

Gastrointestinal Society

# 2016 SURVEY RESULTS

Irritable Bowel Syndrome (IBS)



The GI (Gastrointestinal) Society represents Canadians living with gastrointestinal diseases and disorders including those who have irritable bowel syndrome (IBS). We offer patient education on a wide array of GI conditions in text and video formats that covers the disease or disorder processes and provides descriptions of treatments available. The Society advocates to ensure Canadians have access to the best treatment and care.

During early 2016, we hosted a survey on our websites in English ([www.badgut.org](http://www.badgut.org)) & French ([www.mauxdeventre.org](http://www.mauxdeventre.org)) to help understand the way that IBS affects patients living with this condition. To qualify, survey participants had to confirm that they were either an individual diagnosed with IBS or the parent of an individual diagnosed with IBS. We had 2,961 respondents: 2,505 in English and 456 in French.

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## Follow-up IBS Survey

If you have IBS or take care of someone who does, please consider taking our short, five question follow-up survey whether you completed the original survey or not.

[www.badgut.org/ibs-follow-up](http://www.badgut.org/ibs-follow-up)



## BACKGROUND

IBS is a chronic, often debilitating, functional gastrointestinal disorder with symptoms that include abdominal pain, bloating, and constipation or diarrhea, or alternating between the two stool consistency extremes. It is the most common gastrointestinal condition worldwide and the most common disorder presenting to a gastrointestinal specialist (gastroenterologist), even so, only 40% of those who experience IBS symptoms seek medical help.<sup>1,2,3</sup> Disease management includes lifestyle and dietary changes, and medication therapy. IBS can begin in childhood, adolescence, or adulthood and can resolve unexpectedly for periods throughout an individual's lifespan, recurring at any age.

Diagnosing IBS is a fluctuating process as there is no medical test that can diagnose it outright. In 1962 Chaudhary and Truelove identified IBS as a functional disorder and in 1978 Manning established the first diagnostic criteria. Since 1989, under the auspices of the Rome Foundation, an international group of experts periodically updates the criteria.

Historically, based on the varying diagnostic criteria researchers and clinicians use to assess symptoms, approximately 13-20%<sup>4,5</sup> of Canadians have IBS at any given time. In 2016, diagnostic criteria changed significantly, and while the symptoms of those who were previously diagnosed with IBS

have not changed, a good portion of those who had been diagnosed with IBS might not be included under the new criteria. The main reasons are that in the newest criteria, 'pain' replaces 'discomfort or pain' and stool consistency is no longer associated with the start of pain.

Using the recently updated Rome IV<sup>6</sup> criteria, the overall prevalence of IBS in the United States, Canada, and the United Kingdom is now estimated at 5.7%, but this is the first time that prevalence of IBS has been calculated this low.<sup>7</sup> In Canada and most Western nations, IBS seems to arise significantly more frequently in women (75-80%) than in men, but the reasons for this remain unclear.<sup>8</sup>

Although each person has a unique IBS experience within the range of known symptoms, this condition can significantly decrease a person's quality of life, which is significantly lower than those without IBS.<sup>9,10, 11,12,13,14</sup> People with IBS often suffer in silence, possibly due to their reluctance to discuss their bowel habits.<sup>15</sup> Of those who do go to a doctor, 25% have symptoms that require a referral to and management by a gastroenterologist.<sup>16</sup> Reports from gastroenterology clinics reveal that IBS is the most frequently encountered diagnosis.<sup>17,18,19</sup>

Photo (below): © elgachov | Bigstockphoto.com

## What is the criteria for IBS diagnosis?

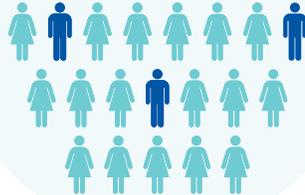
According to Rome IV criteria, the official diagnostic tool for functional gastrointestinal disorders, a person has IBS if they had recurrent abdominal pain on average at least one day per week in the last three months, with two or more of the following criteria:\*

- related to defecation
- associated with a change in frequency of stool
- associated with a change in form (appearance) of stool

\*Criteria fulfilled for the last three months with symptom onset at least six months prior to diagnosis<sup>20,21</sup>

# SURVEY DEMOGRAPHICS

**86% are female**



**90% are between 30-69 years of age**



**Respondents are from all provinces and territories**

(with close proportional representation to the corresponding populations)

**53%**

**53% have suffered with IBS for more than 10 years**

**41% have IBS-M**  
(mixed type)

**35% have IBS-D**  
(diarrhea predominant)

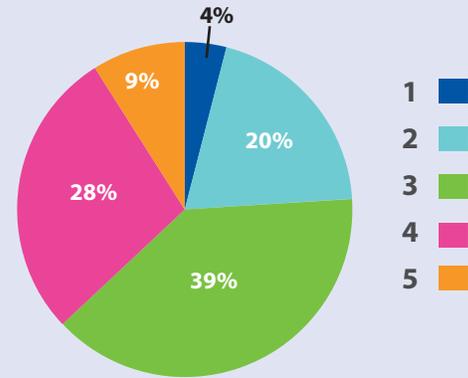
**18% have IBS-C**  
(constipation predominant)

**6% aren't sure**

# SYMPTOM SEVERITY

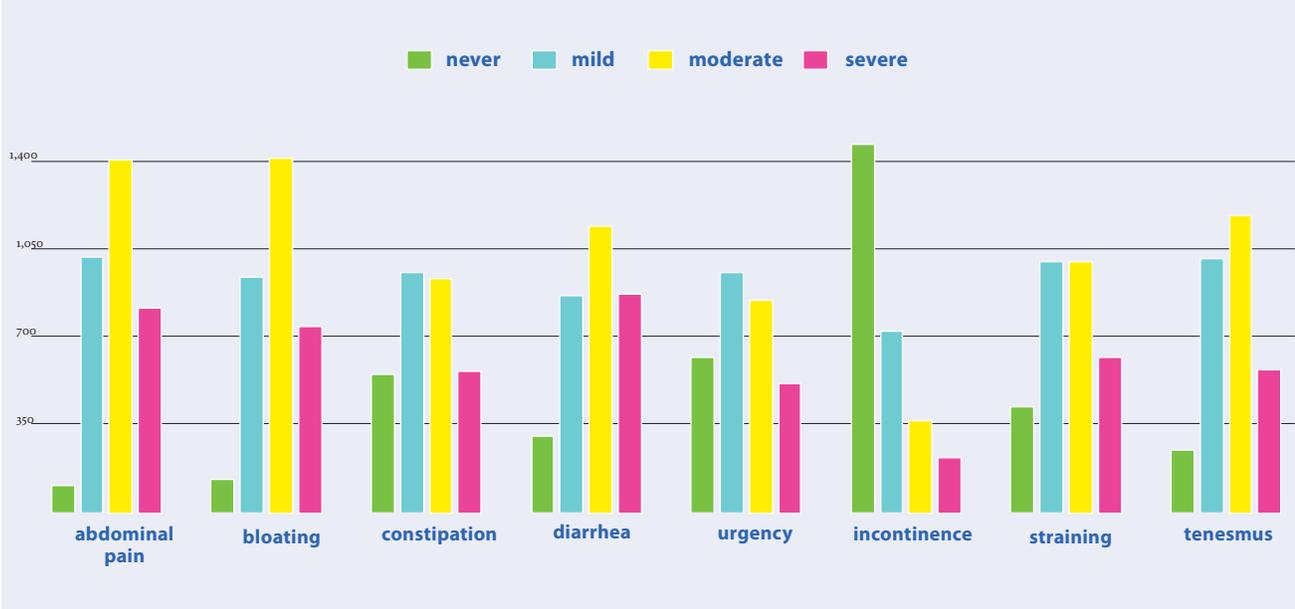
We conducted this survey to learn the impact of IBS on Canadians and to see how symptoms affect them. Abdominal pain is a key diagnostic IBS symptom for all subtypes. Respondents were asked to record all levels of pain they had experience within the last three months. For example, a person could choose mild, moderate, and severe, if they experienced any of those degrees during the time specified. Many individuals had various levels of pain from IBS. When rating the severity level of pain they experienced at some point during the past three months, 39% say their abdominal pain was mild, 53% say it was moderate, and 31% say it was severe. Only 4% of respondents did not experience abdominal pain in the past three months. More than 62% of patients indicate their pain continued after bowel movement (sometimes/often/always). Also allowing selection of more than one level of severity, for bloating, a commonly reported IBS symptom, 5% say never, 36% mild, 53% moderate, and 28% severe in the past three months. Diarrhea (76% moderate or severe) is more common than constipation (57% moderate or severe), but both affect many respondents. Moderate to severe urgency to defecate occurs (sometimes/often/always) in the majority of individuals. Straining, and the constant feeling of needing to pass stool (tenesmus) are all fairly common symptoms, but most IBS patients do not experience fecal incontinence.

**Thinking about your IBS abdominal pain during the last three months, please rate it. (1=no pain, 3= moderate pain 5=worst possible pain)**



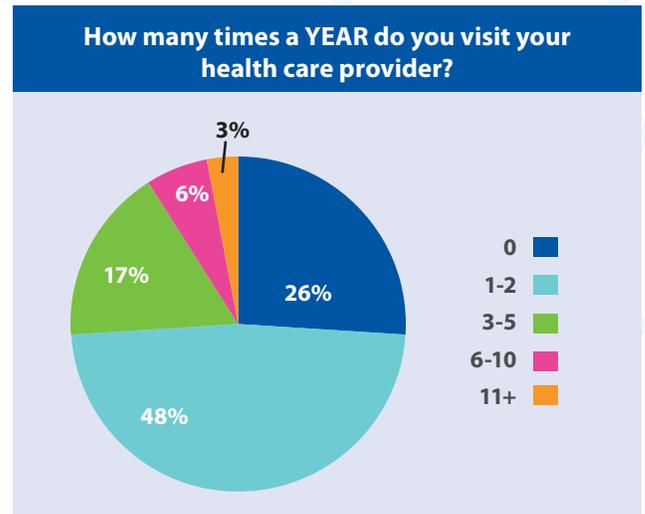
**More than 62% of patients indicate their pain continued after bowel movement**

**Please note the degree of severity for each symptom you have experienced during the last THREE MONTHS.**



## HEALTH CARE SYSTEM

When it comes to the impact of IBS on the health care system, patients most commonly consult their general practitioner due to pain or discomfort, or because their symptoms were beginning to interfere with normal aspects of their lives. Fewer than half of the respondents have ever visited a gastroenterologist. When they went to their physicians with symptoms, the most common diagnostic test ordered by their physicians was a colonoscopy (61%), followed by laboratory tests (36%), gastroscopy (30%), and ultrasound (28%). While 26% of respondents say that they don't visit their health care providers on a yearly basis, 48% get health care for IBS 1-2 times annually, 17% do so 3-5 times annually, 6% do so 6-10 times annually, and 3% visit health care providers 11 or more times each year. In addition, 12% of respondents have been hospitalized for reasons relating to IBS.



## Have you watched our IBS Video?

We have two videos that help explain what it means to have IBS. The first video, IBS Overview, explains all the IBS basics, including diagnosis, symptoms, statistics, and more, and the second explains IBS Treatments.

**[www.badgut.org/ibs-videos](http://www.badgut.org/ibs-videos) or  
YouTube channel 'badgutcanada'**



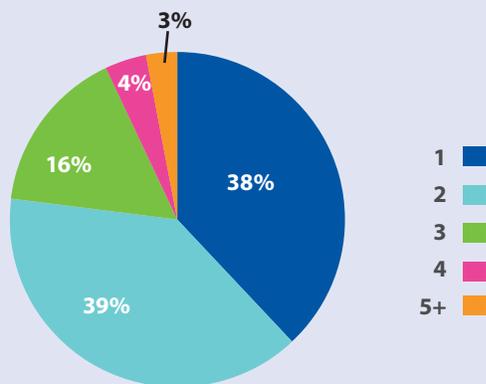
## MEDICATIONS

62% of respondents use two or more medications/treatments on a regular basis to control their IBS symptoms, since most treatments address only one of the symptoms of IBS. Unfortunately, 16% are unable to afford any of their prescribed medications, and 26% can only afford some of them.

A variety of treatments are available for IBS patients, and this survey shows that many are quite popular, especially dietary modifications and fibre supplements. In spite of all these treatments, most respondents are still not happy with their results. Only 21% feel confident that their IBS

symptoms are under control, 45% feel that some of their symptoms are under control, and 34% feel that none of their IBS symptoms are under control. These findings are similar to the 2015 *IBS in America*<sup>22</sup> survey results in which just one-quarter or fewer IBS-C and IBS-D patients were 'very satisfied' with treatments. Specific to IBS-related abdominal pain, the key diagnostic symptom, antidepressants and antispasmodics do not work in the majority of respondents, and pain relievers are not effective for approximately one third of respondents

**On average, how many different treatments do you use on a regular basis to manage your IBS symptoms?**



### Do you have any other medical conditions?

- mood disorders 32%
- gastroesophageal reflux disease 27%
- anxiety disorders 27%
- sleep disorders 24%
- fibromyalgia 15%
- type II diabetes 9%

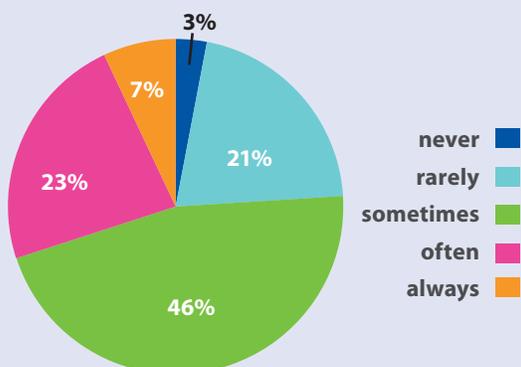
## COMORBIDITIES AND EFFECTS ON QUALITY OF LIFE

Managing IBS on its own can be complex, but many patients suffer from other diseases and disorders in addition to IBS: 32% have some form of mood disorder, 27% have gastroesophageal reflux disease, 27% have an anxiety disorder, 24% have a sleep disorder, 71% experience anxiety (sometimes/often/always), and 83% find that IBS limits their dietary options (sometimes/often/always). Only 3% of respondents say that their IBS symptoms never interfere with everyday life, and 76% say that their symptoms (sometimes/often/always) interfere with everyday life. 37% of respondents

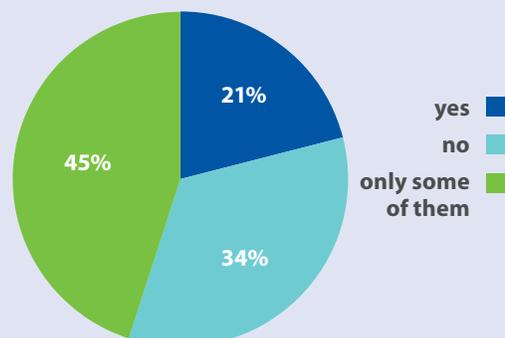
(sometimes/often/always) cannot leave their home due to IBS in an average month, with the percentage increasing in respondents with IBS-D. In IBS patients who work or go to school, 46% say that they miss one or more days in an average three-month period due to their IBS symptoms. 48% of patients indicate they experience poor quality of life (sometimes/often/always) in an average month due to IBS.

**76% say that their symptoms interfere with everyday life**

**How often do your symptoms interfere with everyday life such as work, school, and social situations?**



**Do you feel confident that your IBS symptoms are under control?**



**48% of patients indicate they experience poor quality of life in an average month due to IBS**

## SUMMARY

Individuals who have IBS experience multiple abdominal and bowel symptoms, with IBS-D patients identifying abdominal pain, bloating, urgency, and diarrhea as highly difficult symptoms and IBS-C patients identifying abdominal pain as a distinct difficult symptom that occurs independent of constipation. In fact, the pain/discomfort experienced by patients is the number one motivating factor to see the doctor. Currently, more than 60% of IBS patients use two or more medications on a regular basis to control their symptoms yet only 21% are confident their symptoms are under control. IBS impacts patients' personal, social, and work life, with more than 70% indicating that their symptoms interfere with everyday life and 46% missing work or school due to irritable bowel syndrome.

Many IBS patients cannot leave their home due to their symptoms, and this is more common in those with IBS-D. Interestingly, most patients with IBS rate their general health and overall wellbeing as being good or okay even

though 48% of patients indicate they regularly experience poor quality of life in an average month due to IBS. This could be attributed to the fact that the majority of patients have suffered from IBS for more than 10 years and consequently have come to accept poor quality life as the norm.

There is a clear unmet need in the treatment of IBS, as despite the wide variety and popularity of treatments available, most respondents are still not happy with their results. IBS-related abdominal pain, the key diagnostic symptom, is the number one motivating factor for patients to see their doctor. The majority of patients report that antidiarrheals and antispasmodics do not work for them, and one third of our respondents said that currently-available pain relievers are not effective. The results of this survey show that the majority of sufferers want better control of their symptoms and they need more treatments options to achieve this goal.

## RECOMMENDATIONS

# BASED ON THE RESULTS OF THIS SURVEY

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## 1. Treat the abdominal pain associated with IBS

The majority of IBS patients experience moderate to severe abdominal pain – a key diagnostic symptom of IBS and one of the main predictors of disease severity.<sup>23,24</sup> Abdominal pain is the most difficult IBS symptom to treat and has a

major impact on a person's quality of life.<sup>25</sup> By adequately controlling the pain, the potential for IBS patients to resume their social activities and normal life at home, work, or school is greatly increased.

## 2. Reduce the time it takes for a patient to be diagnosed with IBS and achieve relief from the multiple symptoms associated with IBS

The majority of patients have suffered from IBS for more than 10 years. During this time, they have seen health care professionals numerous times a year, undergone diagnostic tests that frequently do not add to the IBS diagnosis (colonoscopy, ultrasound, gastroscopy), been hospitalized for reasons related to their IBS, and cycled through multiple

courses of over-the-counter and prescription medications.

Increasing collaboration among patients and health care professionals could assist with the identification, monitoring, and management of IBS, and might lessen the duration between the appearance of symptoms and diagnosis.



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**Phone** 604-873-4876  
**Toll-Free** 1-866-600-4875  
**Fax** 604-451-4429  
**Toll-Free Fax** 1-855-875-4429



**Gastrointestinal Society**  
231-3665 Kingsway  
Vancouver BC V5R 5W2



**info@badgut.org**  
**www.badgut.org**



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