Crohn's & Colitis Ireland

Johnson & Johnson Innovative Medicine

Ipsos B&A

Uncovering the Hidden Costs of Crohn's & Colitis

Amy Kelly, Chief Operations Officer, Crohn's and Colitis Ireland

These findings show the true extent of the challenges faced when diagnosed with Inflammatory Bowel Disease (IBD) including the financial burden inflicted. However, it's not just about medical bills, it's about lost wages, dietary adjustments and the constant struggle to access the care people living with IBD desperately need.

We urge the government to listen to the needs of the IBD community and improve access to care by including IBD in the Chronic Disease Management Programme and expanding medical card eligibility, ensuring equitable access to essential medical care. This inclusion would provide free, structured care, potentially reducing patients' out-of-pocket healthcare expenses through fewer emergency room visits, hospital admissions, and lower medication costs.

Dr Orlaith Kelly, Consultant Gastroenterologist, Connolly Hospital Dublin

This report provides valuable insights highlighting the financial and emotional burden people living with IBD in Ireland face. The research shows stark findings that people living with IBD are delaying or skipping essential IBD treatment due to cost, which can negatively impact how their condition is managed and can place an additional strain on the healthcare system.

This research underscores the urgent need for IBD to be elevated on the healthcare agenda and recognised as part of the Chronic Disease Management Programme, to ensure financial barriers do not prevent patients from receiving the treatment they desperately need to manage their condition effectively.

Michaela Hagenhofer, General Manager, Commercial Operations at Johnson & Johnson

At Johnson & Johnson we are honoured to partner with Crohn's and Colitis Ireland (CCI) on this important study. This report reveals the financial and psychological struggles people diagnosed with IBD face every day and provides a critical insight into the supports needed to improve their well-being.

It's vital that the voices of the IBD community are heard and acted upon to ensure that care and support are tailored to their specific needs. We're committed to supporting CCI and the entire IBD community in this important campaign to improve the lives of people with IBD in Ireland.

This report has been developed by Crohn's and Colitis Ireland in partnership with Johnson & Johnson Innovative Medicine.
Ipsos B&A were commissioned by Johnson & Johnson Innovative Medicine to carry out the research and analysis.

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Foreword

The two main forms of Inflammatory Bowel Disease (IBD) are Crohn's disease and ulcerative colitis.

At Crohn's & Colitis Ireland (CCI), we remain deeply committed to supporting and advocating for individuals living with IBD and driving meaningful change. Our mission is not just to provide essential resources and support to help manage the condition but to also shed light on the often-overlooked financial, emotional, and social challenges faced by those impacted by IBD. This survey report is a crucial step in that ongoing mission, offering invaluable insights into the lived realities of people with IBD across Ireland.

The findings within this report highlight the profound struggles that people with IBD face daily. These challenges extend far beyond physical health, affecting finances, employment, education, relationships, and mental well-being. The survey paints a stark picture of the substantial financial strain caused by the costs of treatment, specialised diets, and the indirect financial burdens of lost wages and the ongoing need for medical care.

Two-thirds of those diagnosed report that the cost of managing IBD is a financial strain, but the repercussions extend well beyond that. IBD disrupts people's ability to work, with many experiencing flare-ups that force them to miss work, take sick days, or reduce their hours. Some are even pushed to change careers entirely.

The burden does not stop with lost wages. People with IBD are often denied basic services like life insurance or mortgages simply because of their condition. This denial of basic rights and services exacerbates feelings of exclusion and isolation. When in remission, those living with IBD are active, contributing members of society—working, paying taxes, and engaging in their communities. Yet, when their illness flares, they are left without the necessary support to cope, and this needs to change.

It is time to challenge the status quo. We must recognise that IBD is a condition that fluctuates between periods of flare and remission. Those living with IBD are not defined solely by their illness. When in remission, they contribute immensely to society, but during a flare, they deserve support and understanding. The question is: why aren't we doing more to help people with IBD during their flare-ups? It is not their fault when their illness flares, yet the system does little to support them through the financial and personal strain that follows.

One of the most glaring issues is the lack of recognition for IBD as a lifelong illness. Despite being chronic and incurable, IBD is not classified as a disability in Ireland. This lack of recognition excludes those with IBD from accessing the Long Term Illness Scheme, the Chronic Disease Management Programme, GP and medical cards, and other supports available to individuals with other chronic conditions. This is not a mere oversight—it is a systemic failure that leaves people with IBD struggling without the help they desperately need.

They need the recognition they deserve—recognition that would provide them with the dignity and support necessary to live with this condition.

As CCI continues its work with policymakers and healthcare providers, we are committed to ensuring that the voices of people living with IBD are heard and that the reforms necessary to ease the burden of this chronic condition are put in place.

Amy Kelly, Chief Operating Officer,
Crohn's and Colitis Ireland

Executive Summary

Executive Summary

There are widespread financial struggles among people with IBD in Ireland.

60% have faced financial difficulties in the past year due to the cost of their IBD care, with 15% saying they experience this financial difficulty to a great extent. These financial challenges are greater among those who are more recently diagnosed (69% of whom have faced financial difficulties due to the cost of IBD care in the last 12 months).

The average annual spend on IBD-related medication and dietary changes is €3,252 per person.

IBD care can require multiple concurrent treatments. On average, individuals spend approximately €76 each month on prescribed IBD medications. A further €38 on average per month is spent on over-the-counter solutions. **This equates to an average of €114 per month or €1,368 per year, per person**.

Diet is also a critical component for IBD management, with over half (51%) of respondents spending money on specific dietary adjustments. **This results in an average additional cost of €157 per month, or €1,884 per person on an annual basis.**

This represents a total average spend on IBD-related medication and dietary changes of €3,252 per person on an annual basis.

IBD requires regular engagement with healthcare professionals and services, including hospitalisation.

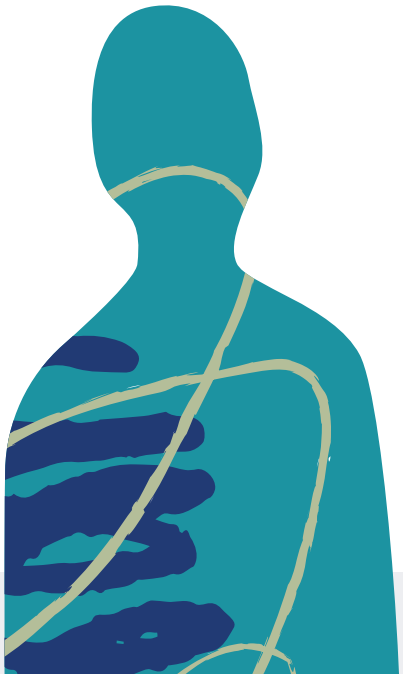
IBD needs ongoing medical attention to maintain remission and manage flare-ups. **Nearly half (45%) of those with IBD need to visit healthcare professionals on at least a monthly basis, if not more often**. About a third (32%) have undergone surgery, while 33% have had been hospitalised within the past year, highlighting the intensive medical needs of IBD.

IBD results in significant out-of-pocket costs in accessing healthcare services.

People with IBD are paying significant out-of-pocket costs to access necessary healthcare services, particularly for visits to GPs, specialist consultations, as well as additional healthcare services such as dietitians, physiotherapy, mental health support and occupational therapy. Accessing public healthcare is also a challenge for many people living with IBD. 38% of public patients have paid privately for essential diagnostics, often due to long waiting times in the public system.

The time expenditure related to IBD is substantial.

IBD management requires significant amounts of time being spent on healthcare appointments. This includes time spent accessing GPs or specialists in the hospital setting or IBD clinics, as well as other ancillary services. In the **public system, respondents spend on average a total of 34 hours per year accessing the services listed**. Meanwhile, in the **private system, respondents spend on average a total of 47 hours per year accessing these services**. The time commitment involves not just the appointment itself but also arranging the appointment, travel both ways and waiting time.



Moving to subcutaneous injections at home can have a financial impact.

29% of people with IBD have moved from in-hospital infusions to subcutaneous injections. Almost half of these cases (44%) say that this move has had an additional financial impact on them.

A range of indirect costs are also having a major impact.

Overall, **85% of people with IBD say mileage and travel costs for their IBD are a financial burden**, while 83% also cite parking costs as a challenge. Other indirect costs acknowledged to be a burden include overnight stays for treatment (62%) and childcare expenses (49%).

Taking leave from work is a necessity for treating and managing IBD.

Among those who are employed, **82% say that missed work or lost wages due to their IBD has been a financial burden**. 58% of those working have had to take frequent leave (five or more days per year) because of their condition, with 62% of those having to take leave due to their IBD saying this has affected their financial situation. The majority of caregivers also find their finances impacted by necessary absences from work to care for someone with IBD.

IBD can disrupt career and education pathways.

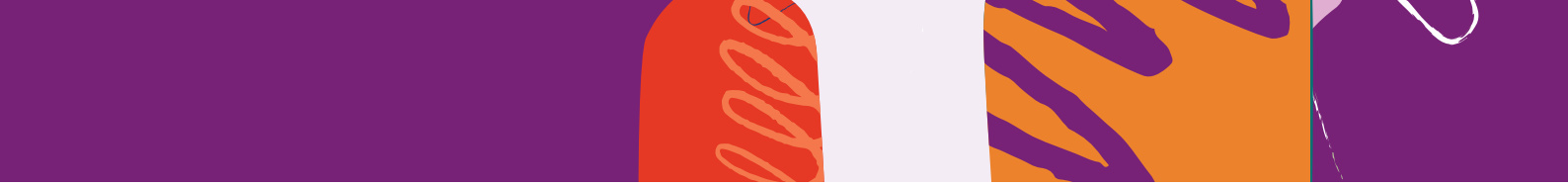
IBD can significantly affect professional and academic opportunities. **Most working respondents (86%) have gone to work even though they needed to take time off for managing their IBD**, while almost two-thirds (65%) say it influenced their decision to reduce their working hours. 67% of those working say their IBD has limited their career advancement or promotion opportunities, and a similar number (65%) say IBD has restricted their choice of education or career.

There are difficulties in accessing appropriate and necessary financial support programmes.

IBD is not recognised as part of the Long Term Illness Scheme or Chronic Disease Management Programme. Applications for some support programmes, such as the Medical Card and GP Visit Card, are often denied because IBD does not meet eligibility requirements. While some of these programmes are means tested, they do not adequately recognise the variability of disease activity in IBD. **A majority (65%) argue that existing government programmes do not sufficiently address the needs of those with IBD**.

Health insurance does not adequately cover IBD costs for most people.

Two-thirds of those with IBD have some form of private health insurance. However, only a minority (9%) of all respondents have most of their IBD-related expenses covered. Of those who have applied for health insurance, 17% reported to have been denied due to their IBD. Meanwhile, 39% have been denied or had difficulty accessing other forms of insurance cover due to their IBD.



High costs force people with IBD to avoid seeking necessary medical interventions.

47% have avoided seeking medical services for their IBD due to the costs involved. Furthermore, **26% have delayed taking their IBD medication** to make it last longer due to the costs involved.

IBD has a profound impact on quality of life.

71% of those with IBD say it has impacted their overall quality of life while 72% say it has impacted on their social activities. IBD has also affected many in their relationships with family (42%) and friends (55%).

The challenges of living with IBD are much more than financial.

Apart from the financial impact, those with IBD experience many physical, emotional and psychological challenges; **96% report fatigue, with 81% saying daily symptom management is a challenge.** Mental health is also impacted, with 75% of those with IBD experiencing anxiety and/or depression, and 65% experiencing social isolation.

There is unanimous agreement that IBD should be recognised as a qualifying condition for additional support.

98% of those with IBD believe that it should be recognised as a qualifying condition for additional support programmes (e.g. disability allowance, Long Term Illness Scheme, Chronic Disease Management Programme, GP visit card, medical card).

Recommendations

"IBD is a lifelong medical condition. Nobody chose to have this illness and as such should not have to face the financial burden of having it."

- Survey Respondent

Recommendations

Access to a Full Multidisciplinary Team

- The government should **reinstate funding that was allocated for additional Advanced Nurse Practitioner (ANP)** posts across Ireland. These posts were approved prior to the HSE recruitment freeze, which subsequently prevented these posts from being filled.
- **Ensure every IBD clinic is adequately staffed with a full multidisciplinary team,** including gastroenterologists; IBD nurse specialists; stoma nurses; dietitians; and psychologists. This is essential to offer comprehensive care and better manage the complexities of IBD.

Recognition of IBD as a Disability

- The government should **review the Long-Term Illness Scheme (LTIS)** to provide financial support for individuals living with IBD, addressing the financial strain caused by the chronic nature of the disease.
- Incorporate IBD into the **Chronic Disease Management Programme, ensuring it is recognised as a qualifying condition** for additional support and social protections. This will enable people with IBD to access essential support schemes that reduce the financial burden of their condition.
- **Review eligibility criteria and means testing for the GP visit card and medical cards** to take into consideration the chronic nature of IBD and associated ongoing costs for those diagnosed to manage their condition.

Inclusion in National Disability Rights Discussions

- IBD should be **included as a subject of discussion** within the Cabinet Committee on Disability.
- **Ensure that IBD is part of national policy discussions** regarding disability rights, promoting fairer access to healthcare and financial support for individuals with IBD.

1. Introduction

"My condition is a condition that impacts me daily - I have to plan every journey - I have to take daily medication - medical costs are astronomical. This is a lifelong chronic medical condition - to me my medical condition is ignored by the State."

- Survey Respondent

1. Introduction

1.1. Background

(Source: Crohn's & Colitis Ireland)

Inflammatory Bowel Disease (IBD) describes a group of conditions in which the intestines become inflamed. The two most common inflammatory bowel diseases are Crohn's disease and ulcerative colitis. Another form of IBD is microscopic colitis.

These autoimmune diseases are lifelong conditions that have periods of 'active' and 'inactive' disease, and the immune system plays a central role. During 'active' phases of the disease people experience increased symptoms including frequent/urgent diarrhoea, often with blood or mucus; pain, which can be severe; weight loss; mouth ulcers; eye, skin and liver problems; depression/anxiety; swollen joints; and fatigue, which can be extreme.

Typically, the immune system protects us from illness, but in Crohn's and colitis, it mistakenly attacks the body, causing inflammation. It is important to know that this is **not the person's fault** – it is not something they caused.

It is not fully understood why the immune system starts attacking, but it is likely due to a combination of triggers such as genetics, bacteria in the gut and environmental influences like diet, stress, smoking, and infections.

Crohn's & Colitis Ireland (CCI) is a patient organisation which provides a community of support for those navigating life with IBD in Ireland. Through essential resources, information, and advocacy, **CCI empower people to live well with IBD**. CCI has partnered with Johnson & Johnson Innovative Medicine to take a deeper dive into understanding the direct financial burden of IBD on individuals and families.

Building on its previous research ("IBD Patient Survey Report 2024"), CCI wished to further explore an issue that people with this condition are burdened by – the cost of IBD. CCI's aim is to work with the government to implement appropriate financial and psychosocial support for those diagnosed with IBD.

1.2. Objectives

The primary objectives of this research were to:

- Understand and quantify the financial costs and psychosocial impact of IBD experienced by individuals, with a focus on financial, emotional and social burdens.
- Identify recommendations to reduce the financial burden for people living with IBD by addressing gaps in financial protection.
- Explore any issues related to access to mental health and dietitian support for people diagnosed with IBD.

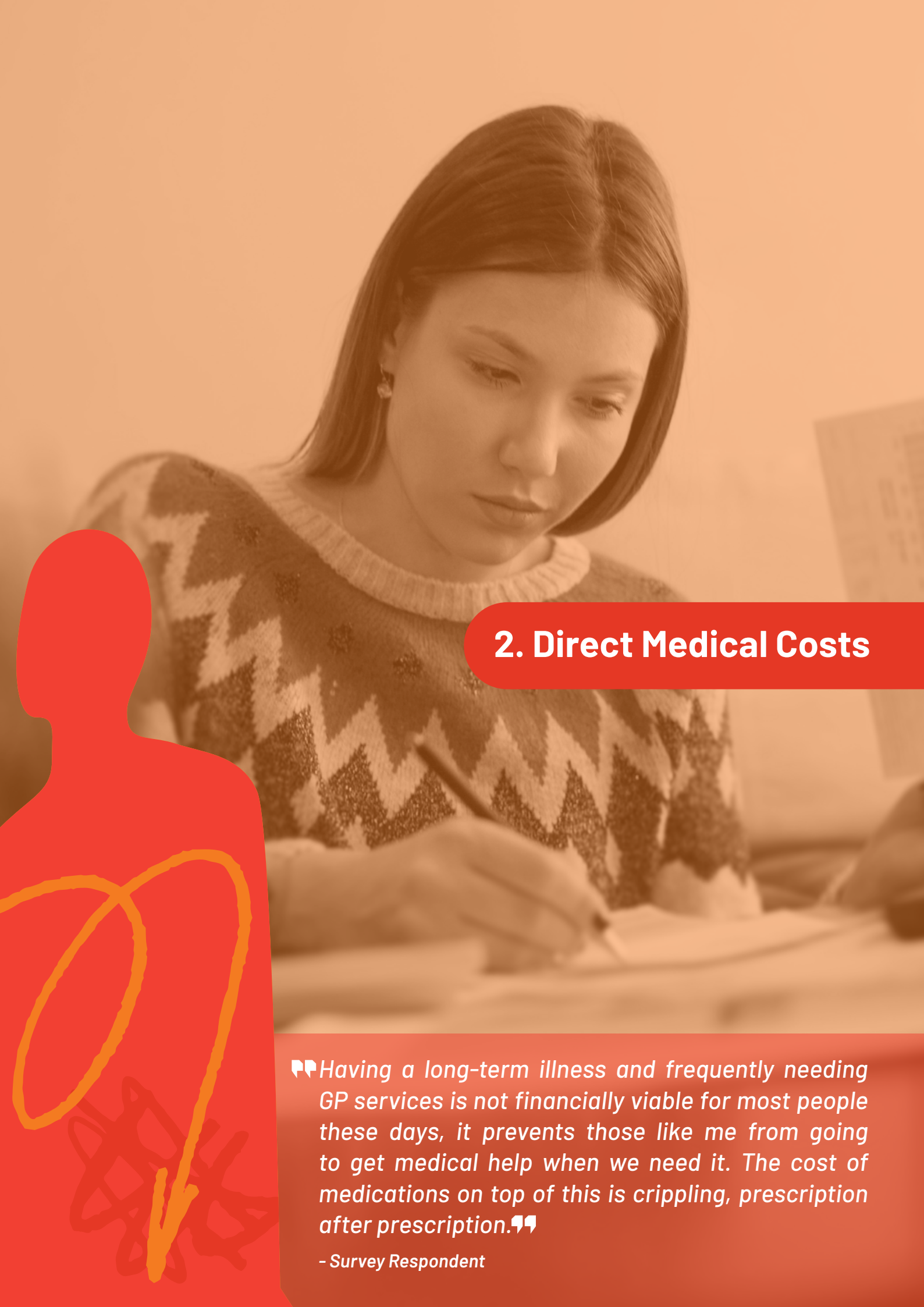
Within those overarching objectives, there was a focus on three primary cost dimensions;

Direct Medical Costs: These include expenditures like out-of-pocket expenses for prescribed and over-the-counter treatments, therapies, required medical consultations and tests, and additional dietary needs. Such costs represent a direct financial challenge which, when reduced, could immediately lighten the burden on patients and their families.

Indirect Costs: Beyond the concrete expenses, indirect costs can include financial losses due to absences from work, the need for frequent travel to attend medical appointments, childcare requirements, and other related expenses. These costs, though less apparent, contribute significantly to the overall financial burden for patients and their families.

Emotional and Social Costs: Finally, there was a need to evaluate the emotional and psychological toll associated with managing IBD. This involves assessing not only the emotional strain but also the logistical aspects like the time spent in accessing required care facilities and services, which cumulatively affect quality of life.

Please note that where percentages do not add up to 100% or similar, this is due to statistical rounding.

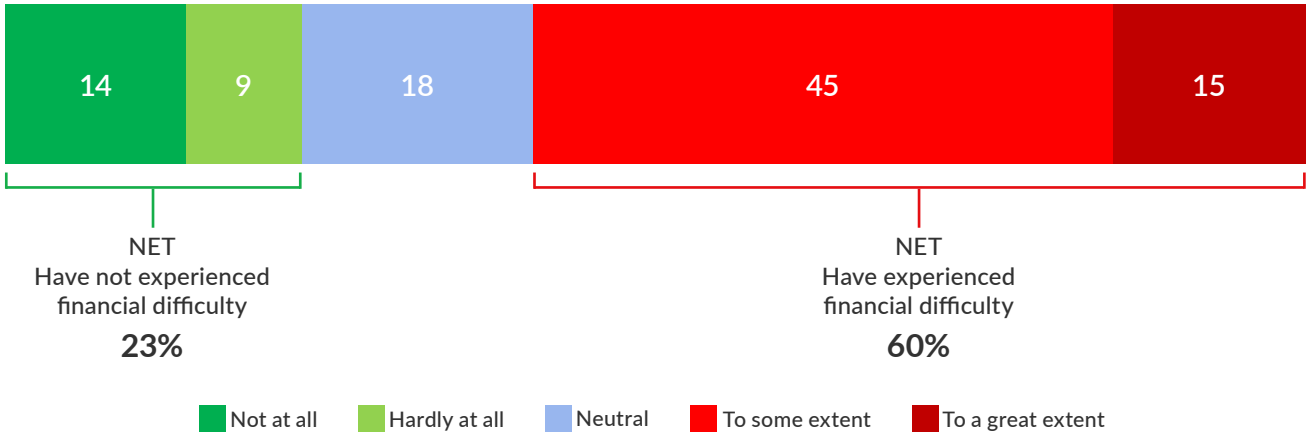


2. Direct Medical Costs

"Having a long-term illness and frequently needing GP services is not financially viable for most people these days, it prevents those like me from going to get medical help when we need it. The cost of medications on top of this is crippling, prescription after prescription."

- Survey Respondent

Figure 2.1. The extent to which people with IBD have faced financial difficulties due to the cost of their IBD care in the last 12 months (%)



2.1. Frequency of financial difficulties as a result of IBD

60%
have faced financial difficulties due to the cost of IBD care in the past year.

One of the core objectives of this study is to examine the direct financial burden that IBD can have on those diagnosed and their families.

The majority (60%) say they have struggled financially because of the cost of their IBD care in the past year. Of these, 15% reported serious financial issues, while another 45% said they had some financial difficulties.

Financial difficulties due to IBD are more pronounced in people who have been recently diagnosed. Respondents who had been diagnosed in the past five years were significantly more likely (69%) to say they have faced financial difficulties due to the cost of IBD care in the past year, compared to those diagnosed over five years ago (55%).

That difference aside, these difficulties are being experienced by people with IBD across all cohorts; those with Crohn's disease and ulcerative colitis, those working and not, those in public and private healthcare settings and those with and without other medical comorbidities. **This indicates the wide-reaching impact of these difficulties in people with IBD across Ireland.**

2.2. Spend on IBD medicines

€76 Average spend on prescribed IBD medications /treatments per month

+

€38 Average spend on OTC IBD medications/ treatments per month

=

€114 Average spend on Total IBD medications/ treatments per month

Once someone is diagnosed with IBD, they can experience a financial burden due to ongoing spending for IBD-related medications and treatments.

Knowing that people diagnosed with IBD can be on a range of treatments for their condition, the survey sought to measure the average monthly spend on both prescribed and over-the-counter medications.

The average amount spent per person for IBD-related prescribed medications or treatments is €76 per month. Meanwhile, the average amount spent per person on IBD-related over-the-counter medications or treatments for which there is no financial support is €38 per month.

When combined, this equates to a significant spend on medications or treatments of €114 on a monthly basis. This total was consistent across most respondent types, with those with ulcerative colitis spending marginally more (€117 per month) than those with Crohn's disease (€108 per month).

Some respondents were spending higher amounts, with almost one in five (19%) spending an average of €150 or more per month on their IBD-related medications and treatments.

If the average spend of €114 per person is annualised over a 12-month period, it equates to **an average spend of €1,368 per year on IBD-related medications and treatments, representing a considerable obstacle for people with IBD**.

2.3. Cost of dietary changes due to IBD

Diet plays an important role in managing IBD due to the way the condition affects nutrient absorption. If the small bowel is inflamed, nutrient and fluid absorption may be impaired, making it difficult for individuals with Crohn's disease to get the energy they need, often leading to deficiencies in vitamins and minerals. On the other hand, inflammation in the large bowel typically affects the absorption of liquids rather than nutrients. During flare-ups, individuals may struggle to eat enough of the right foods, experiencing low appetite, weight loss, or even weight gain due to dietary changes or medications like steroids. Many people with IBD adjust their diet to manage symptoms but this can make it challenging to maintain proper nutrition and can also affect their relationship with food. Balancing the right nutrients is vital for maintaining overall health and well-being.

(Source: Crohn's & Colitis Ireland)

€157
is the average monthly spend on dietary changes/specific foods to manage IBD.

Just over half of all respondents (51%) reported that they are spending additional money on dietary changes or specific foods to manage their IBD each month.

The average amount spent per person on dietary changes or specific foods among survey respondents is €157 per month, which equates to €1,884 on an annual basis. There is no financial support for this essential tool in managing IBD.

This is just one of the many additional spends that people diagnosed with IBD must pay to manage this condition.

2.4. The challenges and expense of accessing IBD healthcare services

People diagnosed with IBD face difficulties with both the expense of and access to essential healthcare services. IBD is a lifelong condition requiring ongoing treatment and monitoring. Aside from medications and treatments, this translates to continuous expenses for doctor visits, tests, and potential hospitalisations, all of which contribute to mounting direct and indirect out-of-pocket costs over time.

Almost three-quarters (74%) of respondents have paid out-of-pocket for GP appointments in the past year. Half (50%) have spent over €100 in that time frame, including 9% who have spent more than €500.

46% have spent out-of-pocket accessing their IBD consultant or gastroenterologist in the past year. Over a third of respondents (35%) had spent over €100 on these specialists in the past year, including 11% who had spent more than €500 in that time frame.

35% of respondents have spent out-of-pocket accessing other consultants or specialists for their IBD in the past year. Over a quarter (27%) had spent over €100, including 11% who had spent more than €500.

85%

of those with IBD do not believe their mental health and well-being are included in their care.

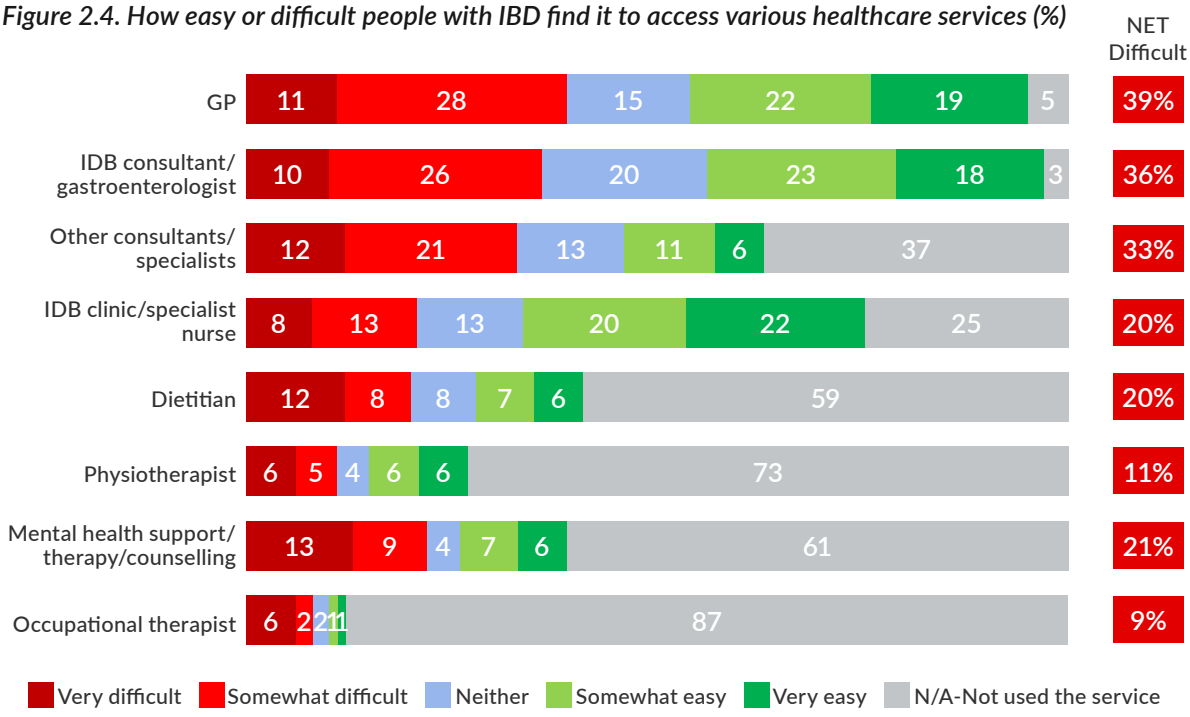
(Source: Crohn's & Colitis Ireland IBD Patient Survey Report 2024)

> *The impact this has on your mental health can be major and if people are like me, mental stress can cause flares.*
>
> *- Survey Respondent*

Spend on accessing mental health support, therapy or counselling is also notable, with 26% spending out-of-pocket on this in the past year. 18% spent over €100 out-of-pocket accessing mental health support in the past year, including 10% who had spent more than €500 on these supports in that time frame.

Out-of-pocket spend is also evident for other vital services. 20% of respondents have spent out-of-pocket accessing physiotherapy; 18% have spent out-of-pocket accessing the IBD clinic or specialist nurse; 17% have spent out-of-pocket accessing dietitians; and 7% have spent out-of-pocket accessing occupational therapy.

Figure 2.4. How easy or difficult people with IBD find it to access various healthcare services (%)



There are also additional difficulties in accessing these specialities due to limited availability of providers and appointments.

Over one in three people diagnosed with IBD report that they find it difficult to access a GP (39%), an IBD consultant or gastroenterologist (36%) or other consultants or specialists for their IBD (33%).

Access difficulties are not limited to specialists, with 21% of respondents have difficulty accessing mental health support, therapy or counselling, while similar numbers have difficulty accessing an IBD clinic/ nurse specialist (20%) or a dietitian (20%).

11% of respondents have difficulty accessing physiotherapy while 9% have difficulty accessing occupational therapy.

Limited access to the appropriate healthcare professionals can delay the ongoing management of IBD, which can lead to complications and impact on prognosis. Regular check-ups are essential for monitoring disease activity, adjusting medications, and identifying potential complications. Difficulty accessing these services can therefore impact on disease management, increasing the risk of flare-ups and hospitalisation[1].

2.5. Public patients paying privately for IBD health expenses

People with IBD often turn to private healthcare due to limitations in public or semi-public healthcare systems.

The survey asked respondents who use only public care for their IBD if they had ever paid privately for tests or scans for their IBD and if they had, the reason for doing so.

38% of these respondents said they had paid privately for tests or scans for their IBD. A further 31% said they have not as they could not afford to do so.

28% of public patients said that long waiting times was their reason to pay for tests or scans privately.

Despite their care being under the public system, this suggests that some patients with IBD must depend on the private system for appropriate and timely access for tests and scans.

2.6. Effect of IBD costs on treatment decisions

Almost half of respondents (47%) have avoided seeking medical services for their IBD due to the costs involved, with almost four out of ten (39%) saying they had occasionally done so and 8% saying they had frequently done so.

47%
have avoided seeking medical services for their IBD due to the costs.

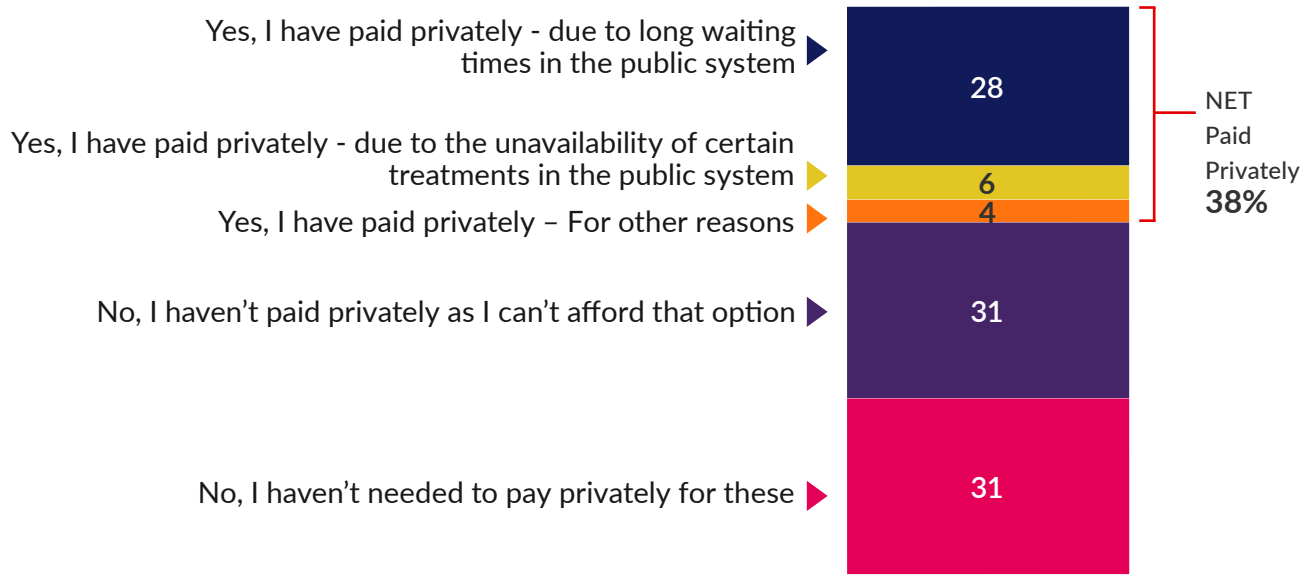
The price of medications can also force patients to make difficult choices about their IBD care.

Over one in four (26%) said that they had delayed taking IBD medication to make it last longer due to cost, with 20% saying they had done so occasionally and 6% saying they had done so frequently.

These findings are a cause for concern, as avoiding or delaying necessary IBD care due to cost concerns can have serious consequences, including disease progression, increased symptom flares, and potentially life-threatening complications[2].

26%
have delayed taking IBD medication to make it last longer due to the costs.

Figure 2.5. IBD public patients paying privately for tests or scans and reasons why (%)



2.7. The most significant financial challenge of living with IBD

Respondents were asked what they believe to be the most significant financial challenge of living with IBD from four categories presented.

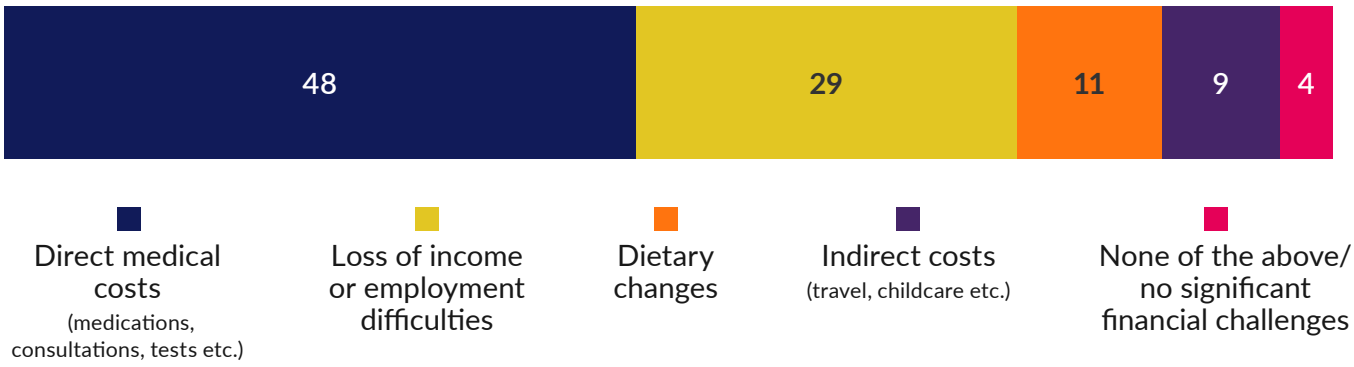
Almost half of respondents (48%) reported that direct medical costs (medications, consultations, tests etc.) are the most significant financial challenge of living with IBD.

Loss of income or employment difficulties was chosen by 29% of respondents as the most significant financial challenge of living with IBD.

Others felt that the biggest financial challenge is the need for dietary changes (11%), while 9% said it is indirect costs such as travel, childcare, etc.

> *If this financial burden was lifted it would allow you to concentrate your energy on supporting your illness as opposed to worrying about financial concerns.*
> ***- Survey Respondent***

Figure 2.7. Most significant financial challenge of living with IBD (%)

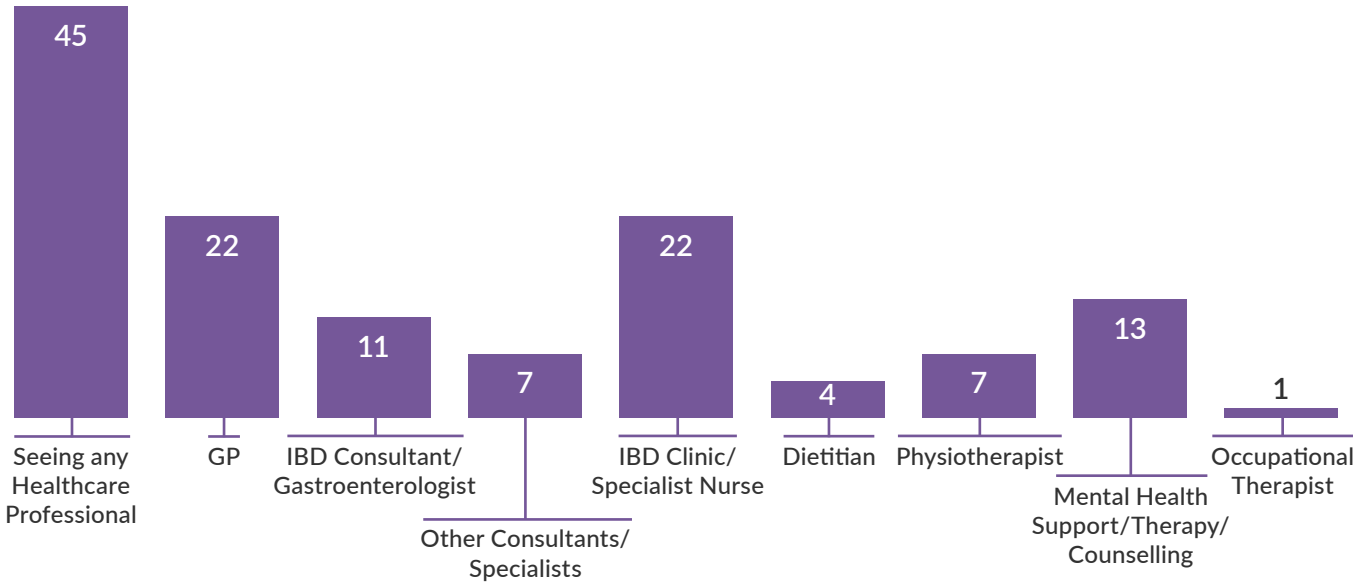


3. Accessing Care for IBD

"It is a long-term chronic condition that has a significant financial burden. You may be fine for a long time but then require a lot of medical intervention. It is not fair to have to pay so much money for medication that is essential."

- Survey Respondent

Figure 3.1. Healthcare Professionals being visited monthly or more for IBD (%)



3.1. Frequency of using services for IBD

There are direct and indirect costs for people living with IBD when accessing healthcare professionals, diagnostics and treatment. To ensure it is effectively managed, IBD requires regular input and guidance from GPs, consultants or gastroenterologists, IBD clinic or specialist nurses, dietitians and mental health support.

The respondents to this survey were asked about the frequency of their visits to these services.

45%
see a healthcare professional at least once per month to help with the management of their condition.

Such visits are frequent, with 45% of respondents seeing at least one or more healthcare professionals at least once a month to help manage their condition.

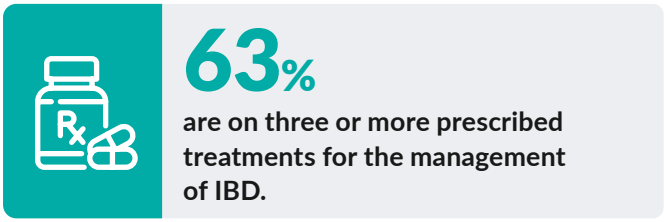
GPs and IBD specialist nurses are seen most regularly by those with IBD, with 22% of respondents attending these services monthly or more often.

Mental health support services, such as therapy or counselling, are seen monthly or more often by 13% of respondents.

While representing a smaller proportion of monthly visits, 11% of respondents report seeing their IBD consultant or gastroenterologist once or more per month, while 78% see them at least twice per year.

93%
of those diagnosed with IBD indicated they have found it hard to cope with their IBD over the past 12 months.
(Source: Crohn's & Colitis Ireland IBD Patient Survey Report 2024)

3.2. Use & Frequency of IBD Medications



63%

are on three or more prescribed treatments for the management of IBD.

Managing IBD involves taking medications to help with symptoms and maintain remission.

74% of respondents are taking prescribed oral medication, with 66% taking them daily.

44% are taking prescribed subcutaneously administered injections at home, while 41% of respondents are taking an infusion administered in their hospital.

Although prescribed medication can reduce inflammation, and induce remission, some patients will have symptoms that are not addressed by this medication and must take over the counter medication also to alleviate the symptoms they are experiencing. 69% of respondents are paying for over-the-counter medications to help with their treatment of IBD.

3.3. Impact of move to subcutaneous injection

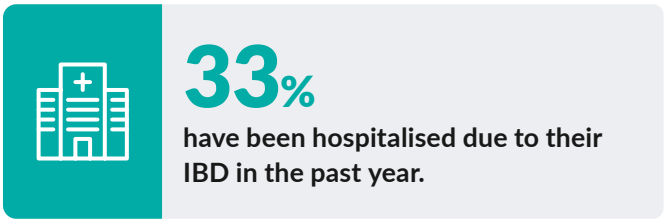
Medications that were traditionally administered through hospital infusions are now increasingly being delivered via subcutaneous injections in the community setting[3].

Infusions that are administered in hospitals are covered by the hospital budget, however, with the shift to subcutaneous injections, patients may incur extra costs for receiving the subcutaneous injection in a community setting.

29% of survey respondents reported that they had been moved from in-hospital infusion to a subcutaneous injection for the treatment of their IBD. Those that had made this move were then asked the extent to which this move to subcutaneous injection had an additional financial impact on them.

44% of those that had made the move said that it had had a financial impact, either to some extent (31%) or to a great extent (12%).

3.4. Surgery and Hospitalisation for IBD



33%

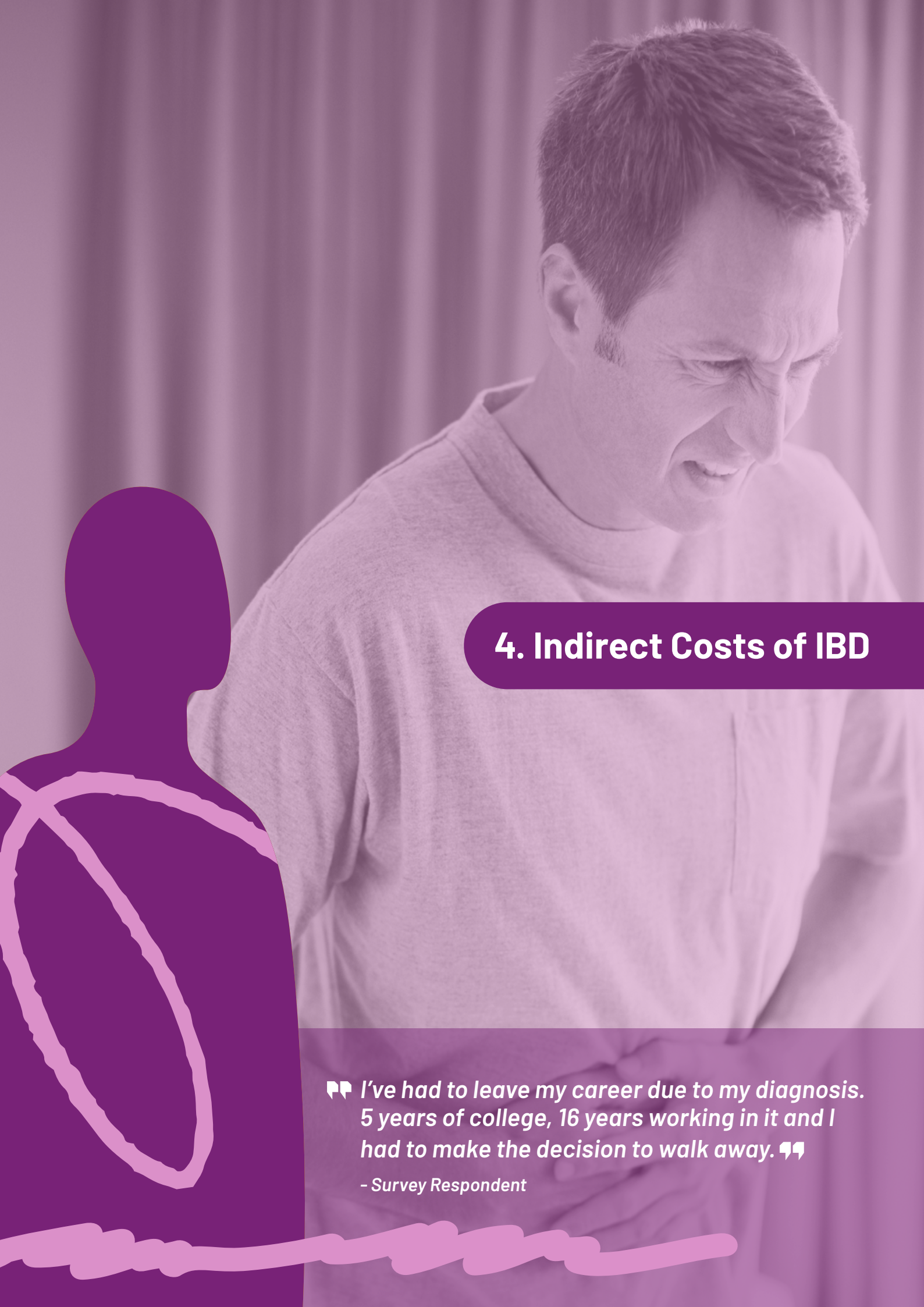
have been hospitalised due to their IBD in the past year.

Complications and progression of IBD can lead to hospital admission or surgery. Given the impact of these events, this survey sought to gather insights on the frequency with which they occur among people with IBD.

One third of respondents (33%) have been admitted to hospital within the last year due to their IBD. Almost half (49%) of those hospitalised have been admitted to hospital more than once in the past year.

32% of respondents have undergone surgery as treatment for their IBD. Among those having undergone surgery, the average number of total surgeries in their life was three. A further 14% have used a stoma bag due to their condition.

> *IBD is an illness that as of now there is no cure for. I did not choose to have IBD, I was unfortunate enough to be diagnosed with.*
>
> *- Survey Respondent*

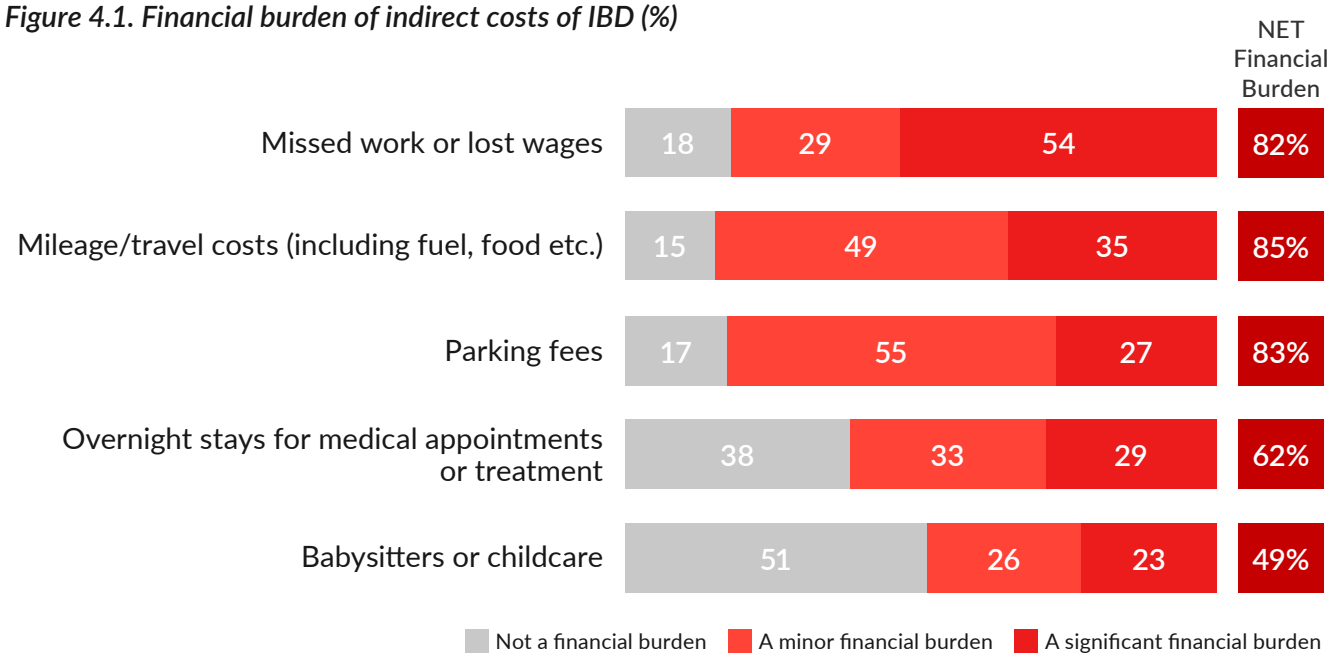


4. Indirect Costs of IBD

"I've had to leave my career due to my diagnosis. 5 years of college, 16 years working in it and I had to make the decision to walk away."

- Survey Respondent

Figure 4.1. Financial burden of indirect costs of IBD (%)



4.1. Financial burden of indirect IBD costs

The survey also examined the level of burden caused by the indirect costs of IBD.

82% of respondents say that missing work or losing wages due to their IBD is a financial burden, with 54% rating that burden as significant.

85% of respondents believe that the impact of mileage and/or travel costs to medical appointments is a financial burden, with over a third (35%) rating that burden as significant.

83% of respondents indicate that parking fees are a financial burden, with 27% rating that burden as significant.

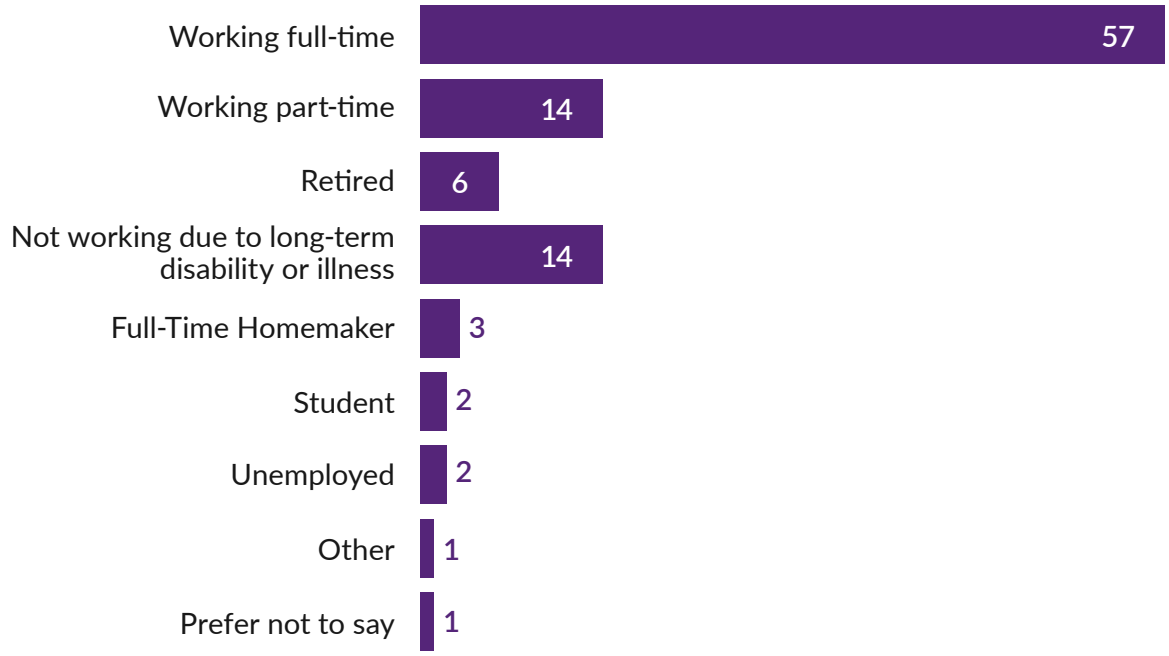
Overnight stays for medical appointments or treatments are a financial burden for 62% of respondents, while childcare or babysitting was considered a financial burden by 49%.

Additionally, for those living more than 45 minutes away from their nearest hospital (43% of respondents), these indirect costs were all more likely to be a financial burden. Among this cohort, 94% say that mileage and/or travel costs are a financial burden, 88% say parking fees are a financial burden and 74% say overnight stays for medical appointments are a financial burden.

82%

(of those working) say that missed work or lost wages due to their IBD has been a financial burden.

Figure 4.2.1. Breakdown of working status of respondents (%)



4.2. Impact of IBD on employment

During a flare-up, a person diagnosed with IBD will experience an increase of their IBD symptoms and feel unwell. These flares can have a significant impact on the life of a person diagnosed with IBD, including their ability to work.

94%
of working respondents have had to take time off work due to their IBD.

71% of respondents are currently working, either full-time or part-time.

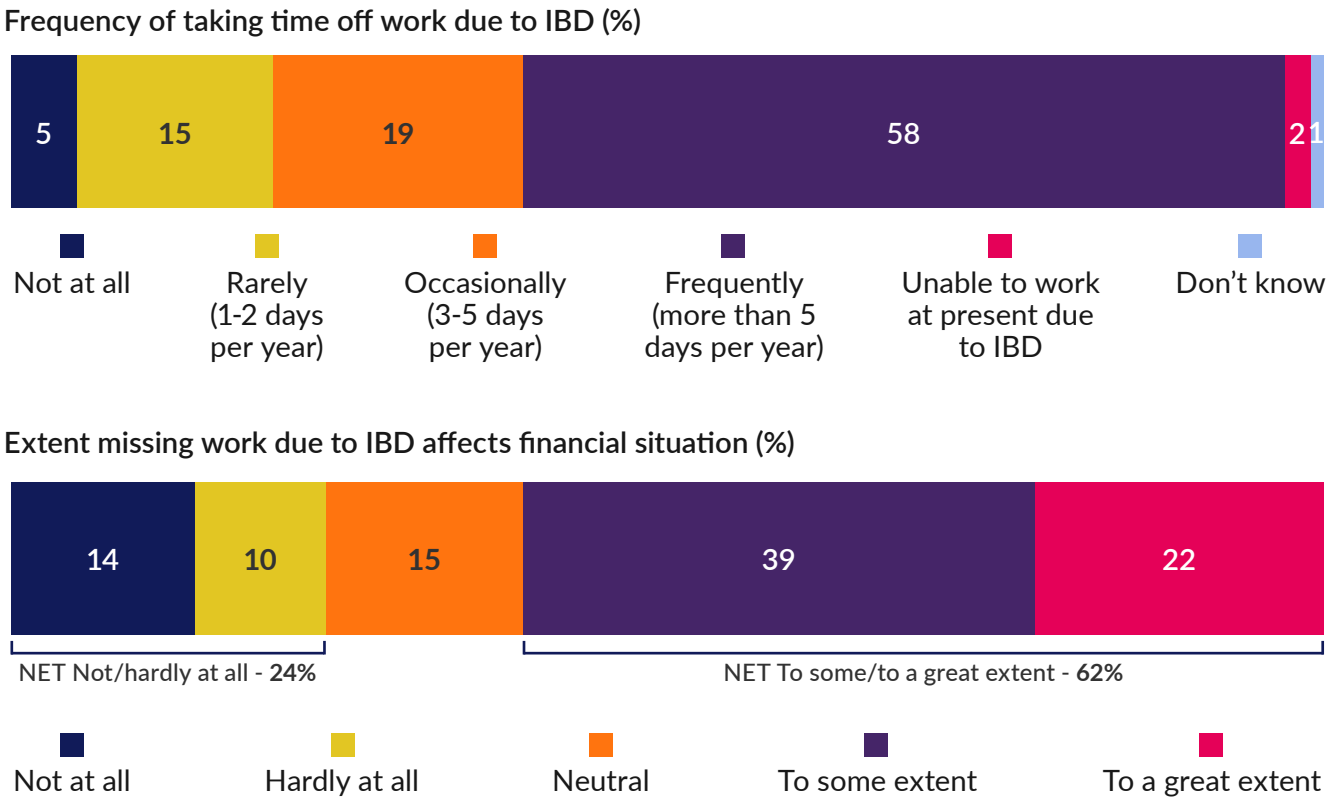
58% of working respondents need to take more than 5 days off work per year due to their IBD. Of those who have had to take any time off work due to their IBD, 62% say that missing work has affected their financial situation.

The necessity to take leave while managing IBD symptoms and flare-ups can lead to running out of paid leave and/or having to take unpaid leave in order to take the necessary measures to recover.

There is a common belief among survey respondents that IBD has negatively affected their ability to work effectively and to their desired potential, with a notable impact on current and potential career opportunities.

86%
of working respondents have gone to work even when they needed to take time off due to their IBD.

Figure 4.2.2. Impact of IBD on work (time off) and how this affects financial situation (%)



> *Because it's a chronic disease and I won't always be able to work. Sometimes in work I'm in so much pain I vomit. So, a medical card would be so beneficial for me that way, I could take time to heal without the financial burden.*
>
> ***- Survey Respondent***

67% of those working indicate that they have been limited in their ability to advance in their career as a result of their condition, with 65% saying that their choices for career or education have been restricted due to their IBD.

Almost two-thirds of working respondents (65%) report their IBD has influenced their decision to reduce their work hours, while 47% say their IBD has affected their ability to maintain their employment. As many as 12% of all respondents state that IBD has caused them to take early retirement.

The sentiment towards employers' accommodation of IBD is mixed, with 65% of those working agreeing that their employer exhibits understanding when it comes to taking time off due for IBD treatment or surgery.

However, **less than half (46%) agree that their employer has taken reasonable steps to accommodate their IBD**. This indicates a need for greater support in the workplace for people diagnosed with IBD to be able to maintain employment and advance in their career.

4.3. Time spent accessing healthcare services for IBD (hours)

	GP	IBD consultant	Other consultants/ specialists	IBD clinic/ specialist nurse	Dietitian	Physio-therapist	Mental health support/ counselling	Occupational therapist	TOTAL
Avg. hours p.a. spent in **public system**	8	11	4	6	1	2	2	<1	**34 Hours**
Avg. hours p.a. spent in **private system**	9	11	11	6	1	3	6	<1	**47 Hours**

Where figures do not add to the total this is due to statistical rounding.

4.3. Time spent accessing healthcare services for IBD

Accessing necessary healthcare services for IBD takes time (including making the appointment, waiting for, attending and traveling to and from the appointment). This time burden holds true for both the public and private system and an individual living with IBD may be trying to access multiple healthcare services.

In the public system, respondents spend on average a total of 34 hours per year accessing the services listed. This included 8 hours accessing their GP, 11 hours accessing an IBD consultant, 4 hours accessing other consultants or specialists, 6 hours accessing the IBD clinic or nurse specialist and 2 hours accessing mental health support or counselling.

In the private system, respondents spend on average a total of 47 hours per year accessing the services listed. This included 9 hours accessing their GP, 11 hours accessing an IBD consultant, 11 hours accessing other consultants or specialists, 6 hours accessing the IBD clinic or nurse specialist and 6 hours accessing mental health support or counselling.

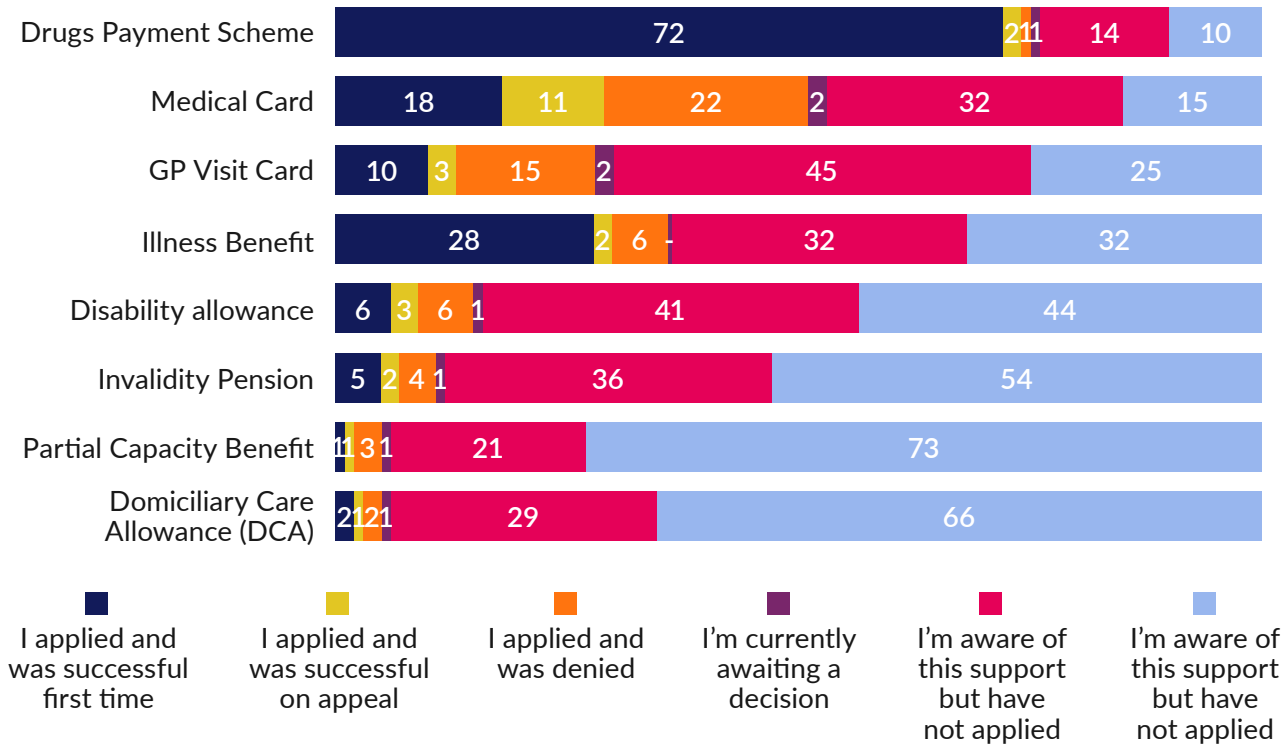
5. Support Programmes & Insurance

Crohn's disease is not recognised officially as a chronic disease - yet all insurance companies add a levy to annual premiums because I've declared myself as having Crohn's. Day-to-day society clearly already regards and treats Crohn's as a chronic illness. Why doesn't the State?

- Survey Respondent

5. Support Programmes & Insurance

Figure 5.1. Status of Department of Social Protection / HSE Support Applications (%)



5.1. Applications for support programmes

Government support programmes are available to provide financial support to people with temporary or long-term illness. However, each of these programmes require an application process and are subject to approval by the relevant bodies. The research also showed that there are mixed levels of awareness of such financial support programmes.

For those diagnosed with IBD, 72% of respondents were successful on their first application for the Drug Payment Scheme (DPS), with a further 2% successful on appeal. The success rates of applications for other support programmes are considerably lower than that of the DPS.

29% were successful in their application for a medical card, but 22% applied and were denied. 15% were not aware of this support.

13% were successful in their application for a GP visit card, but 15% applied and were denied. 25% were not aware of this support.

30% of respondents were successful in their application for illness benefit, but 6% applied and were denied. 32% were not aware of this support. Many respondents are unaware of the range of potential supports available for application.

The most common reason provided for denying applications for the programmes was reported to be ineligibility due to IBD not meeting the requirements for approval. A significant proportion also reported that they were denied due to their condition not being recognised as severe enough.

Finally, another common reason mentioned spontaneously by a significant portion of respondents as a reason for the denial of applications for medical cards and GP visit cards, was exceeding the income threshold and failing a financial means test.

> *I was refused a GP card and Medical Card because my wife earns €42,000 per year - why should my wife have to endure reduced income because of my medical condition.*
>
> *- Survey Respondent*

5.2. Attitudes towards support programmes

65%

of relevant respondents believe that current Department of Social Protection programmes do not adequately address needs of those with IBD.

Respondents were asked additional questions to further examine their attitudes towards financial support programmes people diagnosed with IBD can apply for.

Only 12% relevant respondents (excluding 'not applicable') agree that current Department of Social Protection programmes adequately address the needs of people living with IBD. **Almost two in three (65%) of relevant respondents actively disagreed with the same statement**.

67%

reported having to rely on other forms of financial support due to lack of access to Department of Social Protection programmes.

A lack of access to Department of Social Protection support programmes has led to 67% of relevant respondents having to rely on other forms of financial support, such as savings or support from family.

51% of relevant respondents say that the lack of access to Department of Social Protection support programmes has resulted in significant financial difficulties for themselves or their family.

The application process for Department of Social Protection support programmes has also had a negative impact on people with IBD. 45% of relevant respondents have experienced delays or difficulties in receiving financial support from the Department of Social Protection due to the complexity of the application process.

45% of relevant respondents say that their access to the Department of Social Protection support programmes significantly improves their ability to manage their IBD. However, 25% are neutral in this regard, while 12% disagree.

> *My daughter has an illness for the rest of her life which carries a huge financial cost regarding treatments and medication and specific foods. She will have to take time off work when she is an adult due to flare ups. Many GP and hospital visits and stays will be needed and there is absolutely no help from the government for this. She does not have a GP visit card, a medical card or any support whatsoever from the government. She will have this illness for the rest of her life, the very definition of a long term illness so why is it not recognised as such? My daughter is 13 years old. She was diagnosed at age 11. It will be a very long and financially draining road ahead for us and her with no financial support.*
>
> *- Survey Respondent*

5.3. Insurance cover for those with IBD

Just
9%
of respondents are fully covered by their health insurance.

The survey examined whether respondents have health insurance that adequately covers most of their IBD-related expenses.

Two-thirds of those with IBD (66%) have some form of private health insurance. However, only a minority (9%) of all respondents have health insurance that completely covers their IBD-related expenses.

This leaves the majority of respondents (91%) with the financial responsibility of their IBD.

Just under half (48%) are covered but need to supplement their coverage with out-of-pocket expenses to manage their condition. Meanwhile, 10% say they have minimal coverage only in their health insurance and just over one third (34%) have no health insurance at all.

Of all respondents who have applied for health insurance, 17% reported to have been denied due to their IBD. Among those denied, the primary reasons reported to have been given by the insurance providers were the presence of a pre-existing medical condition (IBD) (77%), being classified as high risk due to IBD (17%), and the insurer's lack of coverage for chronic illnesses (4%).

Those with IBD who have health insurance also report having coverage exclusions or higher premiums due to their condition, with 18% paying higher premiums and 15% having to accept exclusions of some IBD-related treatments or conditions in their coverage.

39%
have been denied or had difficulty accessing other forms of insurance due to their IBD diagnosis.

People with IBD have had difficulties accessing other types of insurance as well.

Because of their IBD, some respondents have been denied or had difficulty accessing life insurance (22%); travel insurance (16%); critical illness insurance (15%); or mortgage protection (20%).

> *IBD is a lifelong, incurable and debilitating condition that is costly to treat and often not covered by insurance plans until years of cover has been paid (regardless of how many flares I actually experience).*
>
> *- Survey Respondent*

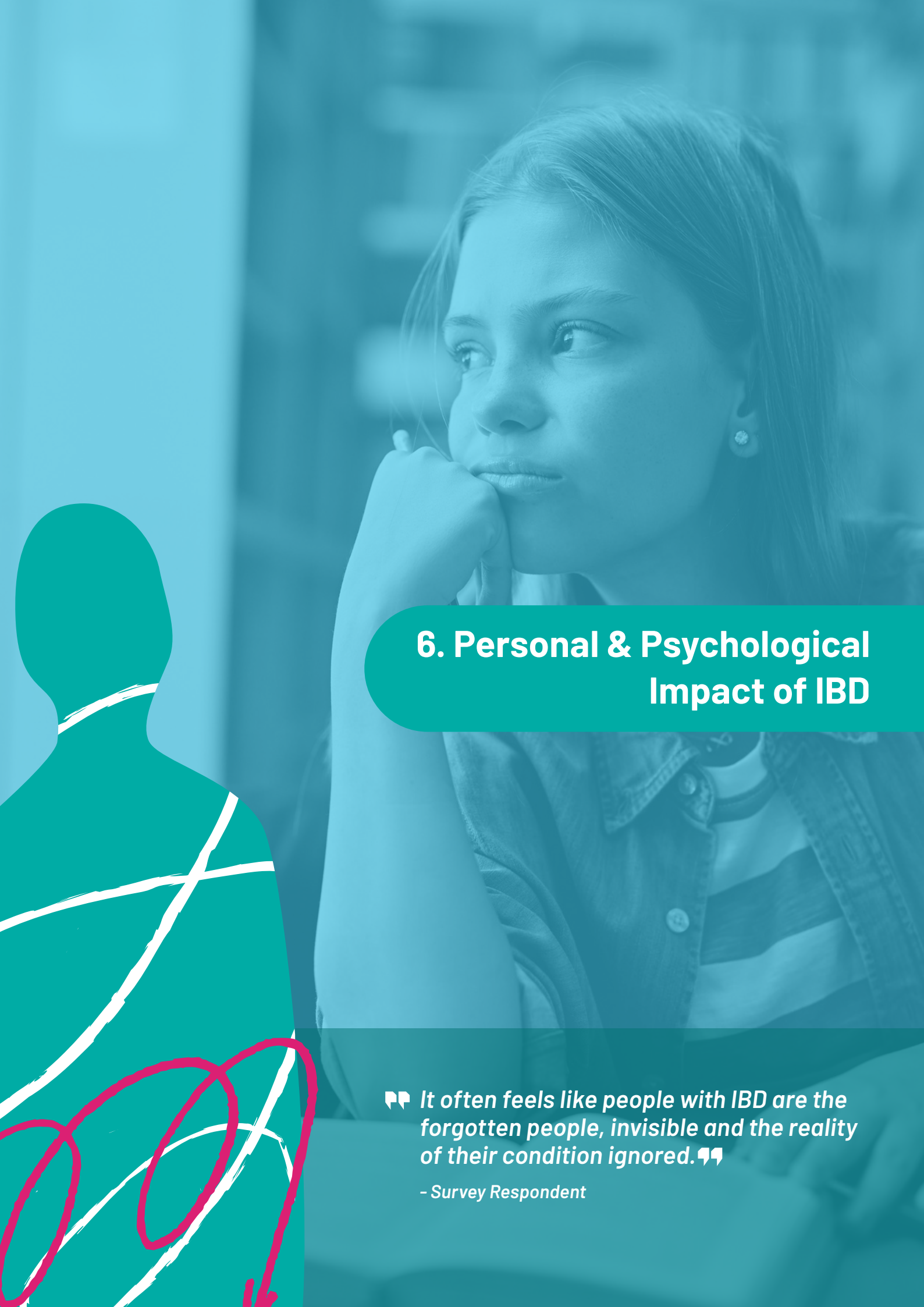
5.4. Recognition of IBD for additional supports

98%
of respondents agreed that IBD should be acknowledged and treated as a qualifying condition.

When respondents were asked about whether or not they believe IBD should be recognised as a qualifying condition for additional support programmes, there was near universal agreement that it should.

Those living with IBD overwhelmingly believe that the current classification of the condition is inappropriate.

> *"By recognising IBD for government support services, Ireland would be acknowledging the serious impact of this autoimmune disease and ensuring that patients receive the financial, medical and physiological support they deserve and need to live dignified and productive lives."*
>
> *- Survey Respondent*

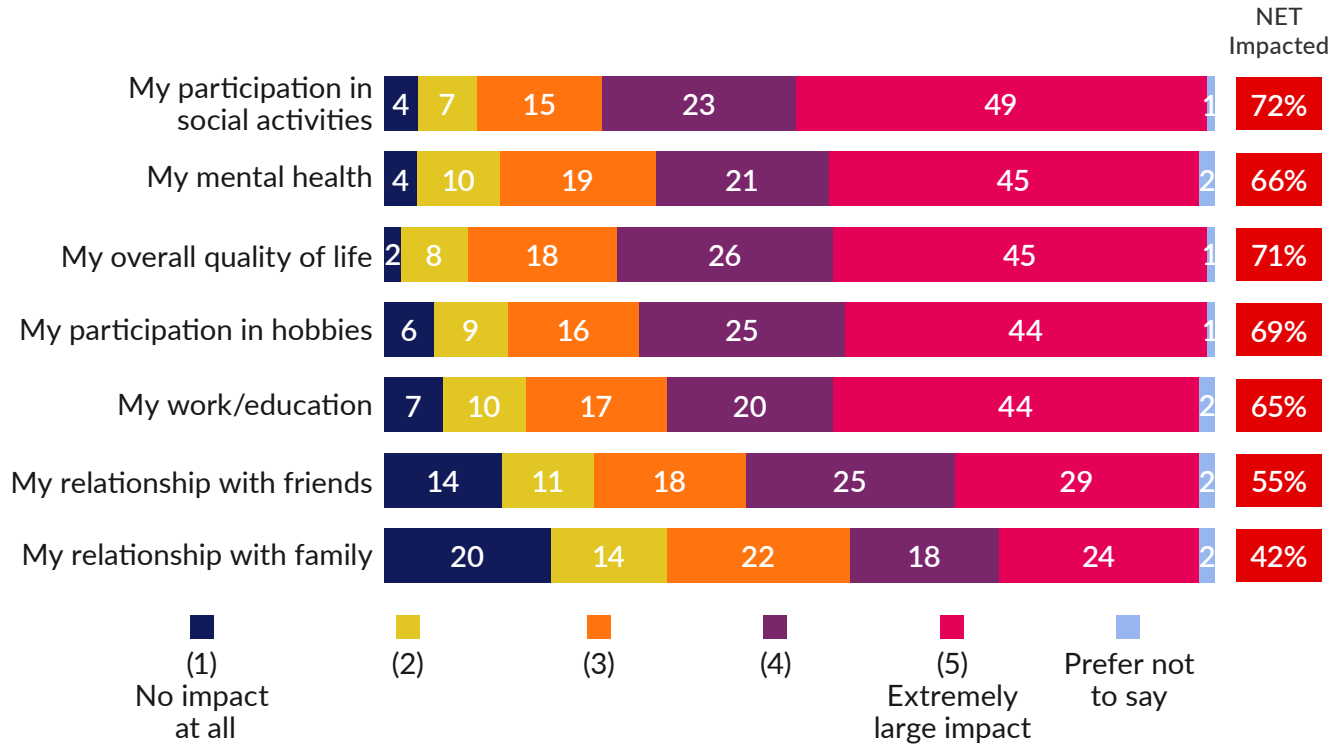


6. Personal & Psychological Impact of IBD

"It often feels like people with IBD are the forgotten people, invisible and the reality of their condition ignored."

- Survey Respondent

Figure 6.1. The Overall Impact of IBD (%)



Where figures do not add to the 100% or similar, this is due to statistical rounding.

6.1. Psychosocial Impact of IBD

71%
say their IBD has impacted their overall quality of life.

The effect of IBD reaches beyond the medical and financial impacts already covered. It affects the daily lives and relationships of those living with IBD, with **71% of respondents say that their IBD has an impact on their overall quality of life** (45% saying the impact is extremely large).

Two-thirds (66%) say that their mental health is impacted by their condition, with 45% saying this impact is extremely large.

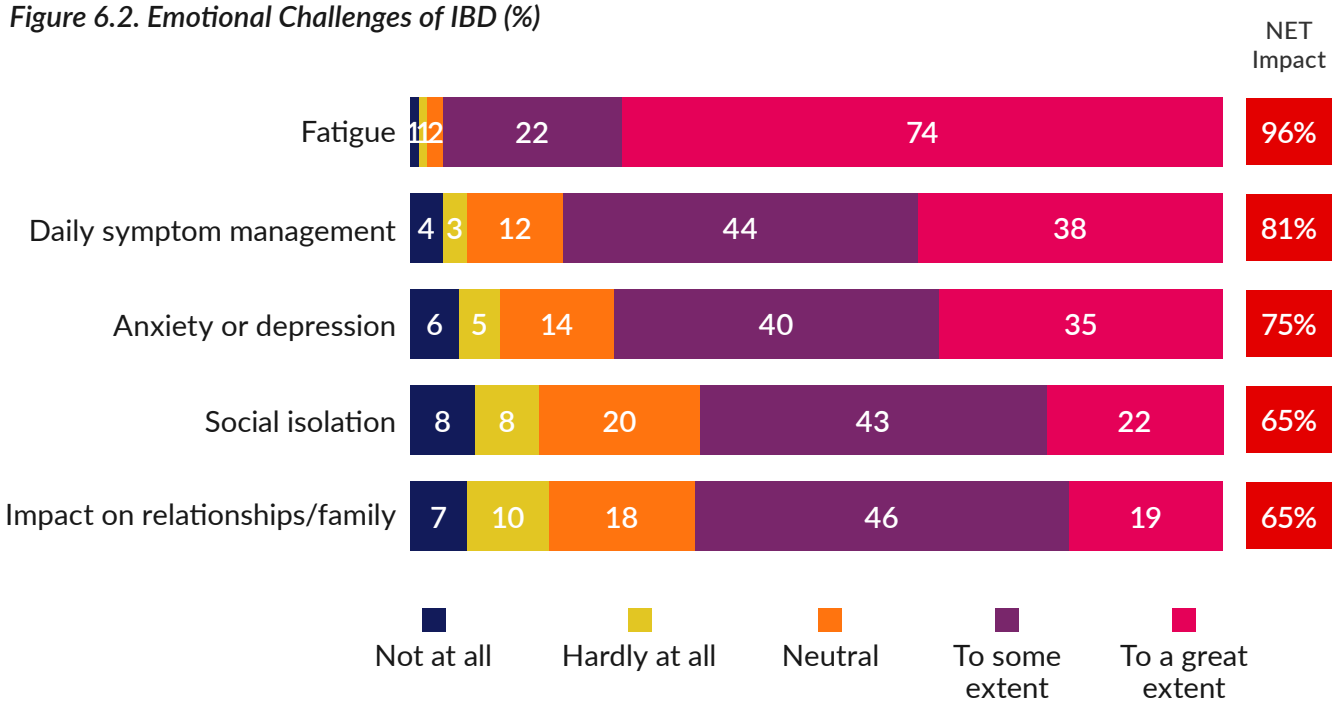
72% of respondents say that IBD has impacted their ability to participate in social activities, while 69% have experienced an impact on their ability to participate in hobbies.

Additionally, 65% of respondents say that their work or education has been impacted by IBD.

The condition has also impacted the relationships of respondents, both with friends (55%) and with family (42%)

> ***"It is an incurable and chronic condition that changes every aspect of your life. Mentally, physically, emotionally, sexually, financially. It has shaped the direction of my life and many sufferers. It impacted my career, my ability to have children, to buy a home. I believe we deserve supports for such a life altering condition."***
>
> *- Survey Respondent*

Figure 6.2. Emotional Challenges of IBD (%)



6.2. Emotional challenges of IBD

Living with IBD involves more than just financial challenges; it also affects a person's emotional well-being.

The fatigue caused by IBD was found to be challenging by 96% of respondents, with 74% finding it challenging to a great extent.

Daily symptom management is a challenge for 81% of respondents.

Anxiety or depression was reported to be a challenge by three quarters (75%) of respondents, while 65% reported social isolation to be a challenge for them.

The impact of IBD on the respondents' relationships and families was also found to be a challenge by a majority of respondents (65%).

> ***"I feel IBD is seen as just 'stomach issues' and it is so much more than that. The fatigue symptom alone is so debilitating and can make going to work and carrying out normal tasks to be so difficult. I feel it's unfair to expect IBD sufferers to carry on life as normal when we often suffer hard symptoms frequently."***
>
> *- Survey Respondent*

7. Appendices

7. Appendices

7.1. Methodology

The survey was designed to gather robust quantitative data to provide valuable insights into key themes related to the cost of living with this condition.

Survey Design and Development

The questionnaire instrument was developed by Ipsos B&A in close collaboration with Crohn's & Colitis Ireland (CCI) and Johnson & Johnson Innovative Medicine. This partnership ensured that the survey addressed relevant topics and was appropriate for the target audience. Before being sent to field, the questionnaire underwent a pilot phase with members of CCI to refine its content and ensure clarity and comprehensibility.

Survey Administration

The survey was administered online, allowing for broad reach and convenient participation for respondents. It was distributed through multiple channels by Crohn's & Colitis Ireland, leveraging their established communication networks to maximise participation. Reminders were used to further boost response.

These distribution channels included direct e-mail communication to individuals subscribed to CCI's mailing list; promotion of the survey through CCI's official social media channels; and sending posters advertising the survey to IBD clinics. This allowed for targeted outreach to individuals engaged with the organisation.

Target Population and Sampling

The target population for this survey was adults (18 years and older) diagnosed with Inflammatory Bowel Disease (IBD) in Ireland. To ensure the inclusion of perspectives from individuals unable to complete the survey independently, such as those under 18 years old, caregivers and guardians were also permitted to participate on their behalf. A total of 32 caregiver/guardian responses were collected.

Sample Size and Fieldwork Period

Data collection took place over a three-week period, from 5th-24th March 2025. A total of 376 eligible individuals completed the survey, representing a total population of approximately 40,000 individuals nationwide, which constitutes a robust sample size for analysis and provides statistically reliable results. The inclusion of the caregiver/guardian responses provides further valuable context to the experiences of living with IBD.

Data Analysis

Ipsos B&A conducted a statistical analysis of the quantitative data as well as a qualitative analysis of additional verbatim responses.

This rigorous methodology ensured the collection of high-quality data, providing a reliable and comprehensive understanding of the experiences of individuals living with IBD in Ireland. The findings from this study will be instrumental in informing future initiatives and improving the lives of those affected by this condition.

Please note that where percentages do not add up to 100% or similar, this is due to statistical rounding.

7.2. Sample Profile

The profile of the survey sample of 376 respondents can be summarised as follows:

- ***Gender:*** The gender profile was consistent with the previous survey conducted by Crohn's & Colitis Ireland in 2024. 73% of respondents were female while 26% were male. Under 1% classified themselves as non-binary and 1% were classified as 'other' or preferred not to divulge their gender.
- ***Geographic location:*** A geographical spread of responses was achieved, with all 26 counties in the Republic of Ireland represented. 26% of responses were from Dublin, 27% from the rest of Leinster region (excluding Dublin), 28% from Munster and 19% from Connaught/Ulster, broadly representative of the Irish population as a whole.
- ***Age:*** 6% of responses were provided by carers or guardians of people with IBD under 18 years; 4% were aged 18-24 years; 18% were aged 25-34 years; 29% were aged 35-44 years; 26% were aged 45-54 years; 12% were aged 55-64 years; and 5% were aged 65 years and older.
- ***Type of IBD:*** 45% of respondents had Crohn's disease while 40% had ulcerative colitis. The remainder had a "combination diagnosis" of Crohn's and colitis, also known as IBD unclassified or indeterminate colitis, which occurs when a person presents with symptoms and features of both ulcerative colitis and Crohn's disease, making it difficult to definitively distinguish between the two conditions.
- ***Years since diagnosis:*** Demonstrating the nature of this chronic condition, respondents ranged from those recently diagnosed less than 5 years ago (34%), those diagnosed 5-14 years ago (32%), those diagnosed 15 or more years ago (34%). The average time since diagnosis across the survey sample was 12 years.
- ***Comorbidities:*** Over half of respondents (59%) had a comorbidity in addition to their IBD, i.e. a simultaneous presence of another diagnosed medical conditions for which they are prescribed medication. The presence of a comorbidity increased with respondent age as might be expected; 42% of those aged 35 and under had another comorbidity, compared to 62% of those aged 36-49 years and 73% of those aged 50 years or more.
- ***Main setting for IBD management:*** Just over half of respondents (52%) said their IBD is managed primarily in a public healthcare setting. One in four (25%) are mainly managed in a private healthcare setting, while the remainder (23%) said their care is managed across both public and private equally.
- ***Medication cost programmes:*** As regards those availing of government programmes that assist with medication costs, 69% of respondents were registered with the Drug Payment Scheme (DPS). Meanwhile, 29% availed of the General Medical Services (GMS) and had a Medical Card. A further 7% had a GP visit card.

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Crohn's & Colitis Ireland

Johnson&Johnson Innovative Medicine

CP-519787
DOP: May 2025

Ipsos B&A