
# Optimizing Engagement to Address the Evolving Needs of Patients With IBD

## Need for Improved Care and Outcomes in IBD

### Disparities in Disease Manifestations and Access to Care

Crohn's disease (CD) and ulcerative colitis (UC) are subtypes of inflammatory bowel disease (IBD), a chronic condition that affects the gastrointestinal tract. The manifestation and course of disease is not one-size-fits-all, but rather varies between individuals and over time.[1-3] Patients' needs evolve with their disease trajectory and personal circumstances. Genetic and environmental factors are involved in the development of IBD.[1,4,5] Patients with IBD see their needs evolving independently of their regularly scheduled follow-up appointments: flares or medication adverse events (AEs) can develop between planned visits and may require urgent care.[6]

In addition, age and comorbid conditions contribute to the diversity of needs patients have for initial therapy to induce remission, for maintenance of remission, and during disease flares. For instance, IBD phenotype, disease extent, and outcomes differ between adolescents and adults, with often more severe manifestations (disease symptoms) in young patients. In addition to the progression of disease itself, teenagers growing into adulthood face the challenges of the transition of care. For elderly patients, therapeutic planning and disease management can be challenging because of the change in immune function due to age and other diseases associated with their age.[7-9]

Analysis of the resources from the Rochester Epidemiologic Project indicates that the incidence (number of people developing IBD over a specific period of time) increased from 1970 to 2010 in a county in Minnesota, USA, with important racial (White, non-White) and ethnic (Hispanic, non-Hispanic) differences.[10] Recent research has documented racial differences in IBD phenotype in adults in the United States. For instance, African American patients with IBD had more active disease in other parts of the intestine than typically seen in White individuals and more prominent extraintestinal manifestations, such as joint symptoms, than were reported for Caucasians.[11]

Disparities in access to care (eg, those related to geography, socioeconomic status, and ethnicity) are also a factor that can affect disease outcomes in IBD. A study conducted with 2136 patients with IBD treated at the Massachusetts General Hospital reported that the need for surgery and immunomodulator and biologic therapy increased with distance from the hospital.[12] Access to a gastroenterologist is an essential component of healthcare utilization; however, this resource is limited in rural areas.[13] Additionally, lower socioeconomic status has been correlated with increased CD-related hospitalization, and lower household income was shown to be a strong and independent factor of higher utilization of emergency services in the IBD population.[14,15]

Altogether, these differences between patients (age, race, geographic location, or other personal factors) have implications for the diagnosis and management of IBD and its complications,[11,14,16] and they necessitate a personalized, patient-centric approach.

**Evolution of Patient and Provider Needs With Changes in the Healthcare Environment**

The COVID-19 (coronavirus disease 2019) pandemic caused by the novel severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) is a recent example of a crisis resulting in the sudden evolution of patients' and healthcare providers' needs. A rapid reorganization of care centers occurred, with a limitation of patient-clinician interactions and changing of clinical priorities to increase the availability of intensive care units.[17] This situation disrupted the classic management of IBD, with patients having reduced opportunities for in-person visits and the cancelling of non-emergency surgeries. To address patients' concerns and to continue to manage their disease, strategies such as maintaining a functional IBD team including virtual support (eg, helplines), infusion suites, and homecare delivery services were implemented. A multinational online survey conducted during the pandemic reported that clinicians adapted quickly, shifting face-to-face consultations to virtual ones using telehealth (phone and video communications), and there is an intention to continue this type of communication even after the pandemic.[18]

Many patients worried about their potentially increased risk of contracting COVID-19 and asked whether they should pause their immunosuppressive treatment.[17] Advocacy groups such as the Crohn's & Colitis Foundation provided online information about the potential risks associated with different categories of treatments used to manage IBD and encouraged patients to talk with their healthcare providers (HCPs).[19]

Considering these gaps in access to specialty care centers and the need to adapt rapidly during evolving situations (eg, flares, limitation of in-person visit), learning how to navigate in a more virtual environment and the use of telehealth tools have been used for patient management and provided timely and personalized interventions.[20] Telemonitoring and telemanagement with online and mobile applications provide support for patients to monitor their chronic condition and collaborate with their multidisciplinary care team between appointments. Telehealth visits help improve patient access to specialists in remote areas.[6] Recent investigations have confirmed that telemedicine is safe and effective to improve costs.[6,20,21]

### Shared Decision Making (SDM) Helps Improve Care for Patients as Their Needs Evolve

While telehealth tools can facilitate communication between patients and physicians,[6] SDM is a process in which patients are actively involved in making treatment decisions with their clinicians; it allows patients to be informed, share their concerns, wants, or needs, and have input in their treatment plan.[22,23] Results of interviews and online surveys of 106 gastroenterologists indicated that the majority agreed that SDM leads to increased patient satisfaction.[24] Overall, patients report wanting to participate in the management of their disease as their needs evolve. Adopting telehealth tools for patients with IBD and implementing SDM may improve access to specialists and patients' satisfaction.[6,23,25-28] This need for improved communication between patients and clinicians was documented by the recent IBD Global Assessment of Physician and Patient Unmet Needs (IBD GAPPS) initiative.

> ***Proactive management and consistent communication about expectations for disease management improve satisfaction and strengthen the patient-provider relationship. Regardless of the practice setting, location, and resources, the components of SDM can and should be incorporated into management of the inflammatory bowel diseases.***
> ***- David T. Rubin, MD; University of Chicago***

## Uncovering Unmet Needs: IBD GAPPS Rationale and Objectives

### What Is IBD GAPPS?

IBD GAPPS was a global initiative seeking to uncover emerging and underrecognized unmet needs for clinicians, patients, and the wider community of IBD stakeholders. It explored perceptions and experiences of patients with IBD and gastroenterologists regarding symptoms and treatment efficacy, management of disease and treatment patterns, treatment satisfaction and goals, burden of disease/care, and communication between patients and clinicians.[29]

### Review and Recruitment

This survey was funded by Bristol Myers Squibb and approved by the Western Institutional Review Board. The Crohn's & Colitis Foundation, with input from patient advocates, reviewed the survey and ensured it utilized effective, patient-friendly language to address patients' needs, and a Steering Committee of IBD experts oversaw the initiative and provided guidance throughout survey development and analysis of findings. Using mixed methodology, including assistance from the Crohn's & Colitis Foundation, more than 2300 patients and 650 gastroenterologists were recruited to participate in the survey. Researchers targeted a 1:1 ratio of patients with CD to those with UC, and physicians were identified and enlisted by third-party recruitment agencies. The surveys were completed online between August and November 2019, in Canada, France, Germany, Italy, Spain, the United Kingdom, and the United States.[29,30]

### Survey Findings

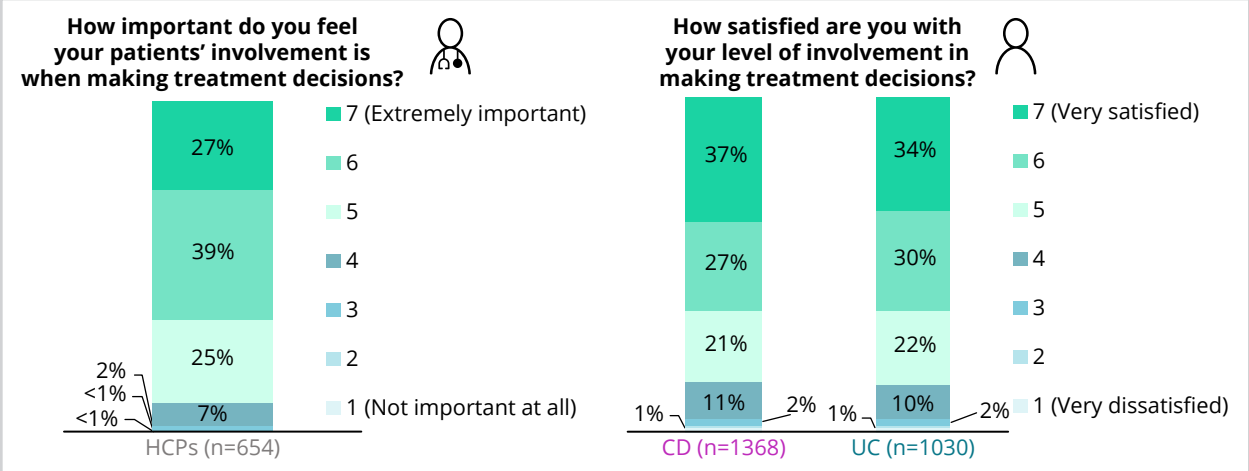
IBD GAPPS indicated that while patients talk with their physicians and generally feel involved and engaged in SDM, there are notable disconnects between patients and HCPs regarding the definition of disease remission, treatment expectations, and the most bothersome symptoms. These findings have been published in *Inflammatory Bowel Diseases* and were presented at Crohn's & Colitis Congress 2020, European Crohn's and Colitis Organisation (ECCO) 2020, and Digestive Disease Week 2020,[29-32] and they support the need for improved communication about these key topics. Misalignment between patients and physicians about achievable treatment goals and expectations can lead to low satisfaction.[29,33-35]

## Potential Implications of IBD GAPPS for Improving Care

### Importance of Engaging Patients With Open and Honest Discussions About Their Treatments

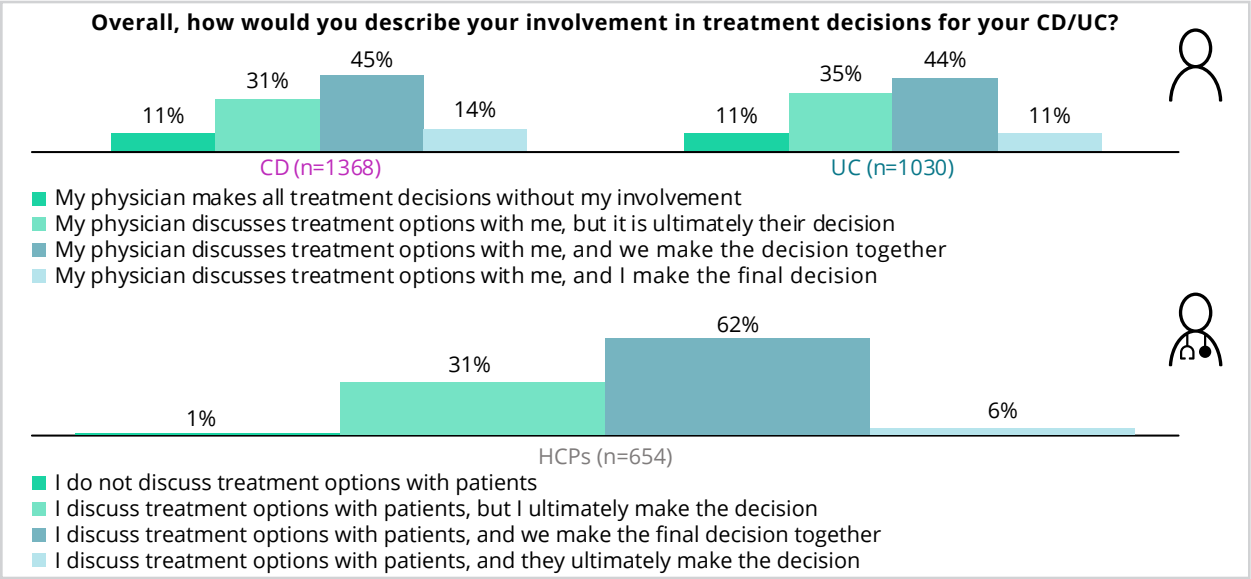
Findings from IBD GAPPS support the importance of patient engagement and effective, proactive communication. More than half of physician respondents strongly agreed that patient involvement is very important when making treatment decisions, and a majority of patient respondents were highly satisfied with their involvement (**Figure 1**).

### Figure 1. Shared Decision Making



Information from IBD GAPPS confirms that a conversation between patients and their physician to select appropriate treatment generally occurs; however, about 1 out of 10 patients reported that their physician did not consult them (**Figure 2**).

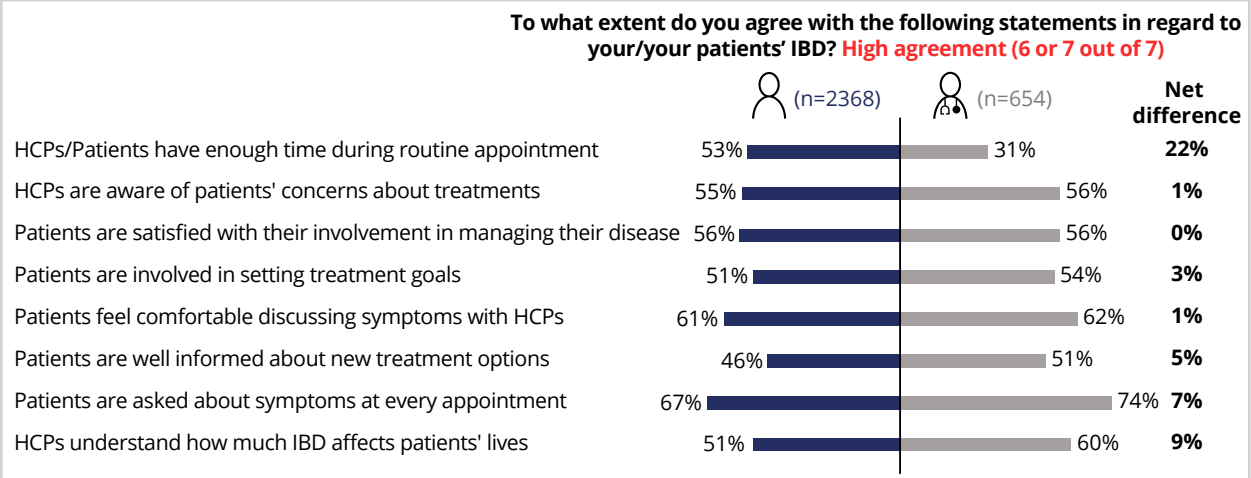
## Figure 2. Participation in Shared Decision Making




This finding underlines the need to engage and empower patients to actively participate in treatment decisions. Resources to guide the conversation exist; for instance, information about SDM processes is available on the Crohn's & Colitis Foundation website and can be shared with patients (https://www.crohnscolitisfoundation.org/shared-decision-making).

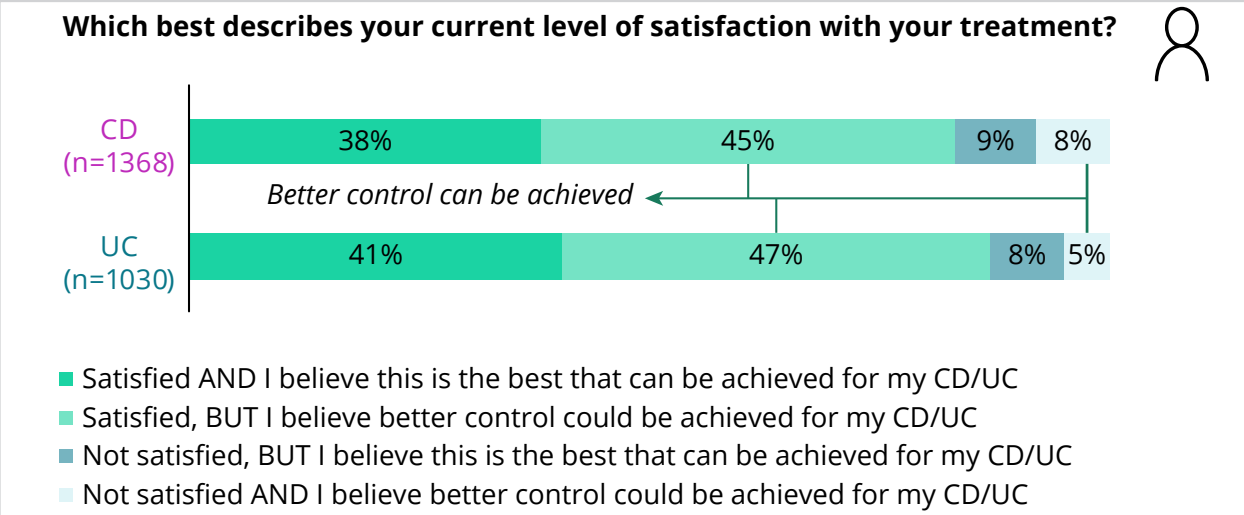
Improved engagement and SDM may enhance satisfaction.[24] Observations from IBD GAPPS suggest that patients talk with their physicians and are involved in treatment decisions, but they also report some dissatisfaction with therapy. More than half of physician and patient respondents highly agreed that patients were involved in setting treatment goals (**Figure 3A**).

## Figure 3A. Satisfaction With Care and Discussion

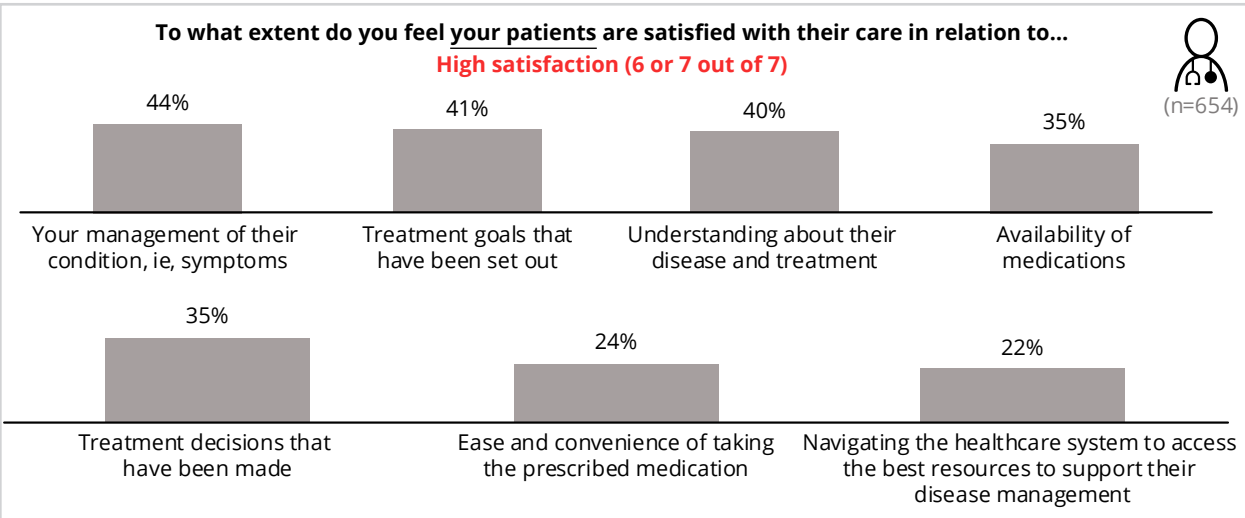


While more than half of patient respondents believe better disease control could be achieved, many physician respondents believe their patients are highly satisfied with their care in relation to the treatment decisions that have been made, the management of their condition, and the established treatment goals (**Figures 3B and 3C**).

## Figure 3B. Patient Satisfaction With Current Treatment and Disease Management




## Figure 3C. Physician Perception of Patient Satisfaction With Treatment Decisions

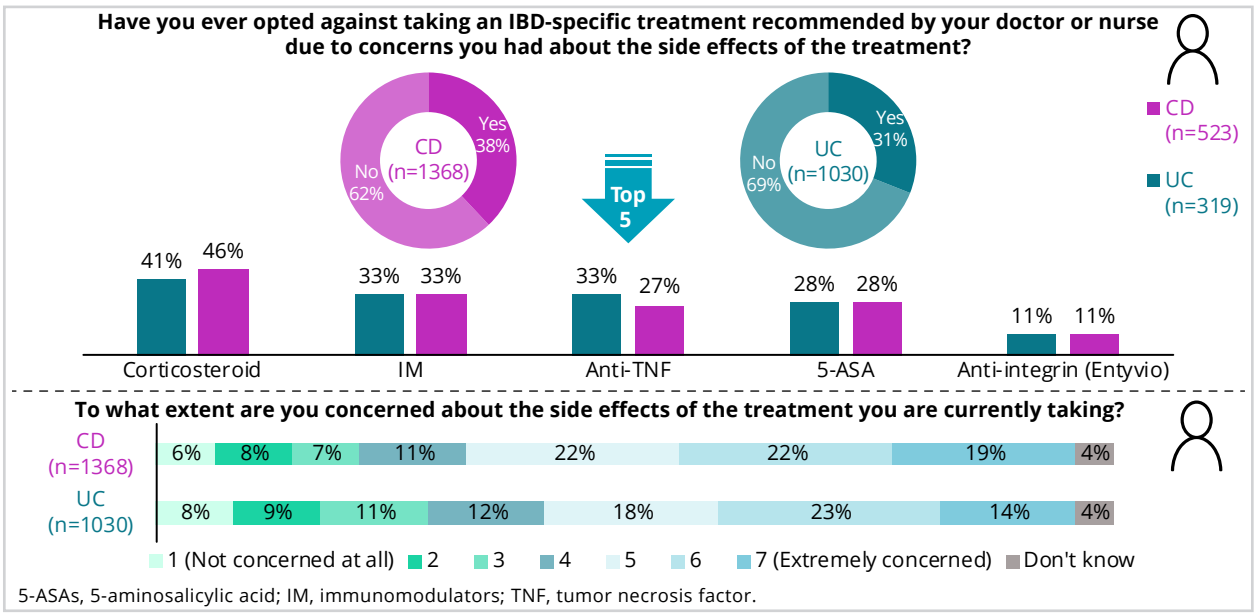



These findings from IBD GAPPS suggest that improved engagement and communication may enhance patients' satisfaction with disease management.

### Addressing Disconnects: Patients' Concerns About Side Effects and Their Influence on Adherence

It is critical for patients to understand the importance of staying on medications as prescribed to avoid relapses.[35-37] IBD GAPPS revealed some factors driving patients' decisions regarding adherence. Treatment AEs were a commonly cited concern for patients with IBD (**Figure 4**).

## Figure 4. Concerns Regarding AEs Drive Adherence

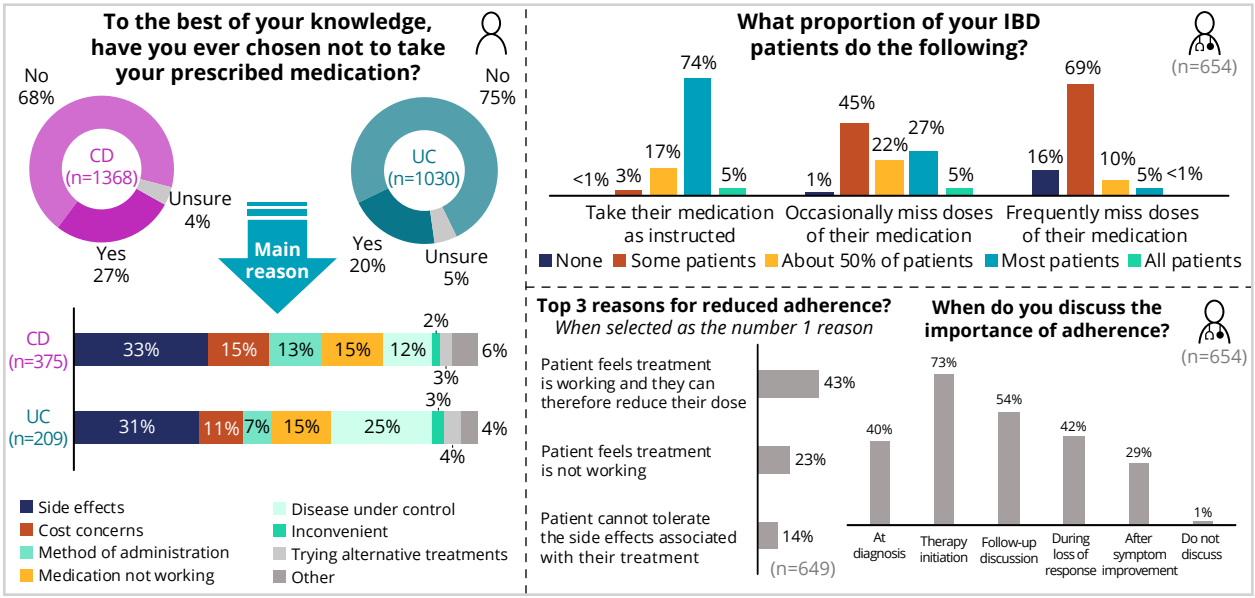



5-ASAs, 5-aminosalicylic acid; IM, immunomodulators; TNF, tumor necrosis factor.

Approximately one-third of patients reported having opted against taking an IBD-specific treatment recommended by their doctor because of concerns about AEs. In addition, more than one-third of patients expressed being very concerned about the side effects of the treatment they were taking (**Figure 4**).

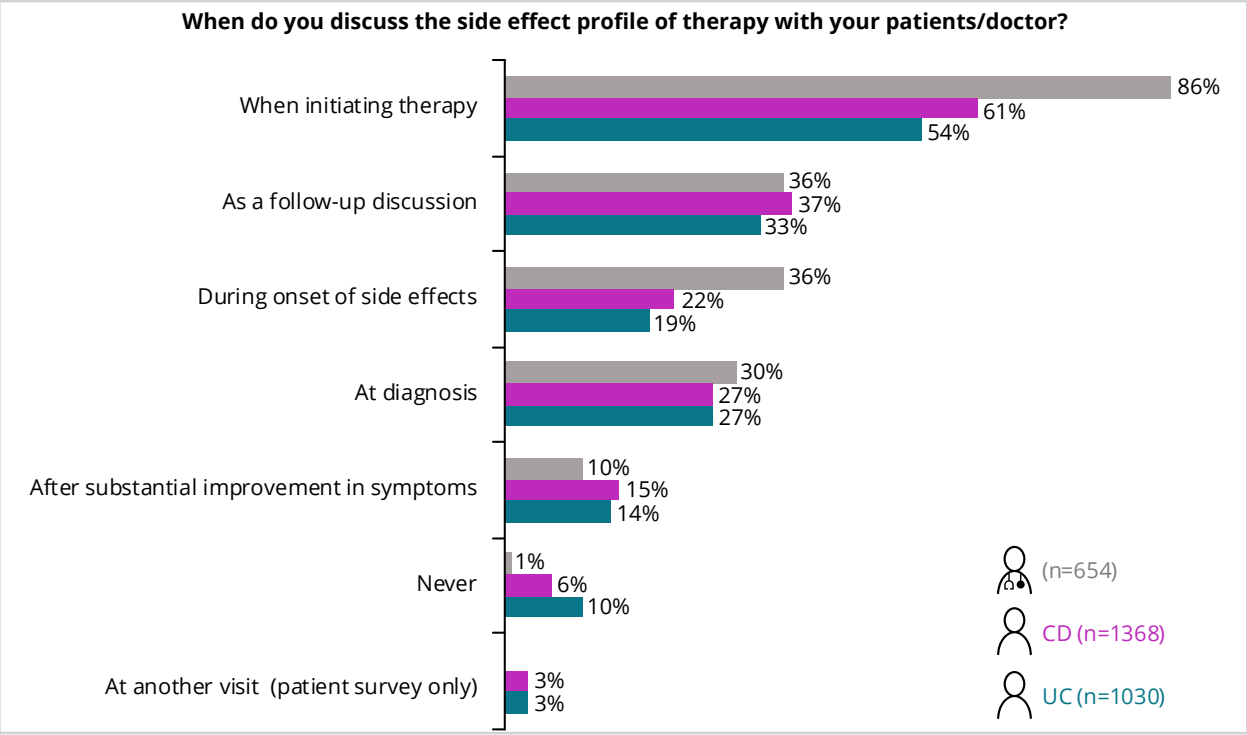
IBD GAPPS responses indicate that while physician and patient perceptions surrounding the prevalence of nonadherence are aligned, the reasons cited were incongruent; patients reported AEs as the main cause, whereas physicians believed it occurs because patients feel treatment is working and therefore can reduce the dose (**Figure 5A**). According to these findings, fewer conversations about adherence are taking place once symptoms improve, and doctors and patients seem to have different opinions about when this discussion takes place.

## Figure 5A. Adherence



While many physicians said they discuss the side effect profile of therapy with their patients at treatment initiation, only 54% and 61% of patients with UC and CD, respectively, said that it occurs at this time (**Figure 5B**). Having a conversation about adherence, and the increased risk of relapse with nonadherence, at *every* follow-up (regardless of treatment outcomes) may encourage patients to talk about potential AEs and feel engaged with their treatment.[33]

## Figure 5B. Safety Discussion




Enhancing engagement and communication about AEs and adherence to treatment may improve patients' experience. In view of the lower percentage of physicians who report discussing AEs and the importance of adherence to treatment during follow-up compared with at treatment initiation, it is important that clinicians make time for these discussions with patients throughout the entirety of their treatment.

## Addressing Disconnects: Remission and Treatment Goals

### Aligning on Remission

Increasing communication about remission and treatment goals and setting clear and achievable expectations may improve patients' satisfaction. Achieving remission is a primary goal of IBD treatment; however, defining it in the realm of CD and UC continues to be elusive, as the term is not standardized. "Remission" can mean many things: endoscopic remission, histologic remission, clinical or symptomatic remission, or even steroid-free remission.[38-40] While patients participating in IBD GAPPS focused on resolution of symptoms, physicians reported evaluating results of tests, including colonoscopy or sigmoidoscopy.[29,30] If patients and physicians are not aligned in their definition of remission, they may have different evaluations of treatment success, and this may result in dissatisfaction and misunderstanding.

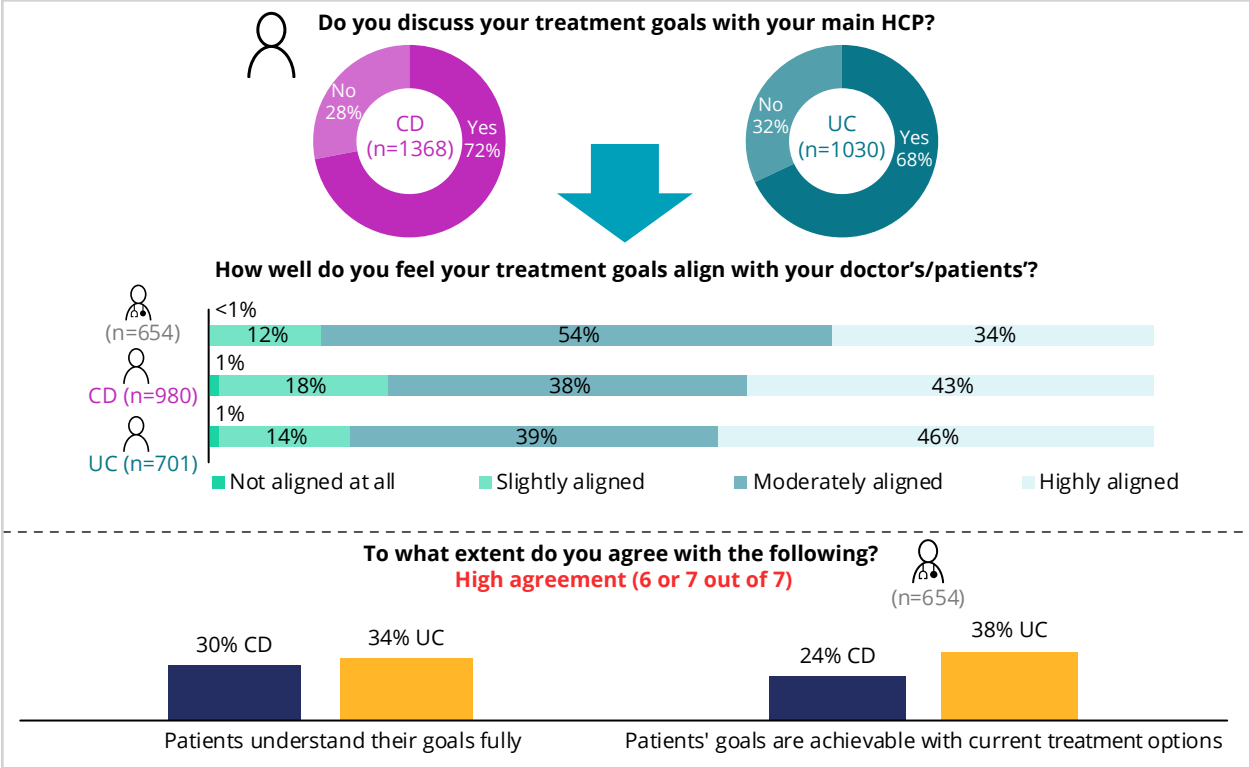
Another parameter to consider is the time to clinical response, as it may depend on disease- and patient-related factors and varies with the drug administered. Thus, this is an important topic to discuss with patients when presenting treatment options, evaluating treatment response, and establishing clear treatment goals and expectations.[41] IBD GAPPS findings revealed that although patients and physicians generally reported discussing disease remission, treatment goals, and satisfaction with treatment, several disconnects were identified about these topics.[29]

> ***We must make time for conversations about treatment goals and verify that patients and physicians are aligned. By having the same objective, we can measure treatment success with the same lens and therefore improve the quality of care provided, as well as patient satisfaction. -Anita Afzali, MD; The Ohio State University Wexner Medical Center***

**Aligning on Treatment Goals**

The findings from IBD GAPPS about patients' and physicians' treatment goals were interesting. Approximately 70% of patients reported discussing treatment goals with their doctors; however, there is room for improvement regarding alignment on the goals (**Figure 6**).

## Figure 6. Discussion About Treatment Goals and Alignment




In addition, when physicians were asked about their patients' treatment goals, only 24%-38% highly agreed that patients' goals were achievable (**Figure 6**). This finding suggests that patients' expectations may differ from what physicians consider realistic and highlights the need for more open and honest communication when treatment expectations and goals are discussed.

**Addressing Disconnects: Symptom Burden**

Improving engagement and communication about the burden of IBD and using a more holistic and patient-centric approach may improve disease management. IBD GAPPS reports a profound negative impact of IBD on patients' quality of life (QoL), and this impact was recognized by physicians.[29] Patient respondents reported feeling comfortable discussing their symptoms with their physicians. However, physician respondents were not well aligned with the top 5 symptoms interfering with the QoL of patient respondents. Some symptoms seemed underestimated, suggesting that better alignment can be achieved in recognizing the most bothersome symptoms.[29]

Similar to the discussion about symptoms, most patients and physicians reported feeling comfortable discussing the emotional impact of IBD on patients' lives. However, observations from IBD GAPPS revealed potential areas of improvement in the management of patients' emotional well-being. Consider having more open and ongoing conversations with patients about how IBD affects them. For patients who need emotional well-being support, consider recommending they contact advocacy organizations and referring them to healthcare specialists trained to provide psychological support.[29]

These findings also support the idea that patient care often requires coordination among a multidisciplinary team including mental health providers.[42] A study evaluating the implementation of a patient-centered medical home, where patients are treated by a localized multidisciplinary team that is coordinated by a gastroenterologist, showed that this care approach can reduce healthcare utilization.[42-44] In a recent attempt to define a quality of care standard, ECCO published a list of criteria adaptable at both local and national levels. It recommended the constitution of an IBD unit providing a multidisciplinary approach to patient care; an identified psychologist or a clear pathway for referral is deemed desirable.[45] However, not all patients have access to such care, and remote monitoring integrated with standard care can decrease healthcare utilization.[25,46]

***Over time, patients can build up a tolerance to uncomfortable IBD symptoms and believe that what they experience is a new normal, hence lowering their quality of life. For this reason, it's important to encourage patients to describe what they struggle with in their everyday life and work with them to find the appropriate treatment and support that allow them to achieve meaningful goals and improve their well-being.***

***-Charles Sninsky, MD; Digestive Disease Associates***

## Summary: Applying Lessons Learned to Improve Patient-Provider Communication and Strengthen Relationships

Because of the chronic nature of IBD, the diverse symptom manifestations that evolve throughout the disease trajectory, and the increasing variety of therapeutic options, patients may benefit from using an SDM approach to optimize care.[23,26,47,48] Patients, including those who participated in IBD GAPPS, expressed interest in being involved in treatment decisions, and most believe SDM is important.[29,49,50] Increased involvement of patients in decision making has been shown to improve patient satisfaction[23]; therefore, patients should be empowered to actively participate in decisions regarding their treatment and in setting achievable goals that matter to them.

In light of disparities in the access to specialists between patients living in rural and urban areas and in disease manifestation among different groups (eg, young vs elderly, different races), and in light of the recent changes in the healthcare environment (eg, the ongoing pandemic), the need for high-quality care is greater than ever. Recent recommendations and study results suggest that a multidisciplinary team can improve disease management.[42,44] Telemedicine and remote management have been shown to provide effective support and appropriate follow-up, even during unexpected situations such as disease flares.[6,21]

These lessons learned, including those from IBD GAPPS, should help patients and physicians communicate better and understand what is important in regard to treatment and adherence, as well as the definition of relevant and achievable goals. Findings from this global initiative revealed that patients and physicians usually discuss symptoms, the impact of IBD on patients' emotional well-being, and treatment goals including remission, and patients are generally satisfied with the management of their disease. However, important disconnects regarding the definition of disease remission, characterization of the most bothersome symptoms affecting patients' QoL and their emotional well-being, concerns about AEs, and the consensus regarding achievable treatment goals remain.

> ***Open and frequent conversations should be encouraged between patients and providers, especially as patients' needs and the healthcare environment continue to evolve. Reflecting on IBD GAPPS findings and using resources that encourage SDM may help improve communication and establish more effective partnerships between patients and their care teams. Together, we can start to address these identified gaps. -Laura D. Wingate; Crohn's & Colitis Foundation***

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