IBD may also help reduce the isolation and increase overall support patients experience. Respondents of the survey left comments in terms of isolation including that “nobody understood what I was suffering, making a lot of people distance themselves from me” and “living with IBD can feel very lonely even when surrounded with lots of people”. Research suggests that IBD patients may be more likely to experience loneliness due to multiple reasons including the lack of awareness of IBD and the impact of IBD symptoms (Chen et al., 2022; Fourie et al., 2018). [MH13] One respondent highlighted the importance of having a support network, “thankfully due to the length of time I have suffered from this condition, I have a very good close caring family network”. Members of the PPI group also spoke about supportive networks that surround them and often this requires family/friends to research and increase their knowledge about the condition.

Overall, the topic of awareness and knowledge was referred to in many comments of the survey and respondents have emphasised the need for more awareness of IBD. As one respondent puts it, “…educating people on the reality of it [IBD] is so important”. Efforts to increase awareness by the PPI groups work include the release of the short film “Our lives with IBD” at the Edinburgh science festival. This short film explored inflammatory bowel disease, the experiences of those living with it, and the ongoing research in the field. Awareness campaigns also exist via charity networks such as Crohn's and Colitis UK, who holds regular coffee mornings for IBD patients and volunteers to meet each other and share their experiences, which helps raise awareness amongst the patients of strategies for coping with various IBD issues. However, based on the comments of the survey more awareness needs to be raised.

Self-management of IBD

Treatment and management of IBD involves a multifaceted approach including a range of medical interventions covering immunosuppressants and steroids to surgery. Medication adherence and drug management is a vital aspect that requires patients to follow treatment plans to help reduce inflammation. In addition to conventional medical treatments, self-management and alternative methods of care have a significant role in IBD and can contribute to improving overall patient outcomes. The trial-and-error approach inherent in IBD treatment, alongside high failure rates and side effects of current medications, brings a strong interest in patients to turn to alternative methods: “I wish there were better treatment options that don’t involve drugs”.

Respondents commented that they would like to know more about self-management options, such as dietary adjustments or how to exercise with IBD. As different foods and dietary patterns have individualised effects on disease and inflammation, dietary management is vital for symptom control, nutritional status, and quality of life. The PPI group spoke about their experiences of following a specific dietary approach, eliminating foods that may trigger symptoms, and consuming more foods that promote gut health. An important aspect of dietary management for IBD patients is receiving the correct professional support for optimising nutrition and as one respondent puts it, “Dietary support should be readily available”. Exercise can also be used as a complementary approach to IBD management, offering multiple benefits relating to physical function, mental health, bone health, and long-term reduction in inflammation, however choosing the right type and intensity of exercise is important for IBD patients to receive these benefits without worsening symptoms. Communicating safe and effective exercise through improved patient guidelines and plans is therefore crucial for helping IBD patients achieve better health outcomes.

As discussed previously, IBD can have profound impacts on mental health and therefore the psychological aspect of self-management must not be overlooked. Having effective coping mechanisms and approaches to stress management, an issue raised by multiple respondents and experience by the PPI group members, can significantly improve a patient's quality of life. Approaches may include stress management and relaxation techniques, therapy and counselling, or flexibility in an individual's working environment. This requires a collaborative approach between patients and healthcare providers, ensuring the correct dissemination of resources and information.

Self-management can be a desirable approach for patients as it empowers individuals to take control of their condition and improve quality of life. Respondents expressed that they “learn[ed] to tune into bodily wisdom” and a desire to learn “how to better manage oneself [and] take responsibility for myself [to] understand what I can do to improve my condition” and use self-management adaptations to control their IBD. Masi et al (2022), highlight this perfectly with a paper equally balanced on novel medicines and therapies (current drug targets and innovative therapies) with various complementary therapies such as cognitive-physical approaches, FODMAP diets, herbaceous medications etc. However, in the same way that IBD does not affect all patients identically, the resounding theme was every patient must approach alternate methods of care independently. Respondents and members of the PPI team highlighted the variety of ways in which they aim to remain in remission or lesson symptoms, such as eating vegetables and fruits, short bursts of exercise and using supplements. All PPI members had a different approach to self-management techniques; some did gentle exercise like yoga and others did high intensity training, some could eat vegetables but not fruits, while others chose a less fibrous diet. In some cases, this was guided by support from healthcare professionals but in other cases, PPI members spoke about having to figure out what works for them on their own. The PPI group were curious to know more about why self-management approaches seem to be based on individual circumstances as what works for someone may not work for all.

The management of IBD through self-driven approaches and alternative methods allows patients to take a proactive role in controlling their health. An overarching theme across self-management strategies is the importance of knowledge and education around alternative approaches, and so while there is potential for IBD patients to use these methods to achieve better health outcomes, collaboration with healthcare professionals may be required to promote optimal management.

Women’s Health and Reproduction

Women’s Health and Reproduction was an emerging topic that some respondents felt was important to them and should be examined further. The PPI group discussed this topic in relation to the respondents’ comments and brought forward new experiences. It should be noted here that all members of the PPI group are women.

Respondents to the survey shared that menstruation and menopause had a negative influence on their IBD and/or bowels generally. A study conducted in 2015 suggested that menstrual changes occur in the year prior to IBD diagnosis and assessment of menstruation should be considered part of the screening process for a new IBD diagnosis (Saha S et al, 2014). A more recent study found that abdominal pain, fatigue, headaches and other symptoms around menstrual periods affect IBD patients more than healthy controls (Lahat A, et al, 2020). In addition, healthy controls were more likely to report increased bowel changes around menstruation, but acknowledge that IBD patients may be more accustomed to increased bowel habits so may not notice or under-report minor changes. This resonates with respondents to the survey and experiences of the PPI group members, who all spoke about increased and worsening of bowel habits during menstruation, one respondent summarised “…bowel symptoms are absolutely worse with menstruation”. The PPI group discussed how hard it can be to tell the difference between IBD or menstruation bowel urgency and pain as they can often feel similar. The PPI group also spoke about issues with low iron which makes symptoms like fainting and dizziness worse during menstruation. According to research, there is an increased risk of iron deficiency in patients with IBD, due to malabsorption and blood loss from the intestines, but also due to menstrual bleeding (Mahadea, D et al, 2008).

Respondents to the survey shared concerns about fertility, maintaining remission during pregnancy and the impact of pregnancy on IBD symptoms or flares. One respondent shared their experience, “…due to my ongoing issues with chronic vulva crohns… [I] can’t access any fertility treatments…It makes me feel less of woman”. PPI members also spoke about feeling limited in relation to contraception as they worried about extra hormones or side effects that may make IBD symptoms worse. The comments from survey respondents highlighted worries of having a flare during pregnancy, that “IBD during pregnancy is incredibly difficult…The lack of understanding is awful amongst some drs/nurses”. The PPI discussed the challenges faced by young women in managing IBD and repeated flares through their reproductive years. A key concern for the group was how ongoing management of IBD has the ability to steal away time in which they may consider having children. Managing IBD flares, miscarriages, and resulting mental health challenges simultaneously can be deeply traumatic and this struggle often intensifies the emotional toll of living with IBD, as it not only affects their physical health but also their sense of identity and future aspirations, including family planning. Although the Crohn’s and Colitis website offers information about fertility, pregnancy, and breastfeeding as well as sharing research exploring the experiences of mums to be with IBD, the PPI group felt that the impact of IBD on pregnancy and the side effects of IBD medication on pregnancy isn’t well known or widely discussed outside these resources (Crohn’s and Colitis 2023[1], 2023[2], 2013).

The group emphasised the importance of timely discussions about women’s health and reproduction, including proactive conversations and decision-making about treatment options between clinicians and women who want to conceive.

Exhaustion and Fatigue

It is important to note that some core survey questions were aimed directly at understanding fatigue. Despite the fact it was mentioned in the survey, these respondents reemphasised the impact. Crohn’s and Colitis report that 4 in 10 patients are affected by fatigue at any one time whilst in remission, to add to this only 5 in 10 patients are asked about their fatigue in appointments with their consultant (Crohn’s and Colitis UK, 2022[1]).

From the comments in the survey around fatigue, many were centred around the notion that “fatigue is underrated” in its effects on daily life and that it can “often [be] one of the biggest side effects of IBD”. When looking at alternate methods of care for fatigue, many online sources advice is often limited or not written from a patient aspect: “eat better or take supplements”, “get tested for anaemia”, or simply “get a better sleep schedule.” However, patients with IBD from either the survey or the PPI team have stated how tackling fatigue is not as straightforward as improving sleep schedules or taking more vitamins and minerals. From the literature, fatigue has no links to being in flare or remission, or between ulcerative colitis and Crohn’s disease, so being fatigued is unpredictable (Uhlir et al, 2023). Uhlir et al, did note a correlation between depression and fatigue within IBD patients with respondents supporting this by saying “fatigue has affected [their] mood as well.” This highlights how severely patients are affected both mentally and physically by fatigue compared to how low it scores upon a doctors list to inquire. It is possible for severely fatigued patients to receive treatment such as B12 injections or iron infusions, however as one respondent comments “I have to have B12 injections… and I’m still constantly fatigued”, treatment options are not always effective. It is important to note here that some treatments for fatigue, such as injections, do work for certain patients and such treatment options should be an ongoing discussion between the clinician and the patient.

The PPI group also spoke about the unpredictable nature of fatigue and how difficult it can be to plan social aspects of their lives, plan for work or academic responsibilities, and they disclose having IBD to express fully the effects of fatigue. One respondent commented how fatigue “impacts productivity and output at work”. PPI members who had been through school/university exams did express how being able to show a doctor’s note for extenuating circumstances if their IBD flared would alleviate stress at an already stressful period, however they commented on how this was harder to obtain due to the invisible nature of fatigue. The PPI group agreed that mental and physical fatigue are not considered severe symptoms of IBD and there is a risk of looking lazy by employers or school tutors.

The PPI team spoke about how organising their social life along with work to allow for a slower pace was highly beneficial, for example planning social engagements, sports or activity, and working hours to be spread out across the week/month. They also mentioned how they would be as open with peers and colleagues, so in the circumstance of having to cancel events, or work from home due to fatigue, people would be understanding of their condition. However, the group recognised that these approaches are not always possible, and that more understanding and compassion from people without IBD is required.

Body Image

More recently, improving negative body image is increasingly part of mental health awareness in society. Respondents highlighted the particular impact of IBD has on body image, despite it being considered an invisible illness.

A study conducted by Saha et al (2016), monitored how body image was perceived upon diagnosis of IBD, through remission, flares, and between men and women. They saw a peak in dissatisfaction in body image upon diagnosis, which remained high but somewhat stable thereafter. Dissatisfaction was higher in patients on steroid treatment, higher disease activity and side-effects related to IBD, along with disease location (particularly in Crohn's disease). A higher dissatisfaction was also found with body image in women compared to men. All of which ultimately led to poorer mental health and quality of life for patients. Within the PPI team, it was mentioned how some might exhibit "avoidance behaviours" by refusing medications which would usually change body image, such as gaining weight from steroids and having what is known as a "moon face". To further this, IBD itself can cause bloating and rapid weight loss, which again removes the sense of "autonomy" or "possession" over one's own body and identity, especially where making adjustments using diet and exercise, which may be limited due to IBD.

A large issue is battling with societal norms of body image alongside battling a chronic illness. Poorer sense of body identity and body image can influence social engagement, stylistic choices and romantic aspects of life, leaving individuals "feeling unattractive generally". Much of what society sees of a person is their body image, particularly the face and overall presentation. Members of the PPI team spoke about issues such as mouth ulcers or steroid treatments causing facial swelling and rashes on the skin, as a side of effect of IBD, causing them to wear clothing that didn't align with their fashion identity. The PPI group mentioned how, particularly when in flare, they would opt for baggier, more patterned designs to hide stomach bloating or stomas and that often due to these symptoms they would avoid any romantic engagement with others, such as dating or sex.

Experience with Stomas

When Crohn's or Colitis isn't well controlled by medication, sometimes the only option is to have surgical intervention and create a stoma. A stoma is where the end of the bowel is diverted out through the abdominal wall and sits just outside the skin of the abdomen (Crohn's and Colitis UK, 2022[2]). This requires wearing an 'appliance', 'bag' or 'pouch' to collect the waste from the stoma. Nobody who considers stoma surgery does so lightly. It is often the only option when in a life-threatening situation due to complications from flaring IBD.

Many IBD patients are very scared about the prospect of having to have stoma surgery at some point, which the PPI group identified with primarily because there is little knowledge unless you have experience of this. As one respondent highlights, "Other people who don't have stomas just do not understand what it's like". The PPI discussion related to their experience of stoma bags (whether that was themselves or someone they knew). Members spoke about misconceptions and fears during their discussion of this topic, for example, that can be assumed that stoma bags aren't drainable which is false and the fear of problems with consistency of output, seals, skin problems that can then cause leaks, which can be very stressful and upsetting to manage particularly outside the home. Some people with stomas may make dietary adjustments in order to prevent blockages and control the consistency of the output to prevent dehydration and leaks. There may also be an increased risk of developing a hernia after stoma surgery so learning how to prevent or avoid this is important because, as one respondent explained, "Parastomal hernia bulge increases difficulties with body image and pouch reliability". If a patient with Crohn's has a stoma they can still have symptoms, as one respondent mentioned "I have a stoma but my stoma output is higher at the moment in a flare". Therefore, in some cases, a stoma does not necessarily mean that a patient no longer has IBD or related symptoms to manage.

Respondents described how going through stoma surgery can change their self-perceived body image. It’s a huge adjustment and some people cope better than others with this change. One respondent shares, “It [the stoma] does affect how I look at myself in the mirror”. The PPI group discussed how there are fears around how someone’s partner will view them or how dating with a stoma can be daunting. As mentioned in previous chapters, IBD is an invisible condition but that surgery is a visible reminder of the condition and raises concerns about whether “people can see my stoma bag”. One respondent described being in the middle of the process of acceptance “I feel grief at losing the old me. I don’t feel attractive”. The PPI group acknowledged that a stoma challenges ideas about how someone feels confident and attractive, but that there are ways to begin to feel comfortable, such as wearing patterned or loose clothing, in your new body.

Some patients are given access to mental health services to help them work through these issues of acceptance and adapting with life having a stoma. PPI group members who had experience of receiving support for mental health praised its value. However, some patients are given little to no mental health support in adjusting to having a stoma and are left to try and figure things out on their own. As one respondent’s comment accurately describes: “I wish I was offered counselling afterwards and support. I had the appliance for 10 years and my GP surgery wasn’t even aware I had a stoma”. As mentioned in a previous chapter, improving mental health support and awareness of IBD is considered important for respondents and the PPI group.

Ultimately many of the challenges of living with a stoma require development of management strategies, however despite this, having a stoma can really improve a patient’s quality of life. As one respondent explained “I had my bowel removed a year ago and now have a stoma bag which has changed my life for the better, going from 30 times a day to now having control”. When discussing potential stoma surgery with patients it’s important to acknowledge this trade-off as this respondent describes: “My stoma has given me my life back. It does come with it’s own challenges, for example fear of leaks. However, I am in a lot less pain and able to do things I could not when I was in a flare up like social things. My quality of life is a lot better with my stoma." And one final respondent sums it up, "My Stoma saved my life. I wouldn't be here without it".

Age

A few respondents left comments about the topic of age in relation to IBD. The comments referred to how IBD symptoms and severity can change over time as well as the worries and concerns patients have about ageing and having IBD. During the PPI group discussions members of the group shared their own comments and experiences in relation to age and IBD.

Studies have shown that the incidence of paediatric (<21 years of age) IBD is continually increasing worldwide including in areas of the world where IBD had not been documented before (Kuenzig et al., 2022). However, IBD can affect individuals across all age ranges and although the severity of IBD is suggested to be greater in paediatric patients the severity can continually change, therefore individuals of different ages may have different experiences and concerns regarding their IBD (Limbergen et al., 2008). During the PPI group discussions, the concerns IBD patients have at different ages was talked about. PPI members who were diagnosed with IBD at a young age spoke about feeling like they do not know what living without IBD is like. PPI members recalled going through IBD diagnosis during growth and development as well as hormonal stages, impacting experiences during these formative years. PPI members spoke about how they were often the youngest person staying on the hospital ward, the youngest person they knew who had IBD, and that this affected general mental wellbeing.

A misconception which was discussed during the PPI group discussion was that of being considered 'young and healthy'. This view can make it challenging for individuals to seek help and to talk about their condition as well as to come to terms with being young with a chronic illness. One respondent also emphasised the added stress that normal parts of life, like working, has on someone with IBD, "I am retired but if it had struck earlier I would have had to stop working. Younger people have it especially tough!". Strategies have been used to help individuals under paediatric care to feel less isolated, to understand their condition more and to direct research in a way that is driven by patients, such the

“Let’s talk about research” paediatric IBD event held at the Royal Hospital for Child and Young People. This event was hosted by the centre for inflammation research in Edinburgh and allowed young people and their families to learn more about IBD as well as brought together scientists, research clinicians and patients.

While research surrounding IBD has previously suggested that young patients are mostly affected by IBD, more recent research has found an increase in elderly (>65 years of age) onset of IBD (Danpanichkul et al., 2023). One respondent comment “My biggest fear is when I get older and not being able to control my bowel”. Despite the PPI group members being in the age range of 20-50 the group were able to discuss elderly onset IBD in terms of the PPI group members future concerns and by referring to the experiences of others. From the survey it was clear there are concerns regarding ageing with IBD, especially when an individual has additional health conditions. One respondent commented “it is complicated and as I’m ageing both of my diseases are changing !!”. Many articles relating to IBD and older adults refer to the challenges of diagnosing IBD due to confounding factors including the physical changes associated with ageing and any additional health conditions the individual may have (Taleban et al., 2015; Tran et al., 2019). One study of IBD patients over the age of 60 suggested that the presentation of IBD in older adults is milder than IBD in younger patients. Additionally, the study suggests symptoms in elderly onset IBD may also be different. Individuals diagnosed with Crohn’s disease in their older adult life were suggested to have more rectal bleeding and less abdominal pain and diarrhoea while older adults being diagnosed with Colitis were suggested to have less rectal bleeding when compared with patients diagnosed with IBD at a younger age (Charpentier et al., 2014). Upon diagnosis it is difficult to know the disease course which makes treating IBD challenging and makes predicting how someone’s IBD may affect them in the future difficult.

Therefore, while IBD and age was only mentioned in some comments of the survey it is a topic which is considered and heavily studied in terms of the prevalence of IBD among different age groups. From the discussions similar as well as the contrasting concerns of IBD patients of varying age groups became more apparent.

Discussion

Through this paper, the PPI group aimed to explore a patient-dominant model and approach to research: where patients lead in defining the topic areas, setting the agenda, and communicating information to the target population, firstly, the IBD population and secondly, clinicians and researchers.

This paper has explored the priorities around research and wellbeing that are important to the survey respondents, with more detailed context provided by additional sources and the experiences of the PPI group. The main topic areas explored for this survey highlight key priorities for research to continue to improve experiences and outcomes for people with IBD. This paper also acts as an example that for research to be effective, it cannot be done without the invaluable knowledge of the patients themselves.

The PPI group acknowledged the interconnectedness of the issues raised in this paper and that there are commonalities between the topic areas, even when individual variation in experience occurred. These included concerns about support from wider circles outside of healthcare settings (family, friends, university or work), reviewing language around IBD, fears about social isolation and loneliness, the responsibility to manage one's own IBD, improved communication from healthcare professionals, and seeking expansion of support for mental health and multidisciplinary teams. It is important to consider these interconnected themes to understand the complexity of managing IBD as well as develop better holistic and patient-centred care plans.

Some respondents to the survey answered the free-text question by saying how pleased they are to fill out a survey focusing on patient-reported outcomes, highlighting how meaningful the survey was to the people who filled it out. In particular, one respondent shared that answering the survey questions changed their perception of their wellbeing and another person shared that the survey questions have highlighted to them that there are other symptoms to consider when thinking about their IBD and wellbeing. This highlights that patient-reported outcomes are not only important for clinicians to understand, but also for patients to expand their knowledge of their or others IBD.

The PPI group found analysing, presenting and communicating patient reported outcomes an ambitious and rewarding experience. The range of skills, including academic backgrounds, created the template for this paper, however other PPI groups with members who have different skills may produce different outputs. The process for this paper was created from the 'ground-up'. Throughout the process the PPI group agreed on the next steps together and each attempted all tasks put forward (aside from initial topic analysis). However, the PPI group reflected that delegation of tasks based on skillset or preference would be more beneficial in the future. Members of the PPI group who have an academic background enjoyed the process of writing and reading about IBD beyond clinical presentation of disease, being able to showcase the complexity of the condition without reducing people to numbers or academic jargon. The group liked having a choice in the direction of the paper and the topics that they would lead for the discussion and write-up. Further consideration of meeting frequency and varied communication may differ depending on the group's preferences.

Additional opportunities presented through this work included sharing experiences and having the opportunity to bond with other members of the PPI group. Sharing information, learning not only from the process but more about IBD and the variation in experiences from each other and the survey respondents, often provided PPI members with new perspectives on different topics areas. Additionally, the PPI group reflected on surveys, such as this, where results are not usually disseminated by the patients and for the patients.

The PPI group agreed that it was an empowering research project to embark on and valued the opportunity to act as a voice for people with IBD and produce a paper that reflects some the varied experience of IBD Wellbeing.

Conclusion

This experience of patient involvement as a collaborative process has been rewarding for the PPI group, allowing them to provide a voice to the survey comments and produce something meaningful. It highlighted to the group that their experiences are just that, their own, and that despite the group's best efforts to capture the variation, there will always be more to understand.

Although it is rewarding to have the patient involved in the decision-making process around research and to have their voices represented in this paper, the group would like to see wider impact of this work steering conversations in new ways. In particular, around the clinical-research community where co-produced and patient-led models are perhaps not frequently seen as beneficial or worthwhile.

The PPI group would like to thank the survey respondents for giving up their time and detailing their experience of wellbeing with IBD for the purposes of this study. The group would also like to thank Dr Gwo-Tzer Ho for allowing them to ‘take the reins’ of this research and produce work that platforms the voice of people with IBD.

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