Quality of Life

Impact of IBD on physical and emotional health: Findings from an IBDrelief survey

May 2022

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IBDrelief

Helping people live better with
inflammatory bowel disease

The IBD Quality of Life Survey and Report has been developed with IBDrelief in partnership with, and funded by, Janssen-Cilag Limited.

Contents

When we began talking with Janssen about creating a survey to capture the full experience of people living with IBD – including the physical, mental and emotional aspects of the disease – we knew that we needed to get patients involved in the creation of the survey itself in order to get a true picture.

On too many occasions we have seen surveys that aren't co-created with those living with the disease, which can result in content not fully relevant to people with IBD, questions being misinterpreted and important topics being missed altogether. With this background, we were excited to work with 10 people living with IBD in developing and reviewing the survey before its publication. These reviews informed a number of important changes to the survey content and helped make it possible to deliver the great insights detailed in this report.

Before receiving the data from the survey, my IBDrelief colleagues and I had our own thoughts about what the results might show. Through my own experiences as someone living with IBD, along with observing the many different IBD patients we interact with on a nearly daily basis, we anticipated that the results would indicate that IBD has a strong detrimental impact on mental and emotional health. However, we also held out hope that we were only seeing the extreme end of the spectrum and that the reality for most would be different.

Sadly, this was not the case.

Our hope now is that the results from this survey can help support healthcare practitioners and those living with IBD by acting as a catalyst for change in IBD care, so that a more holistic approach to treatment – for example, encompassing emotional and mental health – can be delivered and, ultimately, become the new standard.

Seb Tucknott
CEO, IBDrelief

Executive Summary

Inflammatory bowel disease (IBD) is a chronic, lifelong condition that affects 500,000 people in the UK and can significantly impact every area of a person's life.[1] Although the physical symptoms of IBD are well characterised, the emotional and mental impacts are less well understood and people living with IBD may need further support in this area.

To further explore the emotional and mental impacts of IBD on the lives of patients and their views on perceived levels of support, IBDrelief and Janssen collaborated on an online survey that was live between 19th May 2021 and 15th June 2021 to people living with IBD in the UK. All survey questions were reviewed by 10 people living with IBD and feedback was incorporated before the final survey was made available online on the IBDrelief website and on social media.

This report details findings from the 167 survey respondents and their views of the impact of IBD on:

- Daily life
- Toilet visits
- Fatigue
- Emotional health
- Perceived levels of help and support
- The COVID-19 pandemic

The findings may help to:

- Inform educational resources for healthcare practitioners (HCPs) such as doctors, nurses, and other IBD practitioners
- Help patients and HCPs to discuss IBD and wellbeing
- Help support patients and HCPs in setting treatment goals that put patient priorities at the forefront

Key findings from the survey are as follows:

IBD can have a large impact on the daily living and future plans of those living with the illness

- Most respondents report being able to participate in everyday life tasks such as leaving the house (66%), being in a job (58%) and socialising (55%) when in remission, but struggle with these same tasks when their disease flares
- Over two-thirds of respondents anticipate that their condition will make it more difficult in the future to improve their overall health (69%) and to travel (67%)
- Two-thirds (67%) of respondents aged 18–34 feel that their condition will make it harder to have children

Symptoms can have a huge impact on the lives of people with IBD, particularly during a flare

- Respondents report spending 40 minutes per day on average using the toilet when in remission and 2.5 hours per day during a flare
- 4 in 10 respondents report that they have accidents ‘occasionally’; 18% of patients with moderate-to-severe IBD say they have accidents ‘daily’
- Nearly half of respondents who are impacted by the number of toilet visits rate the impact on their emotional wellbeing as 10/10 (highly significant impact) during a flare
- 3 in 4 respondents say they experience fatigue daily. For respondents with moderate-to-severe IBD, 6 in 7 in respondents report daily fatigue
- On average, respondents rate the impact of their fatigue on their emotional wellbeing as 7.6/10 (where 10/10 is most significant)

IBD can have a large, often overlooked emotional impact on people living with the illness

- Over half of respondents worry about their disease daily*
- 7 in 10 respondents said they feel embarrassed by their disease at least some of the time[+]
- Anxiety, low mood and low self-confidence were reported as the main negative impacts of IBD
- Respondents said that the most challenging aspects of their condition are managing the physical symptoms and the need to plan ahead when travelling or when out
- Most respondents said that they have taken steps to manage their condition such as avoiding stressful situations and missing social occasions

People with IBD may need support for more than just symptoms from their IBD teams and outside the clinic

- Only one-third of respondents said their consultant has discussed a long-term plan with them
- Two-thirds of respondents said their consultant has not explained the link between physical symptoms and emotional health
- Only a quarter of respondents have discussed emotional wellbeing with their IBD teams
- A third of respondents have sought support from other sources or organisations, and another third would like further direction about where to go
- Almost two-thirds of respondents say much more support is required than what they are currently receiving

The COVID-19 pandemic significantly impacted people with IBD

- 6 in 10 respondents were told to shield due to their IBD
- Just under half of respondents say that COVID-19 has impacted their management plan
- Over half of respondents reported a decrease in their emotional wellbeing due to COVID-19
- Over half of respondents said that the amount of available support for their illness has declined since the onset of the COVID-19 pandemic

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* Includes respondents who worry about their condition constantly (23%) and every day (35%).

[+] Includes respondents who feel embarrassed by their condition sometimes (28%), frequently (28%) and daily (14%).

Introduction

In the UK, an estimated 500,000 people have inflammatory bowel disease (IBD), and this figure is currently on the rise.[1,2] The two main forms of IBD are Crohn's disease and ulcerative colitis (UC) both of which can be associated with abnormalities of the immune system that can be triggered by a genetic predisposition, diet or other environmental factors.[2–5]

> My quality of life is significantly impacted by my IBD… to stay in remission takes a lot of hard work and is depressing sometimes e.g. giving up alcohol, strict diet, resting, not doing too many social activities each week etc.

IBD can be extremely debilitating and can have a considerable impact across an individual's life. The impact of IBD may also be via treatment burden, that is, the effect treatment may have on the individual's overall health and quality of life.[6] IBD is associated with increased hospitalisations, increased mortality risk and increased risk of cancer (e.g. colorectal cancer).[6,7] The illness can also negatively impact quality of life, economic productivity and social functioning.[6-8] It can follow an unpredictable course, with relapses and remissions, and symptoms may include pain, cramps or swelling in the stomach, recurring or bloody diarrhoea, weight loss, fatigue, fever, vomiting and anaemia.[3] There is currently no cure for IBD, but symptoms can be managed with specific diets, lifestyle changes, surgery and medicines (e.g. aminosalicylates or mesalazines, immunosuppressants, biologics, or antibiotics).[3] For this, a supportive relationship between the patient and their healthcare team is key.

For example, there can be major differences in how a patient perceives their disease compared to how a physician is treating it. In a recent study involving 2,398 patients with IBD and 654 physicians, patients primarily defined remission by resolution of symptoms, whereas physicians primarily defined remission using test results.[9] If both patients and physicians understand the impact of IBD on an individual, this can help support creating a treatment plan that includes the patient's priorities.

One major area of unmet need for IBD treatment and management is emotional support for patients.[10-17] In order to support healthcare professionals and foster discussions around this need, the survey presented here aimed to explore the impact IBD has on the everyday lives of patients living with the condition. We also asked about the emotional impact of IBD and perceived levels of help and support currently available to patients, both during consultation and outside the clinic. Finally, we sought to determine the impact of the COVID-19 pandemic on people with IBD. Our key findings are detailed in this report. We hope that they will help improve clinical practice, and contribute to improved treatment strategies and clinical outcomes for people with IBD.

Methodology

Survey questions were developed with input from 10 individuals with IBD, in collaboration with IBDrelief, to ensure clarity in the questionnaire and the relevance of topics covered. Janssen-Cilag Limited provided funding and engaged MedEConnect, a healthcare insights agency, to conduct the survey, which was hosted on the IBDrelief website between 19th May 2021 and 15th June 2021. Respondents were recruited using an open link on the IBDrelief website, an IBDrelief email newsletter and signposted by social media channels. 167 individuals with IBD aged 18 or over and living in the UK responded to the survey. Data was checked to ensure that there were no duplicate entries. There were an additional four optional open-ended, text-based questions at the end of the survey, which received 96 responses.

Living with IBD: Impact on physical and mental health

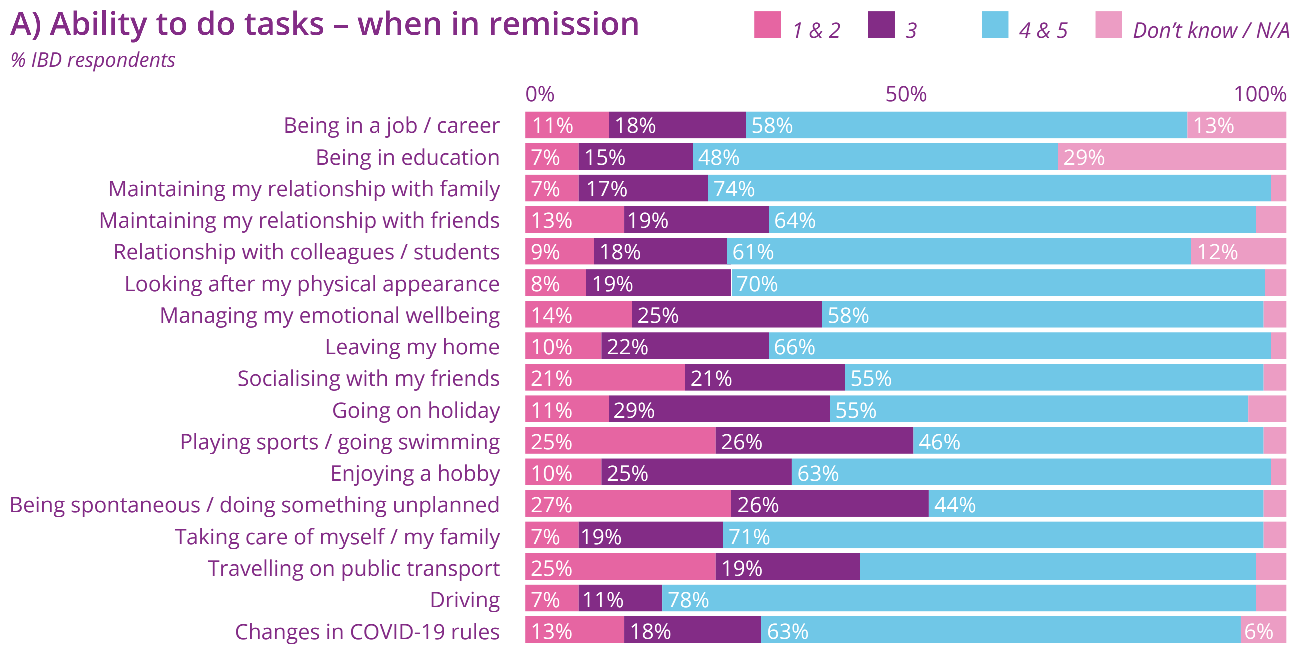
We asked respondents about the impact of IBD on daily life, toilet visits and fatigue levels.

The impact of IBD on daily life

People diagnosed with IBD have to adjust to life with a chronic disease, and associated long-term implications.

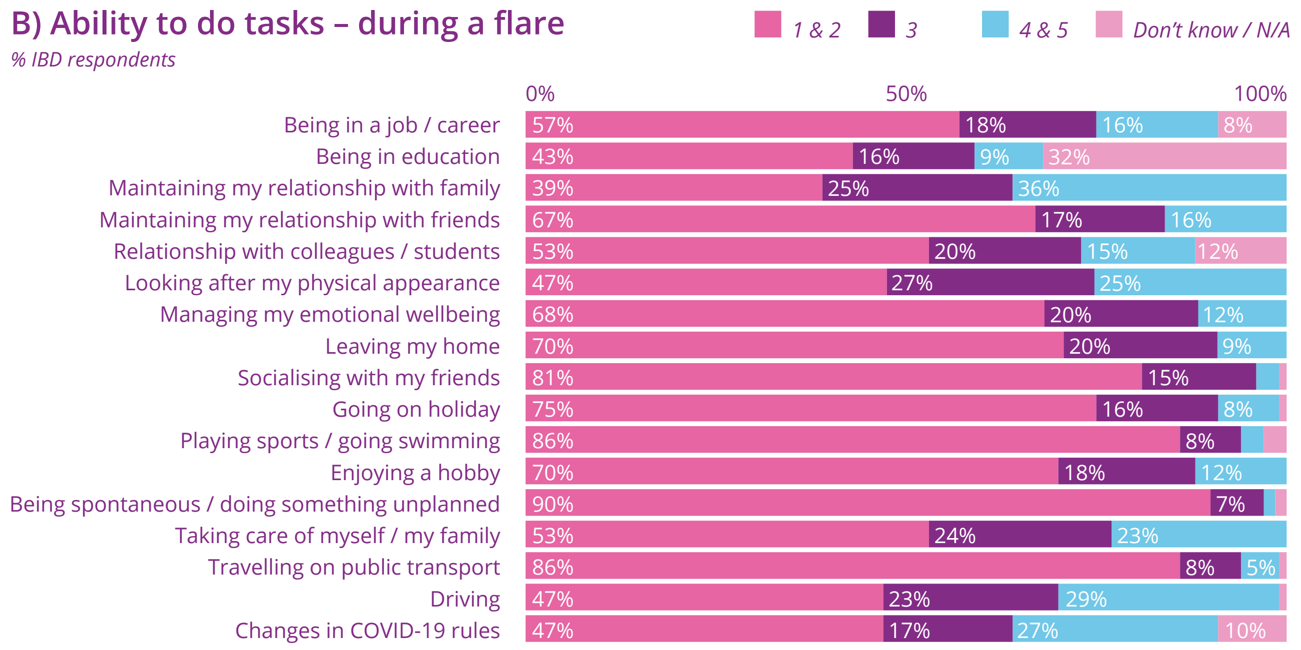
Prior to experiencing symptoms, most respondents said they were able to do all tasks and activities asked about in the survey, including being in a job, career or education, maintaining relationships with friends and family, self-care and leisure activities. This was largely also the case for those in remission, where respondents stated that they are generally able to engage in most of these activities, with the exception of sports, travel on public transport or unplanned activities. However, during a flare, the vast majority of respondents reported difficulty with almost all tasks and activities: on a scale of 1 to 5, with 1 indicating being least able to engage in an activity, 57% rated their ability to be in a job at 1 or 2 and 90% rated doing something spontaneous or unplanned at this same level.

This goes beyond the everyday, with a quarter of all respondents saying that they felt having children would be more difficult as a result of their IBD. This finding is particularly stark when broken down by age, revealing that two-thirds of respondents aged 18-34 years (n=39), and one-third of respondents aged 35–44 (n=30) felt their IBD would make having children more difficult.



A) Ability to do tasks – when in remission

% IBD respondents



B) Ability to do tasks – during a flare

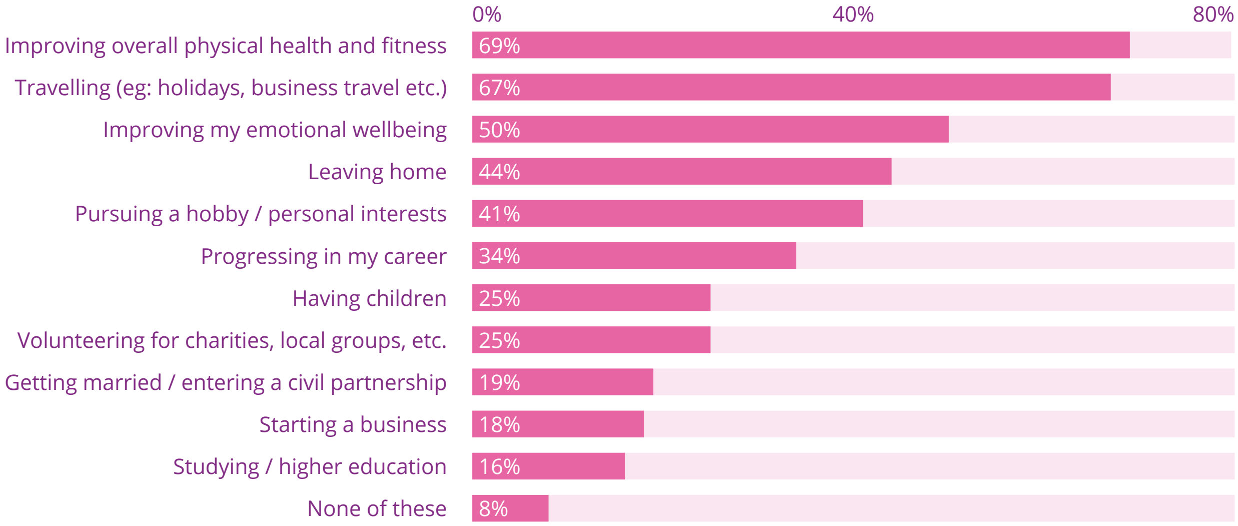
% IBD respondents

(A) Responses to the question, 'Prior to experiencing any symptoms, please rate your ability to do the following'.
(B) Responses to the question, 'Since your diagnosis, please rate your ability to do the following during a flare'.

Both questions were rated on a scale where – 1 = not able and 5 = fully able. 167 participants responded, and were able to rate more than one option. Some percentages may be rounded.

Life events that will be harder to do

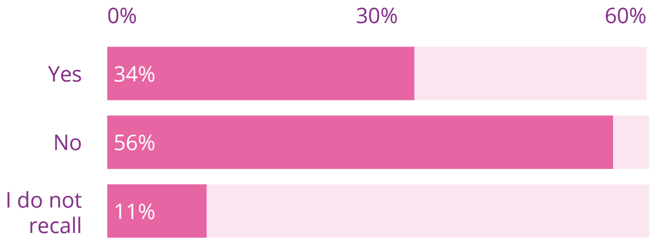
% IBD respondents



Responses to the question, 'Thinking ahead over the next few years, do you feel your condition will make it difficult to pursue any of the following?'. 167 participants responded, and were able to select more than one option. Some percentages may be rounded.

Has an IBD consultant discussed a long-term plan?

% IBD respondents



Region	% Yes
London and South (57)	26%
Midlands and East (36)	31%
North (44)	43%
Devolved Nations (30)	37%

Responses to the question, 'Has your IBD consultant discussed a long-term plan for your disease management with you which considers your personal goals and hopes for the future?' 167 participants responded and were able to select only one option. Responses were further broken down by region participants were based in (London and South, Midlands and East, North or Devolved Nations). Some percentages may be rounded.

In our survey, people with IBD reported feeling that life can become increasingly difficult to manage.

Our survey found that the majority of respondents felt that improving their overall physical health and fitness became more difficult to manage post-diagnosis. This also applied to wider issues that may affect quality of life or ability to work. For example, 67% said that travelling (for holidays or business) has become more difficult since diagnosis and one-third of respondents thought that their career progression would be hindered. Furthermore, 18% and 16%, respectively, felt that starting a business or studying/pursuit of higher education would be impacted by their IBD. Once more, the effects go beyond the practical issues: half of respondents (50%) also said that improving their emotional wellbeing will become more difficult.

Our survey showed that living with IBD can mean being unable to participate in spontaneous activities.

Respondents said that the most challenging aspect of their condition was managing physical symptoms and the need to plan ahead. Even in remission, over 1 in 4 respondents said they could not do something unplanned or spontaneous, and this rose to 90% during a flare.

Survey respondents reported that IBD-related changes to lifestyle, future plans and personal finance can affect emotional wellbeing.

In the responses to open-ended questions, one respondent mentioned that staying in remission takes a lot of work and can be upsetting – for example, due to adhering to a strict diet, giving up alcohol, resting when possible and abstaining from having a busy social calendar. Regarding future plans, another respondent commented on the impact IBD may have across life domains: on travelling, that it can cause breakdowns in relationships, may result in losing work and potentially mean not having children. It was also noted by a respondent that living with IBD, over the years, can cause people to feel more anxious, less confident, and less social. Loss of work can also lead to financial problems.

We found that only 34% of respondents said their consultant had discussed a long-term plan with them; this was higher for respondents who lived in the North of England when compared to London and the South, Midlands and East or Devolved Nations, though the reasons for this difference is not clear.

> You have to cope with sometimes drastic changes in your life – breakdown of relationships, losing a job and the social side of having a job, finding out you probably won't have children. These aren't things that you ever really 'get over' as they change the direction you thought you had and shape your future decisions. I don't think enough attention is paid to helping people with IBD deal with all the extra baggage that comes with diagnosis and subsequent treatments.

The impact of toilet visits

IBD greatly increases how often, and how long individuals spend visiting the toilet.

People with IBD often need to plan and assess before they leave home, ensuring that they are aware of the nearest toilet in the event of an being unable to reach the toilet in time. This can be distressing and can negatively impact quality of life.[9,18,19]

In our survey, we found that on average, respondents used the toilet four times a day during remission, and 13 times during a flare. 79% said the number of toilet visits increases restrictions on day-to-day activities, and the vast majority of respondents said multiple toilet visits had a notable impact on their emotional and physical wellbeing.

Accidents can be highly distressing for people with IBD.

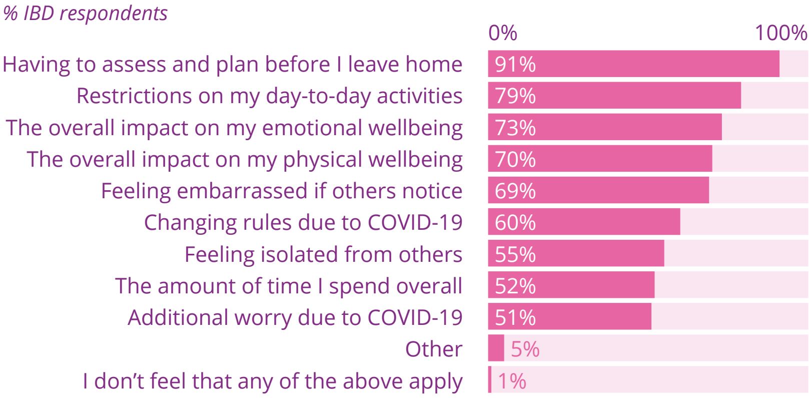
In relation to the need for toilet visits, more than 2 in 5 respondents said they have accidents 'occasionally', and, when split by grade of IBD, more than 1 in 6 of patients with moderate-to-severe disease (n=39) said they have accidents 'daily'.

Following on from this, 9 out of 10 respondents said that 'having to assess and plan before I leave the home' was the most difficult aspect of having to make multiple toilet visits a day.

> Make it more normal for people to be able to use toilets anywhere, and for all accessible toilets to have a sign stating not all disabilities are visible.

Most difficult aspects of multiple toilet visits

% IBD respondents



Responses to the question, 'What do you feel are the most difficult aspects of having to make multiple toilet visits in a day?'
128 participants responded, and were able to select more than one option.
Some percentages may be rounded.

During a flare, respondents on average ranked the impact of toilet visits on emotional wellbeing as **8.5/10** and impact on physical wellbeing as **8.3/10**

(where 0 indicates no impact and 10 indicates a highly significant impact).

The impact of fatigue

Fatigue can have a considerable impact on the physical and emotional wellbeing, quality of life and work productivity of people living with IBD.[9,20-23]

Fatigue is defined as an extreme and persistent tiredness, weakness or exhaustion, and is a common, complex, debilitating symptom of IBD.[24] Previous research has found that people with IBD often feel that fatigue is not fully addressed in clinical consultations.[24,25,26]

In our survey, we found that 70% of respondents rated their fatigue at a level of 7/10 or higher. Further, over half of respondents rated their fatigue as 8 or higher on this scale.

Digging deeper into these survey responses shows that fatigue was not limited to those with moderate or severe disease; even amongst those in remission, more than 1 in 5 reported this symptom, with a mean rating of severity of 6.2/10. Approximately two thirds of respondents said their fatigue had a 'high' or 'very high' impact on their life. When the impact on emotional wellbeing was investigated further, we found that, on average, respondents rated the impact of their fatigue as 7.6/10, with 73% of individuals rating it at a level of 7 or more out of a maximum of 10.

Our findings on the impact of fatigue on people with IBD are broadly consistent with data previously published in scientific journals.[9,20]

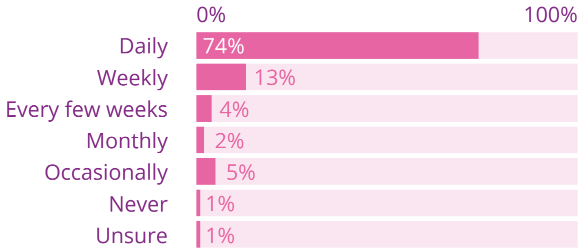
Approximately three-quarters of people with IBD (**74%**) said they experience fatigue daily.

In individuals with moderate-to-severe IBD, **85%** report daily fatigue.

> I would like more education about chronic fatigue. I have had times where I've been physically too tired to respond to a text message; the fatigue is unreal.

Frequency of experiencing fatigue

% IBD respondents

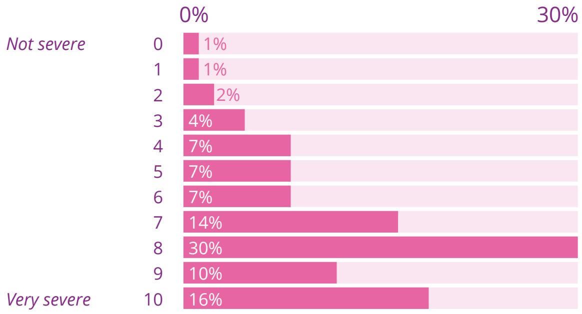


Disease status	% Daily
In remission (37)	51%
Mild-to-moderate (91)	79%
Moderate-to-severe (39)	85%

Responses to the question, 'How frequently do you experience fatigue/tiredness associated with your IBD?' 167 participants responded and were able to select only one option. Responses were further broken down by grade of IBD (in remission, mild-to-moderate or moderate-to-severe). Some percentages may be rounded.

Severity of fatigue

% IBD respondents



Disease status	% Daily
In remission (37)	6.2%
Mild-to-moderate (90)	7.1%
Moderate-to-severe (39)	8.2%

Responses to the question, 'When you experience fatigue/tiredness associated with your IBD, how would you rate the severity of this?' 166 participants responded, and were able to select only one option. Responses were further broken down by grade of IBD (in remission, mild-to-moderate or moderate-to-severe). Some percentages may be rounded.

Supporting people living with IBD beyond the physical

Emotional impact

Survey findings show that the emotional and mental impacts of IBD can be considerable and wide-ranging, and should not be underestimated.

Respondents reported anxiety, low mood (58%) and low self-confidence (56%) as the main negative impacts of their condition.

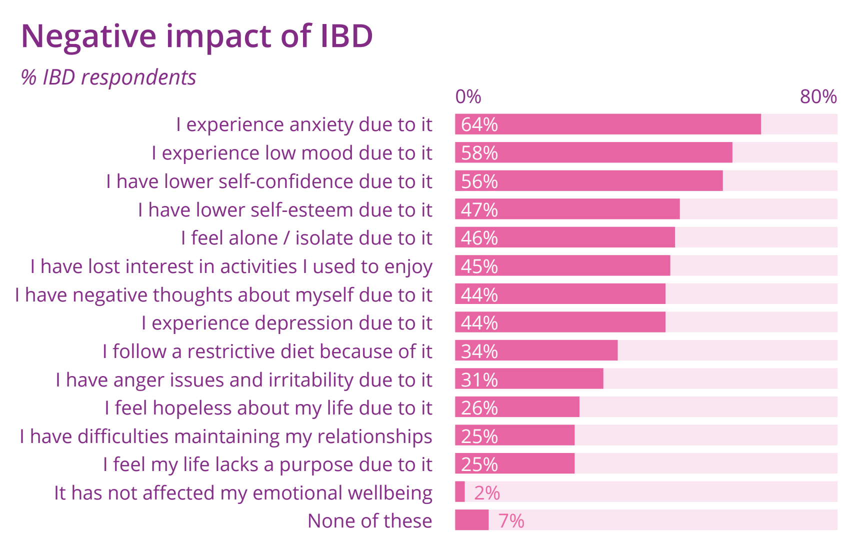
Worrying about their condition can be ever-present, with over 1 in 5 respondents (23%) reporting that they worry constantly and a further 35% worrying about it every day. Conversely, only 8% of respondents reported being worried 'occasionally' or 'rarely'. Consequently, most people with IBD say they have taken steps to manage their condition such as avoiding stressful situations (75%) and missing important social occasions (72%), steps which can themselves have an impact on emotional wellbeing.

In the open-ended responses section of the survey, a respondent commented "I have recently realised how much this has affected me mentally. I have daily anxiety attacks and I can't leave the house". This individual was not alone in experiencing this; other respondents noted that IBD can cause a loss of self-confidence and self-worth and increased reclusiveness. Most respondents (72%) said that they felt embarrassed at least some of the time by their IBD.

Emotional wellbeing improved once patients had received a diagnosis.

When patients were asked to think back to when they were experiencing symptoms of IBD, but had not yet received a formal diagnosis, just over half of respondents (52%) reported their emotional wellbeing as 3 or lower out of a maximum score of 10 (mean score 4.1; median score 3). Following a diagnosis of IBD, emotional wellbeing improved somewhat with only 18% rating it at

> Every time I've been in clinic, it's 5–10 mins tops, and it's all about IBD symptoms – nothing else like how you are mentally or emotionally. It's like they just care about the IBD side and forget that living with this illness causes mental and emotional problems to the patients too.


Negative impact of IBD

% IBD respondents

Responses to the question, 'How did your condition negatively affect your emotional wellbeing prior to the COVID-19 epidemic?' 167 participants responded and were able to select more than one option. Some percentages may be rounded.

The majority of people with IBD report feelings of anxiety, low mood and low self-confidence. These feelings can also lead to a sense of isolation.

3 out of 10 or lower once diagnosed, illustrating the positive emotional impact of having an explanation of symptoms and beginning to pursue a treatment path.

As might be expected, respondents who were in remission (n=37) rated their emotional wellbeing to be better when compared to respondents with mild-to-moderate (n=91) or moderate-to-severe (n=39) IBD (ratings of 7.7 vs 6.0 vs 4.2 out of 10, respectively), showing how changes in disease course can impact emotional health.

Few survey respondents had discussed their emotional wellbeing with their IBD team.

While the survey results show that the impact on emotional wellbeing is a significant part of living with IBD, we found that only a quarter of respondents had discussed their emotional wellbeing with their IBD team. In fact, half of respondents said that their IBD team had never asked how they were feeling emotionally and 69% said that their consultant had not explained the link between physical symptoms and emotional health.

Among IBD patients who are not confident discussing their emotional wellbeing, the main reason is a lack of time during the consultation.

Unfortunately, of the 59 respondents who answered the question around why they did not feel confident discussing their emotional wellbeing, almost a third noted that they had tried to discuss their emotional wellbeing with their HCP but did not receive the support they desired. Additionally, almost a third noted they would like to discuss their emotional wellbeing but were not sure about the reaction they might receive. More than 1 in 5 felt embarrassed or did not trust their HCP enough to discuss their emotional wellbeing.

Among respondents who were not confident discussing their emotional wellbeing with their IBD consultant (n=59), the main reason was lack of time during consultation, noted by **58%** of respondents.

Regarding psychological comorbidities, IBD follows a similar model to other illnesses with an impact on mental health. The mental health comorbidities associated with IBD are more prevalent during active disease, when the symptoms are difficult to keep under control compared with when in remission.[11,27] Overall, our findings align with published scientific literature.[28] For example, in 2019, survey responses from 302 patients with IBD found that 80.5% of patients reported that the frequency and severity of their symptoms had a moderate-to-severe impact on their daily life, 81.5% said IBD caused them anxiety and 75.5% said it caused them depression.[29]

Despite the emotional harm IBD causes patients, 35% of respondents noted that, as a result of their IBD, they now feel more empathetic towards others. Additionally, 30% of respondents commented that they have developed greater resilience than they previously had.

Help and support

Respondents highlighted a lack of emotional support provided in the clinic.

While the literature recognises that IBD has an impact on mental health and emotional wellbeing, only one third of respondents to our survey (33%) have received some form of support in this regard, either via telephone consultations, referral to a psychologist or counsellor, information about patient support groups, charities or patient communities or face-to-face support during appointments. Conversely, 23% of respondents indicated receiving no emotional support in the clinic, and 36% said that they have not asked for emotional support.

> …a diagnosis of IBD involves, for the patient, a whole lot more than 'just' dealing with the physical condition. I'd like to see a more holistic approach with patients offered support from a range of professionals with IBD expertise, from dieticians to counsellors and even financial/ benefit advisers.

Our survey adds to evidence that a lack of support negatively impacts overall quality of life for people with IBD.[21,31]

We found that respondents feel there is insufficient help and support for IBD, either as a result of limited time and resources or HCPs not addressing their condition holistically. One respondent commented, "I feel we need a lot more support from our own medical team and [need to] be made to feel like a person, not just [known] by a hospital number."

The majority of respondents felt more emotional support is needed for people with IBD.

In our survey, we found that 86% of respondents said that at least somewhat more emotional support is needed for people with IBD, with 63% saying much more support is needed overall. Open-ended questions revealed that a lack of emotional support may be linked to an inability to get an appointment due to staffing or availability of appointments, a lengthy waiting list, inadequate signposting, lack of support from the IBD team or lack of understanding. For example, one respondent noted, "I have only had two meetings with the consultant in four years".

People with IBD can have difficulty discussing their condition.

Our survey found that many people living with IBD feel embarrassment about their condition, with only 54% of respondents saying they were very comfortable discussing their condition with their close family (scoring their level of comfort at 8 or above, out of maximum of 10 points). Furthermore, only 27% said they were comfortable discussing their condition with their friends (rated as ≥8/10).

Respondents said that they felt most comfortable discussing their condition with their IBD specialist nurse, or IBD consultant (**74%** and **75%**).

The results of our survey are broadly consistent with findings in published scientific literature. As an example, in the IBD Global Assessment of Patient and Physician Unmet Needs Surveys (GAPPS), a large survey involving 2,398 patients with IBD and 654 physicians exploring current experiences and perceptions of patients with IBD found that half of patients were happy with their involvement in setting treatment goals, and approximately 60% of patients felt comfortable discussing symptoms with their physician. Interestingly, although half of patients felt that physicians had enough time during routine appointments, only 31% of physicians felt the same.[9] Additionally, in a survey of more than 4,000 people with IBD across 25 European countries, 54% of patients thought that they did not get a chance to tell their gastroenterologist something potentially significant, and 64% thought that their gastroenterologist should have asked more probing questions.[28]

The impact of COVID-19

COVID-19 has greatly impacted IBD care across the UK.

Research shows that COVID-19 restrictions resulted in alterations in treatment plans, daily life, and greater levels of perceived stress in patients with IBD compared to pre-pandemic levels.[32] In our study, we found that the COVID-19 pandemic negatively impacted people with IBD for a combination of reasons, from the isolation of shielding to disruption of their IBD management plan.

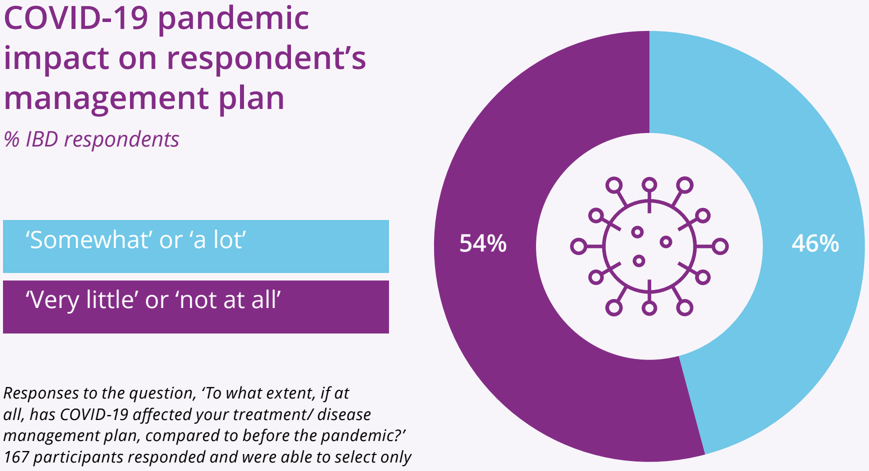
Overall, 6 in 10 respondents (62%) reported that they were told to shield due to their IBD, and this was slightly lower for patients in remission (49%). Of these individuals, 17% told to shield had comorbidities, which may have contributed to the advice. Our survey revealed that the COVID-19 pandemic impacted respondents' emotional wellbeing; over half (55%) of respondents reported a significant or slight decrease in their emotional wellbeing due to the pandemic. Approximately half of respondents reported that the amount of support available had declined since the pandemic started (53%), although almost one-fifth of respondents (17%) reported 'no change', and a quarter (26%) reported that they do not know if the amount of support has changed. There may be regional discrepancies explaining the level of support available for individuals, but our survey did not probe this.

46% of respondents said that the COVID-19 pandemic has impacted their management plan either 'somewhat' or 'a lot', compared to **54%** who said 'very little', or 'not at all'.

> I feel much more anxious because of COVID-19 and have experienced more panic attacks. This has affected my IBD and made me much more stressed.

COVID-19 pandemic impact on respondent's management plan

% IBD respondents



Responses to the question, 'To what extent, if at all, has COVID-19 affected your treatment/ disease management plan, compared to before the pandemic?' 167 participants responded and were able to select only one option. Some percentages may be rounded.

Conclusions

Our survey sought to explore the emotional and mental impact of IBD on the lives of patients, including the effect of IBD on toilet visits, fatigue, daily life, emotional health, levels of support and the COVID-19 pandemic.

Overall, we found that people with IBD are heavily impacted by the increased need for toilet visits and fatigue when compared to before they had symptoms of IBD. Daily life can be more challenging overall for people with IBD compared to before symptom onset and is greatly more difficult when the disease is flaring compared to in remission. Crucially, this can take a major toll on the future outlook and emotional health of those living with IBD.

As one might expect, the COVID-19 pandemic has had a negative impact on patients and may have accentuated these challenges. The level of perceived support for patients was somewhat mixed, but overall the findings in our survey suggest that a considerably greater level of holistic support is required.

Next steps

Overall, our survey findings underscore the impact of IBD on patient's physical and mental health, highlight their unmet needs and provide insights into how best to support these patients.

This survey raised several key areas where attention could be focussed:

One	Two	Three
Share and use these findings in educational materials to further raise awareness of the burden and everyday impact of IBD.	**Raise awareness of the impact of fatigue and increased need for toilet visits.**	**Support for HCPs and patients to open the conversation around the emotional impact of living with IBD and how this can be addressed.**
These findings can provide powerful statistics and quotes to help illustrate what it means to live with IBD.	In our survey, both fatigue and the need for toilet visits were reported as having a large impact on the lives of people with IBD. Increased awareness of these symptoms could help support those living with IBD.	It is not always easy for HCPs or patients to discuss the impact of IBD beyond the physical, but survey respondents were clear that this is a key element of living with IBD.

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The IBD Quality of Life Survey and Report has been developed with IBDrelief in partnership with, and funded by, Janssen-Cilag Limited.