



Unmet Needs in Inflammatory Bowel Disease **SURVEY** REPORT

JUNE 2024 // **Gastrointestinal Society**

 **badgut.org**

Inflammatory bowel disease (IBD) is a condition defined by inflammation in the digestive system. There are two primary subtypes of IBD: Crohn's disease and ulcerative colitis, which differ in the area affected. In ulcerative colitis, inflammation always begins at the rectum and moves upward, affecting only the mucosa of the large intestine. In Crohn's disease, inflammation can affect any part of the digestive system, continuously or in patches, and can penetrate the depth of the bowel wall. However, there are also several other types of IBD, including microscopic colitis (lymphocytic colitis and collagenous colitis), diversion colitis, ischemic colitis, radiation enteritis, and indeterminate IBD. Symptoms are often severe and can include abdominal pain, frequent diarrhea, rectal bleeding, fever, nutritional deficiencies, weight loss, and many others. While there are plenty of treatments available for IBD, including medications, surgeries, and dietary approaches, individuals living with IBD often still have trouble achieving remission, a state defined by mucosal healing and a decrease in symptoms.

Methods

The Gastrointestinal Society, along with the Canadian Society of Intestinal Research, hosted a survey on its website (www.badgut.org), in both English and French, from February 6, 2024, to May 27, 2024, about the unmet needs in IBD. This was a follow-up to two surveys we conducted between 2018 and 2020, but with a focus on how the worldwide effects of the 3Cs: COVID-19, Climate, and Conflict are affecting healthcare for those with IBD. This survey was open internationally and the only qualifying factor was an IBD diagnosis.

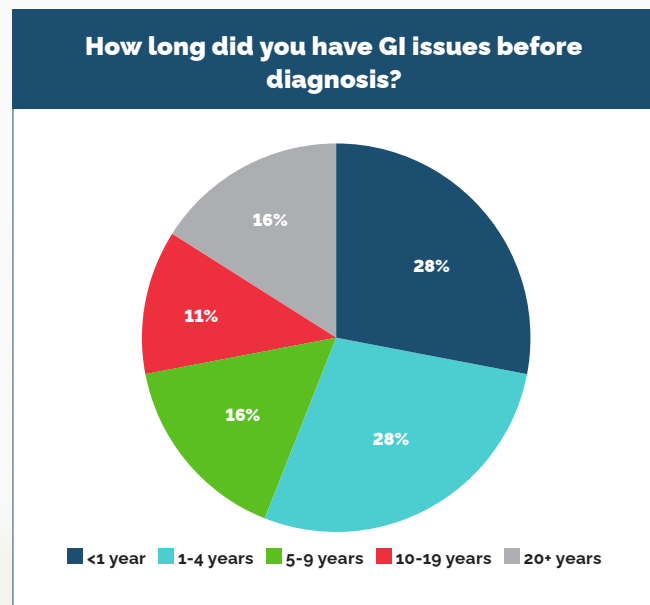
Results

Demographics

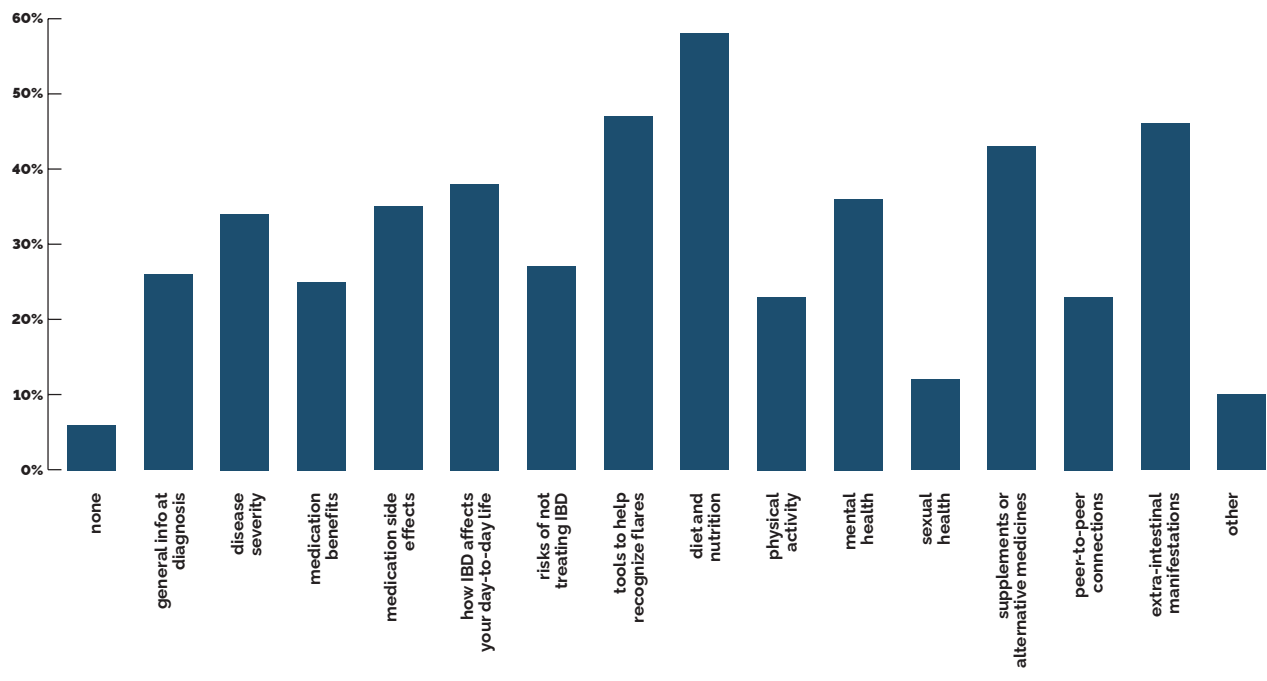
We had 651 respondents complete the survey. Women were more likely to respond, with 80% of survey participants being female and 20% male. Most respondents were from Canada (79%), particularly Quebec (31% of Canadians), Ontario (24% of Canadians), and British Columbia (18% of Canadians). Individuals from the United States made up a further 16% of respondents, and there were 7 respondents each from the United Kingdom and Australia, 6 from France, 3 from the Netherlands, 2 from Ireland, and 1 each from Bulgaria, Germany, Italy, Lebanon, Sierra Leone, and South Africa.

Crohn's disease was the most represented type of IBD, affecting 41% of respondents, followed by ulcerative colitis (29%) and unspecified IBD (24%). Another 10% indicated having microscopic colitis and 1% had ischemic colitis.

We asked respondents how long they had gastrointestinal issues before being diagnosed with IBD. While more than half (56%) received a diagnosis within 4 years, 16% had symptoms for 20+ years before diagnosis. These numbers are considerably worse than our 2020 survey, in which 72% had a diagnosis within 4 years and only 6% had to wait 20+ years.



On which of these topics would you have liked your healthcare provider(s) to give you more information?



Experiences with Healthcare

Wait times continue to be an issue for individuals living with IBD. Only 26% of respondents were able to get an appointment with their general practitioner within a week, 49% had to wait 1-4 weeks, 14% for 1-3 months, 3% for 4-11 months, and 1% for more than a year. Worse, 7% indicated that they had no access to a general practitioner. Predictably, it took longer to get an appointment with a gastroenterologist, with 5% waiting less than 1 week, 29% for 1-4 weeks, 31% for 1-3 months, 16% for 4-11 months, 6% for more than a year, and 13% did not have access to a gastroenterologist. Long wait times can be a serious issue for those who experience an IBD flare, as inflammation can rapidly worsen, leading to mucosal damage and increased symptoms and complications as the individual waits to see a doctor for help.

“It is very difficult to access treatment when flareups occur, the wait to see a physician makes it difficult to get treatment in a timely manner.”

Even after getting an appointment, respondents’ experiences with care varied. When asked if their needs and concerns were addressed by their gastroenterologist after their appointment, 12% said not at all and 44% only somewhat. However, 32% were completely satisfied with their appointments.

IBD specialty nurses are an important part of IBD care, but only 19% of respondents said they have regular access to one (66% no, 3% sometimes, 12% not sure). Specialty IBD nurses who work in the community at centres associated with gastroenterologists help manage appointments for patients for testing and monitoring. They are also readily available for patients between visits with the gastroenterologists, providing support and guidance to manage diet and nutritional deficiencies, and to address any symptoms that might arise. These nurses provide educational, self-care, and lifestyle modification advice to help manage symptoms, as well as offer support for emotional wellbeing and the psychosocial impact of living with IBD.

Another aspect of healthcare that respondents found lacking is patient education. When asked which topics they would have liked their healthcare providers to provide more information on, only 6% said none. Popular topics included diet and nutrition, tools to help recognize flares and what to do if they have one, extra-intestinal manifestations, supplements or alternative medicines, how IBD affects their day-to-day life, and mental health.

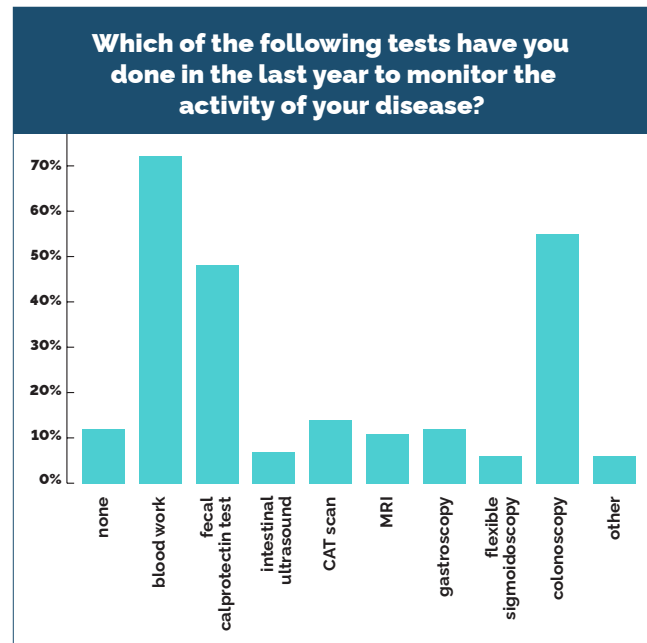
This is especially disappointing, as 61% of respondents list their physician or healthcare team as one of their preferred sources to learn about IBD, yet they aren't getting the information they need. Other popular sources of information include web searches (43%), which come with a heavy risk of misinformation, as well as patient groups (37%) and IBD patient education tools (31%).

Some respondents also expressed frustration at the lack of communication between different specialists, as there is a lot of overlap between IBD and other conditions.

"I also see an oral pathologist for another autoimmune disease, and I feel there is a lack of knowledge and continuity between the disciplines involved. IBD goes beyond the gut, and I think there needs to be more integration between specialists. Treatment plans should be holistic in my opinion."

In the past year, only 12% of respondents had no tests done to monitor their disease activity. Other respondents had multiple tests done, including blood work, colonoscopy, fecal calprotectin, and more. The 12% of respondents who had no tests done were less likely to have access to a physician, with 11% having no access to a general practitioner and 39% having no access to a gastroenterologist.

IBD flares can be severe, and often require immediate medical attention. Because of this, visiting the emergency room (ER) is a common occurrence for those living with IBD. Most survey respondents did not need to visit the ER (68%) in the past year because of their IBD. However, 12% of respondents visited the ER and were admitted within 24 hours and 5% were admitted but had to wait more than 24 hours to access a bed. Others had the difficult experience of full ERs, with 5% being accepted at the ER but not admitted due to lack of beds and 1% being turned away at the door because the ER was full.

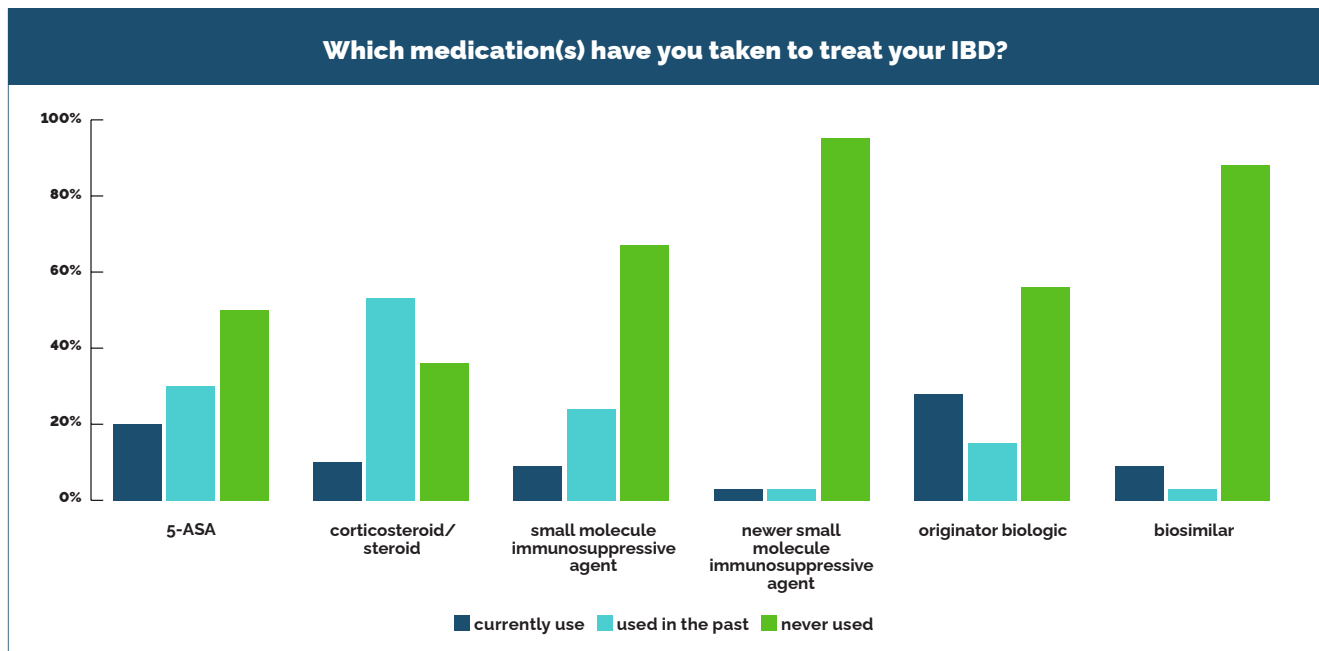


Medication Use

The treatment process for IBD often involves using one medication, then switching to another medication (or adding another medication to an existing routine) if it doesn't work or if it stops being effective. Some individuals need to regularly repeat this process before finding an ideal regimen. The chart on page 5 shows the wide variety of medications respondents have used throughout their time with IBD.

Fortunately, several new medications for IBD have hit the market over the past few years, but there are still people living with IBD who find it difficult to get relief. In our 2020 survey, 33% of respondents did not believe that their IBD was well-controlled by their current medications. In our 2024 survey, this number was 29%, compared with 38% who did find it well-controlled and 33% who were unsure.

Each person living with IBD has a different experience. This is why it is so important that those living with IBD have access



to varied treatments. What happens when they run out of options that work and are affordable? When asked how concerned they are about running out of treatment options, 82% were at least somewhat concerned.

Route of administration is another concern, as some medications come in forms that require the patient to go to a clinic or hospital to receive an infusion. These medications are often highly effective, but it can be difficult or costly for individuals who need to take time off work or school, pay for transportation, arrange childcare, etc. While 30% of respondents have no preferred route of administration, 41% prefer a daily oral medication, and monthly injections were less preferred.

Medication Coverage

Coverage of medications by private and public plans is another important aspect of IBD care. It doesn't matter how many groundbreaking medications are available if people can't afford them. In our survey, 70% of respondents did not have difficulty obtaining insurance coverage for their IBD medications. However, for the individuals who did have problems obtaining coverage, reasons included not having access through government drug plans, private plan insurance not covering the drug, being told they need to try other drugs first, not having any coverage, and out-of-pocket costs that are too high. Respondents highlighted some of their difficulties.

"My UC is well controlled by Stelara, but the Alberta Seniors Drug Plan does not cover it even though I tried Simponi (which is covered) first and it failed after a year."

"Remicade took care of all my symptoms better. Ontario government forced us off. Gastroenterologist switched me to Stelara. Not as good. Gastroenterologist has now retired. No one else available in our rural area."

"Insurance only approves X number of pills per month, not the amount prescribed by doctor."

"As a senior, Entocort was not covered through the government plan, and I don't have other drug insurance coverage, and quite frankly if I did, I doubt they would have covered it."

"The drug company has me on their compassionate care program for now. I hope that continues. The drugs should be cheaper so more people can get them."

Disease State

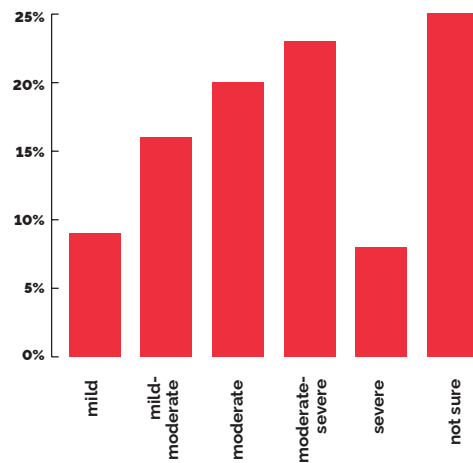
Physicians typically classify IBD according to its severity, which is important when looking at which types of treatments might work best for a specific patient, and some medications are only available for those with a certain IBD severity. We asked respondents how their doctor classified their IBD, but 25% weren't sure. However, we don't know whether this is because the physicians never told them, the physician couldn't decide, or the respondent forgot. Of those who did know their IBD severity, it ranged from mild to severe. 47% of respondents agreed with their physician's classification, 35% were not sure, and 10% disagreed.

When treating a chronic disease without a cure, such as IBD, it is important that physicians and patients are on the same page about treatment goals. We let respondents choose multiple answers when asking what their definition of being in remission is, and 59% indicated absence of symptoms, 43% said being able to enjoy things they enjoyed prior to diagnosis, and 38% said a decrease in symptoms. Overall, most individuals feel they are in remission when their IBD stops limiting them from living their lives, such as when they are able, in the words of respondents, ***“to leave the house without fear of losing control, go on holidays, complete normal tasks,”*** or ***“to trust my body again. Fecal incontinence is an absolutely devastating occurrence,”*** or ***“to enjoy social events a bit more, not anxious about being in close proximity of washrooms.”***

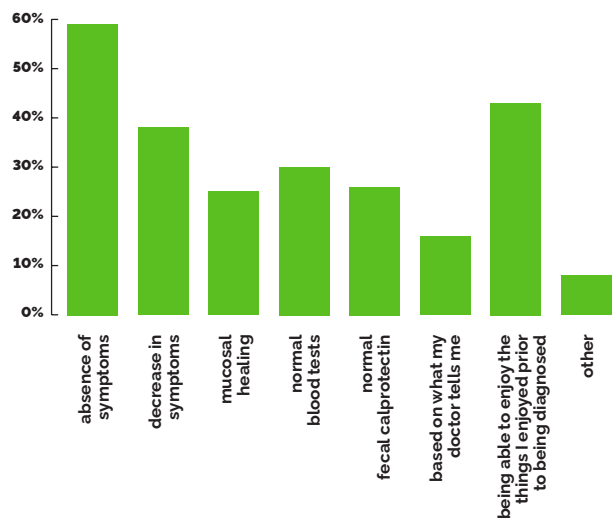
Another individual explained the changes in the way they think about wellness after living with IBD.

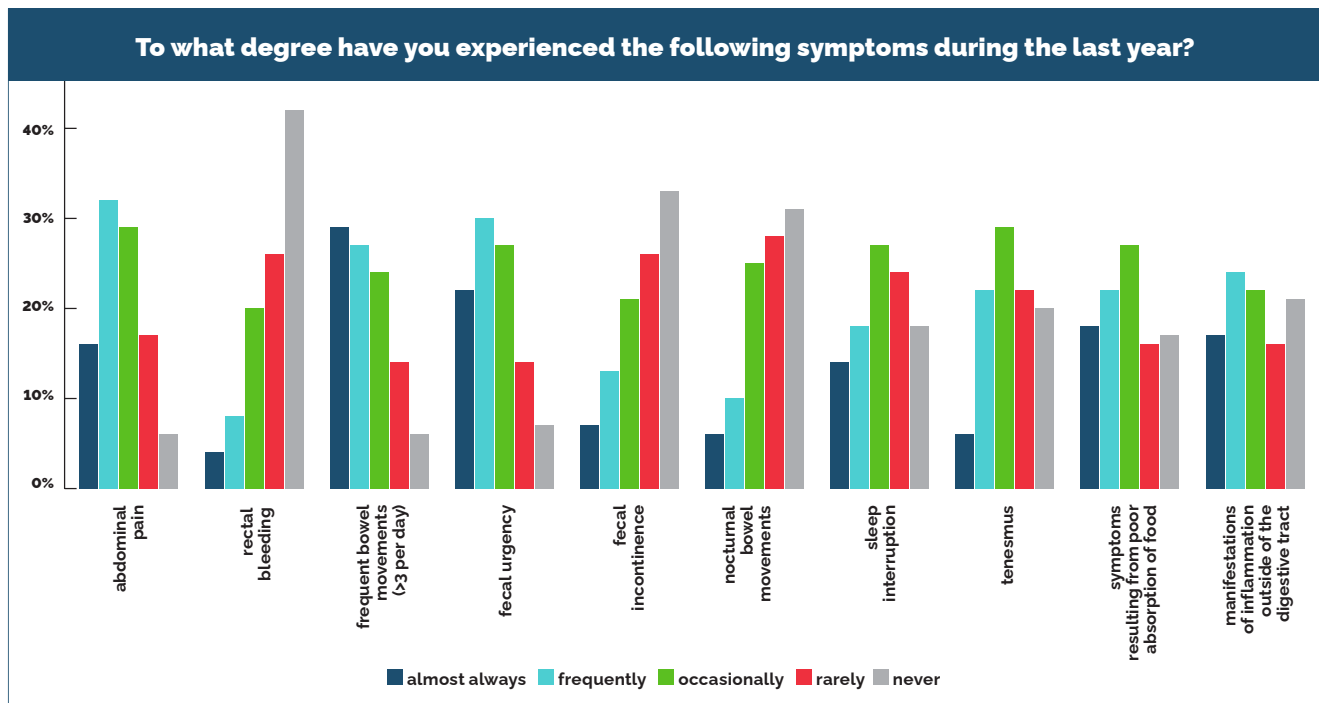
“This is a complicated question. I understand that my bowels can be in remission (nice healthy pink bowels – mucosal healing) but I can still be dealing with other symptoms that affect my quality of life (anemia, fatigue, diarrhea, medication side effects etc.). I checked off the box being able to enjoy the things I enjoy but I would delete ‘prior to being diagnosed’ as I stopped measuring against my ‘pre-diagnosis’ self a couple of years after diagnosis and my ‘yard stick’ changes based on adapting to disease changes like surgery, etc. Adjustments take time but are needed.”

How does your doctor classify your IBD severity?



What is your definition of being well-controlled/in remission?





Symptoms

Those living with IBD are plagued by numerous symptoms that can range from mild to so severe they require hospitalization. We asked respondents about which symptoms they had faced in the past year and found a wide range of experiences. The most common symptoms were abdominal pain, frequent bowel movements, and fecal urgency, with more than 90% of respondents having experienced these in the past year. The least common symptom was rectal bleeding, which still affected 58% of respondents in the previous year.

The systemic effects of IBD are clear in the number of respondents who experienced manifestations of inflammation outside of the digestive tract (e.g., arthritis, skin problems, liver disease, kidney stones, and eye inflammation) and symptoms resulting from poor absorption of food (e.g., weight loss, delayed growth, fatigue, anemia, nutritional deficiencies). These issues affected about 80% of respondents.

Some other difficult symptoms they encountered include fecal incontinence, nocturnal bowel movements, tenesmus, and sleep interruption.

Microscopic Colitis

An aspect of IBD care that came up frequently in our survey was the lack of information for, and attention to, those with microscopic colitis, which includes collagenous colitis and lymphocytic colitis. These types of IBD involve inflammation that isn't visible during a colonoscopy but becomes apparent when biopsy tissue is analyzed under microscope.

Some individuals found that their healthcare team was dismissive of their diagnosis, such as one person whose, ***“GI nurse practitioner told me that collagenous colitis is considered a ‘nuisance’ disease because it will not kill me. That did not ease my mind at all. It scared me even more!”*** Another individual stated, ***“I think like most microscopic colitis patients we feel we’re the neglected party in the colitis family. We’ve been told everything from you don’t have IBD to you should be grateful you only have microscopic colitis, you’re lucky.”***

Overall, most IBD resources focus on Crohn’s disease and ulcerative colitis. ***“We need more information and research on Microscopic Colitis. It might be less severe than other IBDs but is still life altering.”***

Quality of Life

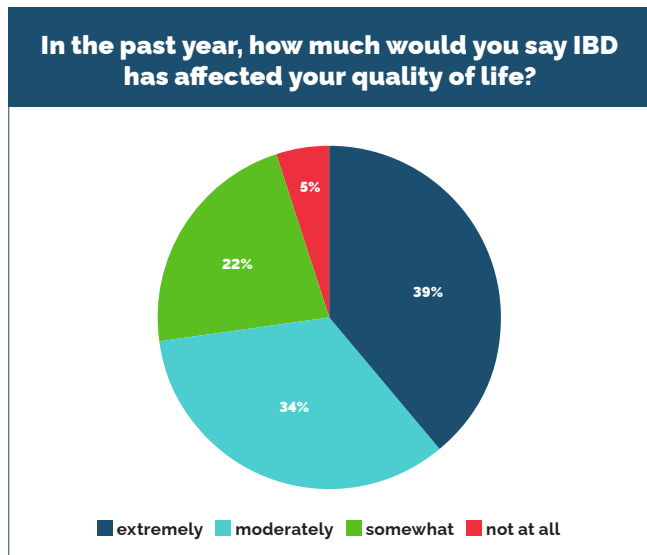
The effects of IBD on day-to-day life can be extreme, as the symptoms affect an individual’s ability to work, go to school, attend social events, and even leave the house for mundane errands. IBD is often an invisible illness, and many others might not understand just how life-changing it can be. As one respondent puts it, *“people seem to dismiss the concern that comes with having to stay home when you are having an episode. My anxiety kicks in if I haven’t planned to go out before hand.”*

Of our respondents, 39% said that IBD had an extreme effect on their quality of life in the past year, 34% said it moderately affected their quality of life, 22% somewhat, and only 5% said it didn’t affect their quality of life at all.

“In my experience, some of the most difficult aspects of IBD, pain aside, are its unpredictability and the constant, often overwhelming fatigue. It takes time to figure this out and develop one’s own coping mechanisms. I think it’s helpful to know that this is part of the experience, and that it’s not insurmountable.”

Many respondents missed work or school due to IBD. While 46% of respondents said this was not applicable to them (e.g., they do not work or go to school), 20% missed 1-5 days in the past year, 9% missed 6-19 days, and 10% missed 20 or more days due to IBD. Only 17% said they didn’t miss any days of work or school because of IBD.

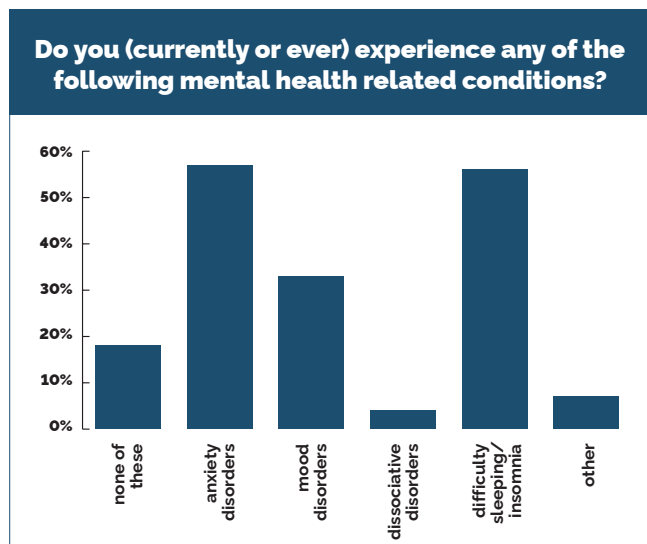
“This disease is livable. I’ve learned to live with it. For example, the first thing I do when entering or visiting somewhere is locate a bathroom even if I don’t need to go right away. Also, I can not attend any activities if there is no bathroom nearby. My biggest issue is how far the bathroom is from where I work. I’ve almost had accidents due to this. So, it affects my life everyday, but all I can do is accept it and learn to live with it, just the unfortunate card I was dealt with.”



Mental Health

Problems with mental health are often entwined with IBD. In many cases, the life-altering nature of IBD can lead to stress, anxiety, and low mood. Both those who struggle with pre-existing mental health conditions and those who don’t might find it difficult to deal with the symptoms, increased doctor visits, strict medication schedules, and other changes to day-to-day life brought on by this disease. Several respondents wrote about the mental effects of IBD.

“Just sad because I miss my former quality of function, spontaneity, work performance.”



“Just afraid to go out to the mall without protection as I’ve had a very embarrassing experience.”

“Hopelessness, for although I have done everything I can humanly do and researched my problem, I can’t get any medical professional to listen to me or help or refer me. However, I was approved for MAID within 3 months time!!”

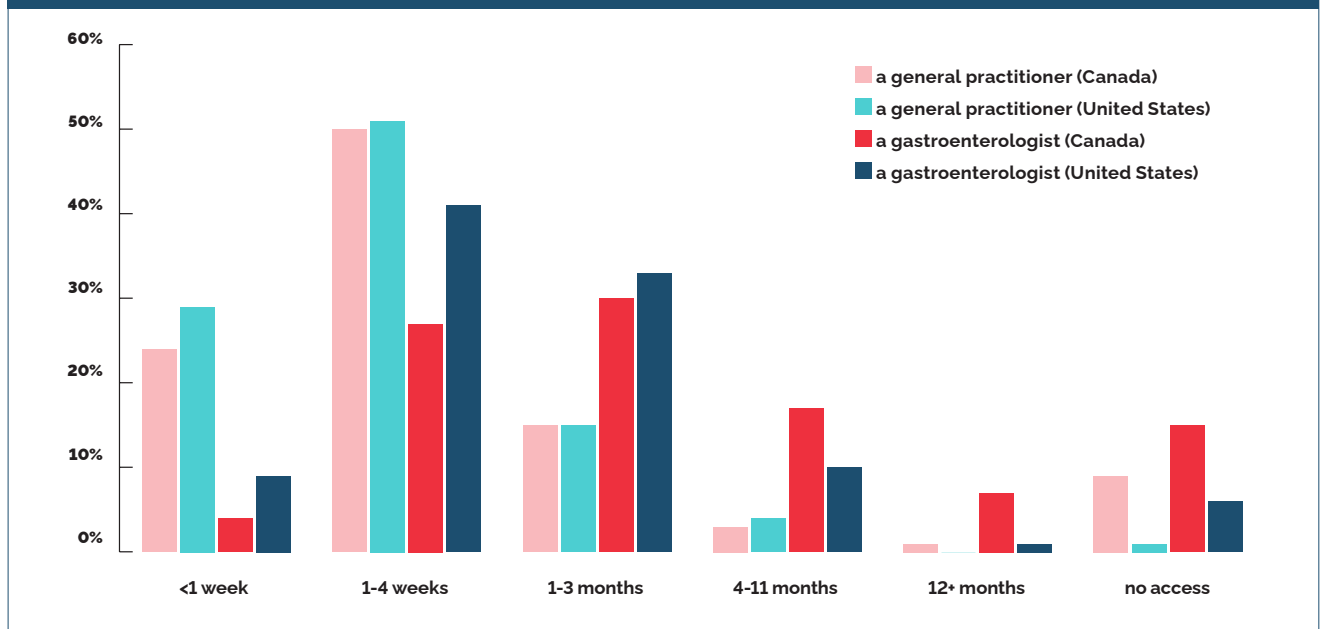
“Sadness with a disease that makes it hard to travel or participate in some social activities.”

“It takes almost a year to determine a drug isn’t working and then we do a scope, change drugs and the cycle starts all over again... over and over with no improvements... depressing and making me feel suicidal.”



Only 18% of respondents indicated that they don’t have any mental health conditions. Anxiety disorders, including generalized anxiety, social anxiety, and post-traumatic stress disorder (PTSD), were most common, affecting 57%, followed closely by difficulty sleeping or insomnia at 56%. Mood disorders such as depression or bipolar were also prevalent at 33%, 4% of individuals had a dissociative disorder, and 7% indicated another mental health condition. These results signify an increasing need to integrate mental health supports in the management of IBD.

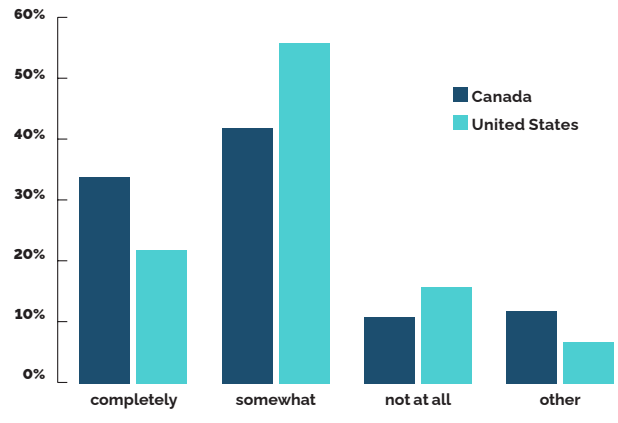
How long do you typically have to wait to get an appointment with:



Canada vs the United States

There are numerous differences between Canada’s healthcare systems and those in the United States. Our American respondents tended to have better access to a family doctor, with only 1% not having access to a doctor, compared to 9% of Canadian respondents. When it came to access to a specialist, 6% of American respondents had no access to a gastroenterologist, compared with 15% of Canadians. They also tended to get appointments with their gastroenterologists much sooner than Canadians. However, despite the quicker access, the Americans were less likely to feel that their needs and concerns were met by their physicians.

After you had an appointment with your gastroenterologist, to what extent do you feel your needs and concerns were addressed?



Conclusion

Our survey results indicate that those living with IBD face many barriers in receiving the care they need. From long wait times at all levels of care to a lack of access to healthcare professionals, patients are often left suffering. They typically try many medications before finding something that helps them enter remission, and even then, the medication can lose efficacy.

Individuals living with IBD often worry about how their symptoms prevent them from going places where they have limited access to washrooms and feel embarrassment and shame over fecal incontinence and other symptoms. Many want more information from their healthcare team, and find that patient education in certain areas, such as diet and nutrition, flares, and extra-intestinal manifestations of IBD, is especially lacking.

As inflammatory bowel disease grows increasingly common, we need more research, collaboration, and meaningful engagement to improve the lives of those who struggle daily with IBD and better manage this chronic disease.

Please Note

The gastroenterologists overseeing this survey are:
 Guy Aumais, MD, CSPQ, FRCPC, Montreal, QC
 James Gray, MD, CCFP, ABIM, FRCPC, Vancouver, BC
 Mark MacMillan, MD, FRCPC, CAGF, Halifax, NS
 John Marshall, MD, MSc, FRCPC, CAGF, AGAF, Hamilton, ON
 Remo Panaccione, MD, FRCPC, Calgary, AB

Thanks to these individuals and groups for sharing the survey link with their followers on social media platforms: Brad Watson-Davelaar, Crohn’s and Colitis Canada, the US’s Crohn’s and Colitis Foundation Northwest Chapter, Guts & Glory, Ildiko, IMAGINE SPOR Network, The Colitist, and the Toronto Immune and Digestive Health Institute.

We are grateful for the unrestricted educational grants and sponsorships to conduct this survey from: AbbVie Corporation, Ferring Inc., Janssen Inc., and Takeda Canada Inc.

Percentages have been rounded to whole numbers. Quotes in bold are from survey respondents.

The Gastrointestinal Society does not intend that this report replace the knowledge or diagnosis of your physician or healthcare team, and we recommend seeking advice from a medical professional whenever a health problem arises.

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Gastrointestinal Society

231-3665 Kingsway, Vancouver, BC V5R 5W2
 Phone: 604-873-4876 or toll-free in Canada 1-866-600-4875



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