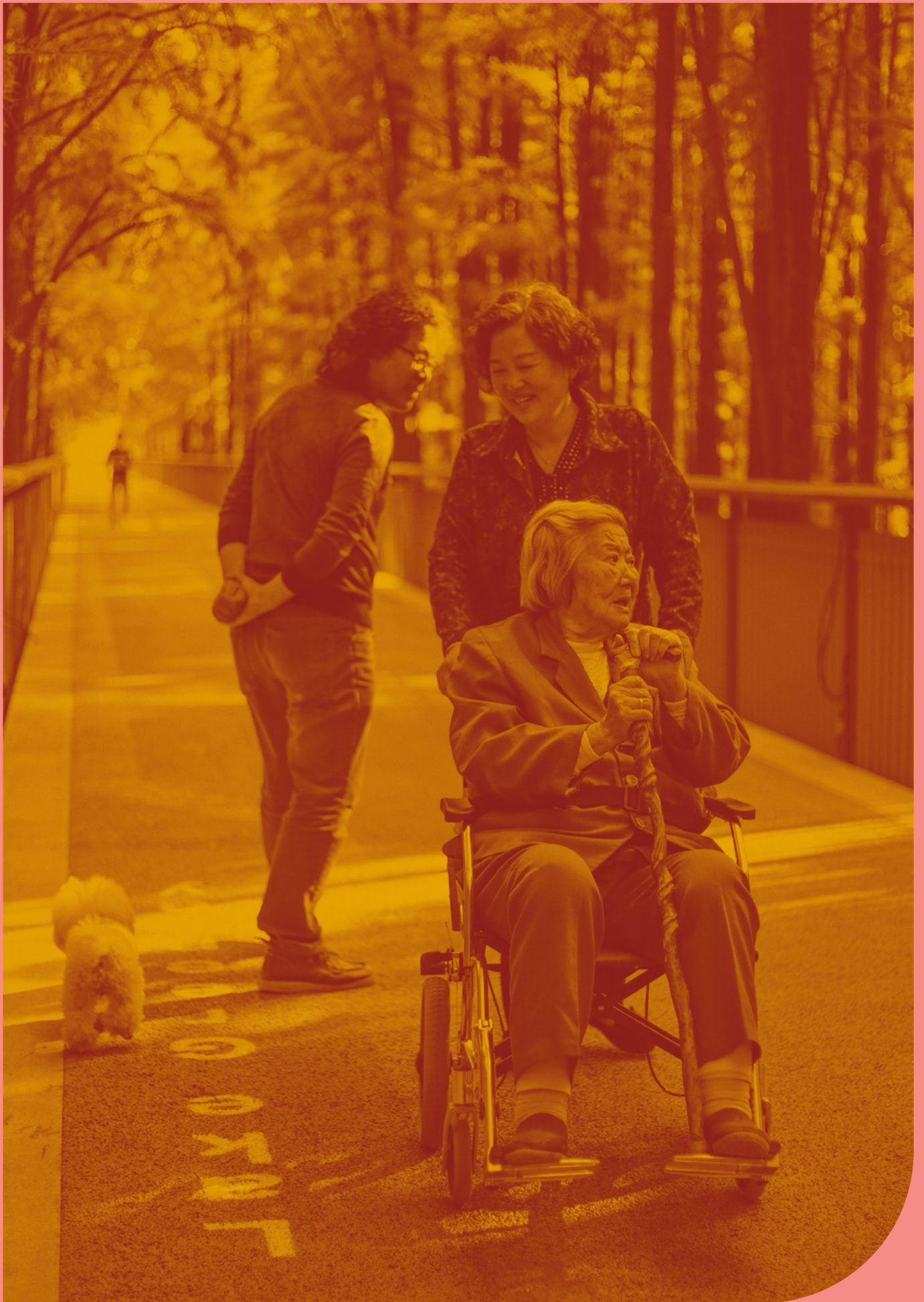




# Takeda GI Perceptions Audit:

Evaluating Awareness and  
Attitudes Towards Gut Conditions





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## Section 01

# Introduction: An overview of gut conditions

At Takeda, we put patients at the heart of everything we do to drive our strong heritage in gastroenterology. Having spent over 30 years supporting the GI patient and research community, our every thought, action and attitude must put those who live with these conditions first.

Our aim is to give patients a voice by making their often “invisible” conditions seen and heard through pioneering innovation, now and in the future. Building on our longstanding heritage, we are invested in breakthrough science that helps improve disease outcomes and patients’ quality of life.

Gastrointestinal (GI) diseases such as inflammatory bowel diseases (IBD) are a global issue, and their prevalence is rising across every continent. IBD is a term used to describe two chronic conditions, Crohn’s Disease and Ulcerative Colitis, which cause severe abdominal pain, diarrhoea, and chronic inflammation of the GI tract.<sup>1,2</sup> Prolonged inflammation can result in damage to the GI tract,<sup>2</sup> and IBD is associated with an unpredictable relapsing-remitting cycle<sup>3</sup>. According to the European Federation of Crohn’s & Ulcerative Colitis Associations (EFCCA), as many as 10 million people worldwide and 3.4 million people in Europe are living with IBD.<sup>4</sup>

Given this context and wanting to better understand the needs and challenges of people living with gut conditions, in 2023, Takeda initiated and commissioned two surveys on GI perceptions. As part of this, the surveys also captured insights into the levels of awareness and perceptions of gut conditions among the general population and policymakers in Europe and Canada. The aim was to generate supportive evidence to drive more meaningful conversations to identify solutions with policymakers and decision-makers, and ultimately contribute to improvements for those living with gut conditions. The results of these two surveys are summarised in this report.





## Section 02

# Background to the surveys

The General Population and Policymaker GI Perceptions Audits are surveys that were conducted in March and April 2023 by Savanta, a market research company, in order to gain insights into understandings and misunderstandings of gut conditions in selected countries. Please note that the referenced survey results do not characterise medical facts about gut conditions, and are only intended to describe the perceived impact of gut conditions, as reported by people with gut conditions, people without gut conditions and policymakers.

For the GI Perceptions Audit of policymakers, 105 telephone interviews were carried out across a total of eight countries: Spain, UK, Italy, Belgium, Canada, Sweden, Germany and France. The interviews lasted 20 minutes and were conducted exclusively with elected legislators. Out of these 105 policymakers, 61 (58%) were either personally affected or had a family member living with a gut condition.<sup>5</sup>

The GI Public Perceptions Audit was conducted from 14 March to 29 March 2023 in the UK, France, Germany, Italy, Spain and Canada. Approximately 1,000 members of the general public per country (6,336 total) were invited to complete a 10-minute online questionnaire regarding their understanding of GI conditions. This was a nationally representative sample based on age, gender, region, ethnicity/origin (excl. France) and post-secondary education attainment. Out of 6,336 total respondents, 2,069 (33%) had been previously diagnosed with a gut condition.<sup>5</sup>

## Section 03

# Symptoms and exacerbations can impact the lives of people with gut conditions

## Exacerbations and symptoms are frequently experienced by people living with a gut condition

The survey findings showed that the respondents frequently experienced symptoms:

**43%**

experience exacerbations every 2 to 4 weeks

**20%**

experience exacerbations on a weekly basis and;

**6%**

suffer from exacerbations at least once per day.<sup>5</sup>



Furthermore, female respondents generally reported a higher frequency of exacerbations than males.<sup>5</sup>



**50%**

More than 50% of respondents reported experiencing bowel-related symptoms such as bloating, frequent bowel movements and abdominal pain at least once a month.<sup>5</sup>



**49%**

experience constipation



**45%**

experience diarrhoea



**38%**

experience nausea

When asked about whether living with a gut condition has affected their day-to-day responsibilities as a parliamentarian, a policymaker from Italy responded:<sup>5</sup>

“Sometimes you can’t sleep well because of gastric acid and gastric reflux, and then you can’t perform 100%”

Policymaker, Italy

## Living with a gut condition can cause disruptions to an individual's work and career



# 43%

of respondents noted that they have missed work due to their gut condition in the last 12 months.<sup>5</sup>



# 40%

believe that their illness has had a negative impact on their earnings and career progression.<sup>5</sup>

When asked about how living with a gut condition has affected their day-to-day responsibilities as a parliamentarian, a policymaker from Germany commented<sup>5</sup>:

“I live my everyday working life under physical impairment and difficult conditions. It takes a lot of energy. And if I ignore my physical boundaries, I end up in bed for one or two weeks with a fever.”

**Policymaker, Germany**



# Quality of life can be impacted when living with a gut condition



## Social lives:



**32%**

About a third of respondents (32%) feel they are unable to have a normal social, romantic or sex life due to their illness.<sup>5</sup>

## Mental health related to a gut condition:

When asked, respondents shared insights on how their mental health has been affected by their gut condition, noting that:



**33%**

experience anxiety disorders.



**32%**

experience mood disorders.



**24%**

experience depression.



**6%**

Up to 6% experience suicidal thoughts.<sup>5</sup>



Female respondents were more likely to report experiencing anxiety disorders than men.<sup>5</sup>

When asked about whether their family member's mental health had been impacted by their gut condition, a policymaker from the UK responded<sup>5</sup>:

“From a social perspective, it would curtail how you feel, e.g. you are more aware that you need to be around a bathroom...There is also a hint of embarrassment e.g. if you are with someone you don't know and you don't know how to explain it.”

**Policymaker, UK**

## People living with a gut condition sometimes experience stigma and feel that society does not take their condition seriously



**20%**

of respondents have experienced unfair comments and discrimination in their place of work due to their illness.<sup>5</sup>

**40%**

of respondents feel that society does not take their condition seriously. Female respondents were more likely to report feeling this way than males.<sup>5</sup>



**33%**

do not feel comfortable talking about gut conditions in the workplace.<sup>5</sup>



When asked about whether their family member's mental health had been impacted by their gut condition, a policymaker from the UK responded<sup>5</sup>:

“It has certainly impacted my mother negatively. It can be debilitating. It means that she cannot go around with her daily work. She is having to go to bed, is feeling miserable, down and worthless. In addition, there is the constant worry and concern that the pain is going to kick in.”

Policymaker, UK

## Section 04

# People living with a gut condition can experience challenges with their care

**People living with a gut condition sometimes experience poor access to services**



**44%**

of respondents noted that they are not able to access the right specialist for their psychological needs. More female respondents reported not being able to access the right specialist than males.<sup>5</sup>

**People living with a gut condition can experience exacerbations that require visits to the emergency department**



**55%**

Over half of respondents (55%) have been to an emergency department due to an exacerbation, and 29% have visited an emergency department in the last year.<sup>5</sup>

**People living with a gut condition can experience long waits for a diagnosis and referral to a specialist**



**31%**

of respondents had to wait over 6 months to receive a diagnosis from a specialist healthcare professional.<sup>5</sup>



**27%**

of respondents had to wait over a year between experiencing their first symptoms and receiving a formal diagnosis.<sup>5</sup>

When asked about whether living with a gut condition has affected their day-to-day responsibilities as a parliamentarian, a policymaker from France responded<sup>5</sup>:

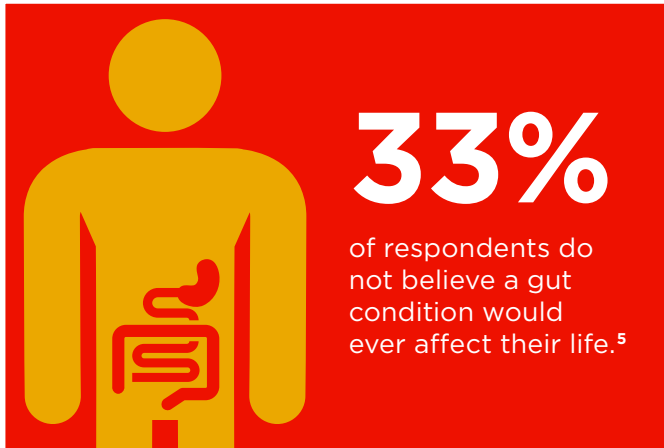
“Not anymore, nowadays, because of the evolution in terms of treatment over the last 30 years...But that is because my disease has been diagnosed. I know some people are waiting years before being diagnosed.”

**Policymaker, France**

## Section 05

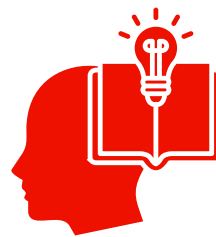
# Common perceptions across people living without gut conditions

Among the general public living without a gut condition (64% of 6,336 general public respondents)<sup>5</sup>:



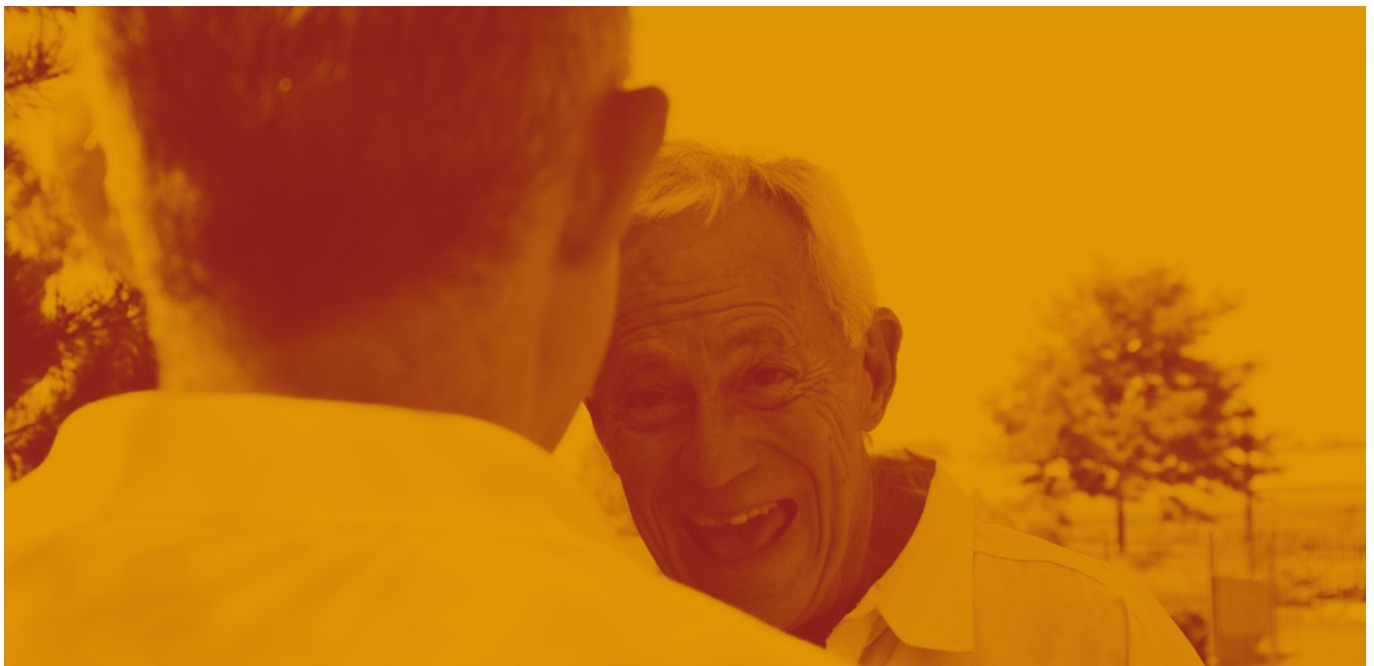
- Respondents living without gut conditions were less familiar with IBD compared to other chronic conditions. 22% were familiar with IBD, lower than familiarity with coronary heart disease (36%), rheumatoid arthritis (40%), asthma (68%), and diabetes (71%).<sup>5</sup>
- While 35% of respondents understand that IBD can affect anyone, 27% believe that it is more likely to affect adults with unhealthy lifestyle choices and 24% associate it with a poor diet.<sup>5</sup>

Among the general public living without a gut condition (64% of 6,336 general public respondents)<sup>5</sup>:



**84%**

of policymakers who are not personally affected by gut conditions in some way feel they know little or nothing about them, reflecting a knowledge gap.<sup>5</sup>



**The policymaker survey highlighted some misunderstandings in terms of the impact and cause of symptoms on people living with gut conditions. When asked about the impact of living with a gut condition on people's physical, mental and social lives, these policymakers answered as following:**

“They are certainly very annoying pathologies, although I would say they are not normally serious and disabling pathologies like others.”

Policymaker, Canada<sup>5</sup>

“A poor lifestyle, a poor diet which could be the cause of poor digestion, illness or intestinal complications.”

Policymaker, Belgium<sup>5</sup>

“It is all about self-management. People who manage it well tend to be less affected. Some people who don't manage it well are more prone to being ill.”

Policymaker, Canada<sup>5</sup>

**In contrast, some policymakers were able to recognise the extent of the impact that gut conditions can have on people's physical, mental and social lives:**

“The impact of a gastrointestinal pathology is quite big because it involves everything, from the mental aspect to the intestinal aspect with physical consequences.”

Policymaker, Italy<sup>5</sup>

“It is very debilitating. It probably limits their ability to work. The psychological aspects of being out in public and then being suddenly being overcome with the condition. Situations like that would be a constant worry.”

Policymaker, Canada<sup>5</sup>



## Section 06

# The way forward: overcoming perceived lack of awareness and understanding to drive change

The findings from this survey highlight the potential knowledge gaps that exist among the general public and policymakers regarding life with a gut condition, especially in terms of impact on quality of life, symptom management and the causes. There are also interesting gender-based insights from the survey; overall, women with a gut condition were more likely to report experiencing more frequent exacerbations and anxiety as a result of their condition. In addition, women with a gut condition responded that they felt less able to access the right specialist for their psychological needs and were more likely to feel that their condition was not taken seriously by wider society. This has important implications for the way we approach the challenges faced by those with gut conditions, necessitating further examination and study.

Most importantly, the findings reveal the scale of opportunity to drive change when it comes to the perceptions from the general public and policymakers. Furthermore, the findings highlight clear unmet needs in terms of care that must be addressed around timely diagnosis, efficient referral to specialists and access to services.

We hope that this report serves as an additional support tool that may be used to raise more awareness and better familiarity with gut conditions when engaging with policymakers and decision-makers to drive meaningful change.

## Section 7

# Appendix: Country-focus with specific key findings from the EU5 and Canada markets from Public GI Perceptions Audit



### United Kingdom:

- Sufferers in the UK (n=339) deal with mental health issues and face challenges accessing care.<sup>5</sup>
- 53% of sufferers say they have experienced anxiety or depression as a result of their gut condition.
- 60% say they can access the right specialist for their physical needs, which is lower than all other countries.
- Despite these challenges, non-sufferers in the UK (n=708) have higher levels of awareness about the challenges of IBD than the other countries surveyed.<sup>5</sup>
- 80% of non-sufferers have heard about IBD, and 61% agree gut conditions can negatively affect earnings and career progression.



### France:

- French sufferers (n=282) have higher rates of severe symptoms but feel the least supported compared to other countries surveyed.<sup>5</sup>
- 33% of sufferers in France have weekly exacerbations, the highest rate among all countries.
- 50% of sufferers in work or school find it supportive in managing their condition, which is the lowest among all countries.
- Non-sufferers in France (n=828) have the lowest awareness and familiarity of IBD compared to other countries surveyed, and low concern regarding challenges associated with the disease.<sup>5</sup>
- Awareness of IBD is lower in France than in other markets (61% vs 70% country average) and it has the lowest familiarity (15% vs 22% country average).
- 47% of women agree that those with gut conditions could suffer from unfair comments or discrimination in the workplace, compared to 38% of men.



### Germany:

- German sufferers surveyed (n=294) report high levels of understanding of their condition but feel less comfortable discussing their condition in all settings than other countries surveyed.<sup>5</sup>
- 75% of sufferers feel informed and supported to manage their condition, and 32% feel very informed and supported, one of the highest among all countries surveyed.
- Despite this, 57% of sufferers feel comfortable discussing their gut condition with their own doctor (vs 76% country average) and 34% feel comfortable discussing with their friends and family (vs 62% country average).
- German non-sufferers (n=769) acknowledge associated challenges of IBD gut conditions.<sup>5</sup>
- Two-thirds of non-sufferers in Germany have heard of IBD.
- Just under half (48%) of respondents agree that people living with gut conditions can experience unfair comments or discrimination in the workplace.



## Italy:

- Sufferers in Italy (n=455) face challenges with their mental health and around half find their workplace or school setting supportive in managing their gut condition.<sup>5</sup>
  - 24% of sufferers say they have not experienced mental health issues due to their condition.
  - Barely half of sufferers found their workplace or school supportive in managing their gut condition and 10% found it very supportive.
- Non-sufferers in Italy (n=597) show concern for sufferers of gut conditions but lack understanding of some of the challenges.<sup>5</sup>
  - 83% say gut conditions should be taken more seriously in general and 76% say they should receive greater funding for research.
  - 37% agree that gut conditions could impact sufferers' social lives, which is lower than other countries surveyed (50% country average).



## Spain:

- Spanish sufferers (n=432) experience mental health issues related to their gut condition and do not feel that their condition is taken seriously.<sup>5</sup>
  - 78% of sufferers say they have experienced mental health issues because of their condition.
  - Spain is the only country surveyed where there is a greater share of respondents that feel wider society doesn't take their condition seriously compared to those that do (45% vs 44%).
- Non-sufferers in Spain (n=608) display a broad recognition of the challenges that gut conditions pose.<sup>5</sup>
  - Two thirds (68%) of non-sufferers in Spain have heard of IBD.
  - There was a broad recognition of the fact that suffers of gut conditions may feel fatigued and worn out in their daily lives (70%) and that they may need to take leave from work (69%).



## Canada:

- Sufferers in Canada (n=263) are the most informed about their gut condition and are more likely to find their workplace or school supportive of their gut condition compared to respondents in other countries surveyed.<sup>5</sup>
  - Sufferers in Canada are the most likely to feel informed and supported (83% vs 77% country average).
  - Canadians working or in school are more likely to find it supportive in managing their condition than most other countries (80% vs 61% country average).
- Non-sufferers in Canada (n=762) are likelier to recognise the challenges people with gut conditions face at work compared to other countries.<sup>5</sup>
  - 59% see the potential negative impact on earnings, and 56% anticipate potential discrimination or unfair comments (vs 49% and 47% country average).
  - Three quarters (77%) of Canadians recognise that people living with gut conditions could feel fatigued and worn out in their daily lives.



## Section 08

# References

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