

Crohn's and Colitis Top 10 Impacts Final Report

Prepared for Crohn's & Colitis UK

June 2024



COMMON →

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**CROHN'S &
COLITIS UK**

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Common uses design and behavioural science to reduce inequality and create and scale social impact. Our team spans a range of disciplines from statisticians to service designers. Common funds the work of the Talking Taboos Foundation.

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Since 1979, Crohn's & Colitis UK has been here for everyone affected by Crohn's and Colitis. We want to see improved lives today, and a world free from Crohn's and Colitis tomorrow.

**CROHN'S &
COLITIS UK**

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1 | Foreword

Foreword from Crohn's & Colitis UK

Over 500,000 people in the UK have Inflammatory Bowel Disease (IBD). That's at least one in every 123 people. The number of people living with the conditions appears to be growing. IBD can be extremely debilitating and impact on every area of a person's life. Crohn's & Colitis UK exists to improve the lives of people living with these conditions.

We commissioned Common Collective to undertake this robust programme of research to determine the top 10 areas of people's lives that are most impacted by living with Crohn's and Colitis in the UK.

They consulted with people living with the conditions across the UK, ensuring that the findings were representative of everyone living with Crohn's and Colitis. This included responses from people who are currently under-represented in our research.

The areas that were prioritised cover a wide spectrum of both tangible and psychological issues that affect physical, social and emotional wellbeing. These insights highlight the necessity for better awareness, comprehensive support systems, and targeted campaigning to advocate for changes to address the diverse and complex needs of everyone living with Crohn's and Colitis.

This work is of considerable strategic importance. By deepening our understanding of which areas of people's lives are most impacted by IBD, we will be able to focus our efforts and work with others on the areas that matter most to everyone living with Crohn's and Colitis to improve their quality of life.

Ruth Wakeman, Director of Services, Advocacy & Evidence
Crohn's & Colitis UK

2 | Executive summary

The main aim of this project was to robustly identify the Top 10 impacts of Crohn's and Colitis for people living with the conditions in the UK. Crohn's & Colitis UK commissioned Common Collective to design and run the Top 10 research.

The project used robust, community-led and innovative approaches to discover and prioritise the impacts of living with Crohn's and Colitis.

Discovering the impacts: The **first stage** of the project involved community outreach to take part in a survey. 1,684 people took part by telling us about the impacts that the condition had on their quality of life.

Refining the impacts: The **second stage** involved two workshops to reduce the longlist of impacts from the first stage to a shortlist to take forward to a final stage.

Prioritising the impacts: In the **third stage** participants from the first survey were recontacted. 970 people with Crohn's and Colitis took part in a prioritisation survey to help identify the Top 10 Impacts.

The Top 10 impacts of having Crohn's and Colitis on people's quality of life are:

1. Fatigue and energy management
2. Anxiety about toilets and accessing them
3. Living with unpredictable symptoms and flares
4. Living with physical symptoms
5. Feeling embarrassed and self-conscious
6. Dealing with poo
7. Complex emotions (e.g. frustration, worry, grief)
8. Always being alert to signs and symptoms
9. Having to plan and strategise activities and events
10. Sleep disruption

3 | Background and goals of the project

The main aim of this project was to robustly identify the Top 10 impacts of Crohn's and Colitis for people living with the conditions in the UK.

In more detail we wanted to...

- Deepen Crohn's & Colitis UK's understanding of all the ways people's lives are affected by the conditions.
- Be led by and consult with people living with Crohn's and Colitis across the UK
- Ensure the Top 10 list was representative of people living with Crohn's and Colitis in the UK by including responses from a diverse set of voices

Crohn's and Colitis UK commissioned Common Collective to design and run the Top 10 research. The project ran for 10 months between September 2023 and May 2024.

Our approach to the project started wide by understanding all the impacts of Crohn's and Colitis on people's lives. We then narrowed down to the Top 10 through two steps of refinement.

1

Understand all the impacts of Crohn's and Colitis on people's lives

Method: People with Crohn's and Colitis told us how their lives were affected by living with the conditions in written reply to a survey question. We also invited 10 people to take part in a diary study documenting their impacts over a few days.

Who took part: Through community outreach and a targeted recruitment boost we received **1,684** responses. 10 people completed the diaries.

2

Narrow down from a longlist to a shortlist for a final survey

Method: Two workshops prioritised the impacts to a shortlist. We also cross referenced the workshop results against the survey responses to ensure representation.

Who took part: The project team, advisory board members and additional lived experience representatives (16 people in total).

3

Robustly identify the Top 10 Impacts

Method: A prioritisation survey - recontacting people who took part in the first survey and had agreed to participate.

Who took part: Of 1,680 people who were re-contacted from the first survey, **970** took part in the second survey.

We used robust, community led innovative approaches to discover and prioritise the impacts of living with Crohn's & Colitis.

- ⇒ **Robustly designed** - validated approaches to data collection and analysis.
- ⇒ **Authentic** - we worked with our advisory board to ensure that the questions and approach were sensitive to those living with the conditions.
- ⇒ **Large samples** - at both survey rounds we had large and diverse samples.
- ⇒ **Rich impact stories** - 1684 stories of impacts shared in 298,041 words. Diaries allowed for consideration over a few days.

- ⇒ **Representative** - using random stratified sampling to obtain representative samples for analysis. That allowed us to ensure the findings represent the Crohn's and Colitis community.
- ⇒ **Analysis at scale** - we used an AI tool and Large Language Models (LLM- Claude) to extract everyone's impacts from the first survey.
- ⇒ **Rigorous analysis to arrive at top 10** - robust quantitative analysis methods were used to identify the Top 10 from the prioritisation survey responses.

Want to learn more about our methodology?
[You can read the technical report here](#)

We re-contacted participants of the first survey to complete the final prioritisation survey

1

Understand all the impacts of Crohn's and Colitis on people's lives

Who took part: Through community outreach and targeted boost we received **1,684** responses. 10 people completed the diaries.

3

Robustly identify the Top 10 Impacts

Who took part: Of 1,680 people who were re-contacted from the first survey, **970** took part in the prioritisation survey.

1,684

responses to the call out for impacts

970

completed the survey

The survey questions



1

Survey 1

Understand all the impacts of Crohn's and Colitis on people's lives

Q1. In what ways is your life affected by your condition?

Please include as much detail as you can and where possible examples / stories to help us understand the ways you are affected.

Free text response

Q2. We now want to understand in more depth how you experience the effects of your Crohn's or Colitis in your life

Please share some more examples or reflections in the space below. This could be other parts of your life that are affected, or more examples of what you've shared in the first question

Free text response

3

Survey 2

Robustly identify the Top 10 Impacts

Q: As someone living with Crohn's or Colitis, how much does [Impact X] affect your quality of life?

More info

- 1- not at all affected
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 - extremely affected

Each of the 23 impacts had a short description

And a longer description

People rated each impact from 1-10

We used robust analysis methods for each survey

1

Understand all the impacts of Crohn's and Colitis on people's lives

Using data from the written text responses to the survey we extracted **42 impacts** from **298,041** words and 10 diaries integrating AI and human powered analysis.

3

Robustly identify the Top 10 Impacts

Participants completed a prioritisation survey to rate how the impacts affect their quality of life.

We conducted data analysis to extract the **Top 10 Impacts** for the whole sample and sensitivity analyses to ensure representativity.

The prioritisation survey included responses from 970 people with Crohn's and Colitis.

Sample profile

Location

We had responses from across the UK:

- 76% from England
- 24% from Scotland, Northern Ireland and Wales
- Around 38% living in rural areas.

Gender

As seen in previous research, women are more likely to respond. Around 27% of respondents were male.

Ethnicity

Around 10% respondents were ethnic minorities. We worked with Caribbean and African Health Network (CAHN) on outreach.

Age, at survey completion includes all age groups:

- 18 to 30 years 17%
- 31 to 40 years 26%
- 41 to 50 years 19%
- 51 to 60 years 20%
- 61 years and over 18%

There was a good mix of Crohn's and Colitis represented in the 970 people

- 53% Crohn's Disease
- 41.9% Ulcerative Colitis
- 5.1% Other IBD

Other comorbidities

53.9% had other comorbidities.

Age at diagnosis

Under 30 years 52.8%, 30 to 50 30.7%, and 50 or above 16.5%

Severity (self classified)

- 20.6% in remission
- 27% mild
- 35.8% moderate
- 16.6% severe

Condition disruption to daily life

11.8% extremely disruptive to daily life

41.3% highly to extremely disruptive to daily life

Flares

42.3% had 3 or more flares in the last year.

Hospital and A&E admissions

30.3% were hospitalised or admitted to A&E at least one time in the last year because of their condition.

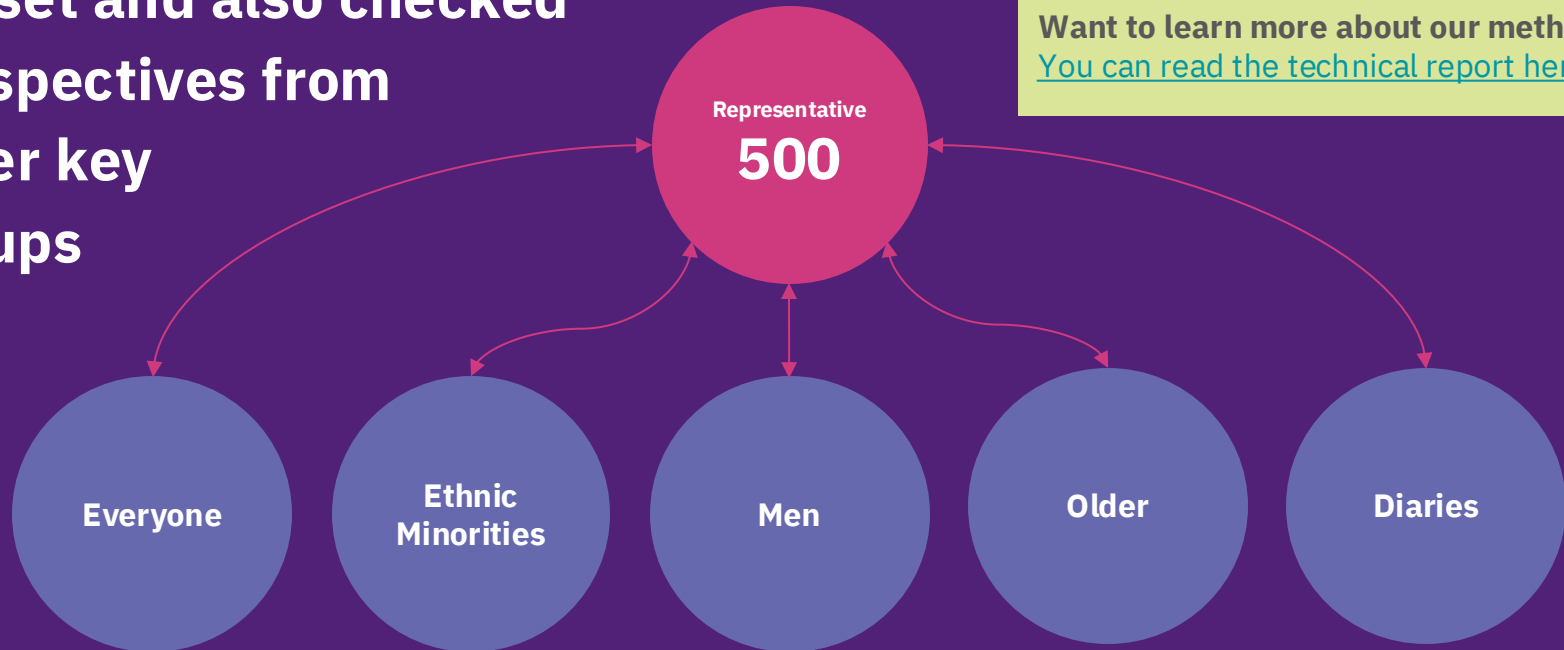
Findings are representative and diverse



From the whole sample we created a representative subset and also checked perspectives from other key groups

This approach gives confidence that the impacts were representative of all people with Crohn's or Colitis in the UK, and that under-represented groups are heard.

Want to learn more about our methods?
[You can read the technical report here](#)



Project team



The project was a collaboration between Crohn's & Colitis UK, Common Collective and a lived and professional experience advisory board



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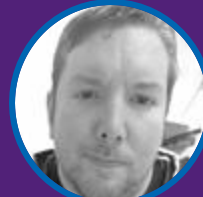
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4 | The Top 10 Impacts of living with Crohn's and Colitis

The Top 10 Impacts of Living with Crohn's and Colitis

1

Fatigue and energy management

2

Anxiety about toilets and accessing them

3

Living with unpredictable symptoms and flares

4

Living with physical symptoms

5

Feeling embarrassed and self-conscious

6

Dealing with poo

7

Complex emotions (e.g. frustration, worry, grief)

8

Always being alert to signs and symptoms

9

Having to plan and strategise activities and events

10

Sleep disruption

The Top 10 Impacts of Living with Crohn's and Colitis

Average impact on quality of life - Means (SD)



Top 10 Impacts

#1

Fatigue and energy management

#1 Fatigue and energy management

Impact Definition

Fatigue and energy management

Fatigue is the experience of tiredness or exhaustion, weakness and reduced energy. It impacts physical and mental energy.

It can get worse during a flare but can occur even when your IBD is more under control. It requires constant attention and attempts to manage and preserve your energy to get through daily activities and upcoming events.

Words used: Lethargic, tired, zapped, running on empty, low energy, brain fog, zombie, spent my energy

Fatigue is about:

- Feeling tired all the time
- Going beyond 'tired'
- Doing normal daily activities is really hard
- Mentally exhausted
- Having to choose where to spend energy
- Functioning but not enjoying - social/leisure feels like a 'chore'
- Constant need to sleep without its benefits

I have such limited energy and there's a pressure to spend it all at work to meet their standards - but I'm parenting a young toddler and it's heartbreaking not having the energy to play with them, let alone meal planning, cooking, playdates - I really lean on my partner and feel so guilty about it

I just feel completely exhausted all the time, my body feels heavy, my eyes are closing, I fall asleep where I'm standing - and I sleep and sleep but it doesn't make a difference, I still feel in a haze

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#1 Fatigue and energy management

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **fatigue and managing your physical and mental energy levels?**

Fatigue impacts physical and mental energy. It can get worse during a flare but can occur even when your IBD is more under control.

Fatigue and energy management impact on quality of life

7.73

on scale of 1 (not affected at all) to 10 (extremely affected)

29.3%
extremely affected
(rating 10)

75.4%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

Fatigue and difficulties managing physical and mental energy levels were ranked as the greatest impacts on quality of life for all participants, regardless their socio-demographic characteristics or the severity of their condition.

Those that self-identified as moderate or severe had higher scores compared to those that self-identified as mild or in remission (Moderate/Severe Mean= 8.30 vs Mild/In Remission Mean=7.09)

Women scores were also slightly higher than men (Women Mean= 7.93 vs Men Mean=7.19)

Top 10 Impacts

#2

Anxiety about toilets
and accessing them

#2 Anxiety about toilets and accessing them

Impact Definition

Anxiety about toilets and accessing them

You can think a lot about, and worry about, toilets - where they are, if there are enough, will they be clean and comfortable enough? Always needing to be close to toilets or access toilets can be a big part of living with IBD.

Poor access to and lack of toilets can cause a lot of worry about accidents. You might have to research where toilets are, plan your life around access to them and sometimes miss out because of lack of toilets in some places.

Words used: alert, can't relax, stress leaving the house, need good access, toilet mapping, fear, anxiety, unpredictability

Anxiety about toilets is about:

- Always needing to know where the nearest toilet is
- Worry about leaving house
- Judging places by access
- Worrying about effect on work day and time spent
- Hard to predict need for the loo which creates anxiety
- Fear of being judged for disabled toilets
- Anxiety about going out generally
- Needing space and facilities for stoma use and care

My work takes me to lots of different locations in a day, and I have to spend so much time planning my routes around toilets, adding in time for emergency stops, I lose money in that time and my day is so much more stressful than my colleagues

I get very anxious making social plans if I don't know that there's going to be a toilet there - sometimes I just don't go, and if I do, I'm on high alert until I've found the nearest toilet and that it's suitable for me

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#2 Anxiety about toilets and accessing them

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **needing access to toilets and your anxiety about toilets?**

Always needing to be close to toilets or access toilets can be a big part of living with IBD. Poor access to toilets can cause a lot of worry about accidents.

Anxiety about toilets and accessing them

7.38

on scale of 1 (not affected at all) to 10 (extremely affected)

29.2%
extremely affected
(rating 10)

67.8%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

Anxiety about toilets and accessing them is part of the Top 3 Impacts for all participants. For those who self-identified as moderate or severe this impact usually was in third place and the Impact “Living with unpredictable symptoms and flares” took this second position.



There were no differences when we compared ordering between men and women, but women scores were slightly higher than men (Women Mean= 7.57 vs Men Mean=6.85).

Top 10 Impacts

#3

Living with unpredictable
symptoms and flares

#3 Living with unpredictable symptoms and flares

Impact Definition

Living with unpredictable symptoms and flares

Flares and fluctuations in symptoms are unpredictable.

This makes it difficult for you to plan day-to-day activities or to do activities spontaneously.

Living with unpredictable symptoms and flares can prompt a feeling of loss of control and uncertainty.

Words used: unpredictable, sporadic, can't plan, hard to trust self, debilitating, one minute to the next

Living with unpredictable symptoms and flares is about:

- Never knowing when a symptom will hit
- Not being able to trust your body to behave
- Challenging to plan - whether short term activities or long term goals
- Anxious about what could/might happen
- Living in fear of something happening

My symptoms are so unpredictable that I feel anxious about leaving the house - I'll be fine one minute, and the next I'm in so much pain I can't do anything! It's distressing and debilitating

Never knowing when the next flare is coming makes it really hard to trust the breaks in my symptoms, or make long term plans for the future. How can I think about my life plans if I don't know how I'll feel tomorrow?

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#3 Living with unpredictable symptoms and flares

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **living with unpredictable symptoms and flares**?

Unpredictable symptoms and flares makes it difficult for you to plan day-to-day activities or to do activities spontaneously. It can prompt feelings of loss of control and uncertainty.

Living with unpredictable symptoms and flares

7.14

on scale of 1 (not affected at all) to 10 (extremely affected)

23.3% extremely affected (rating 10)

68.5% highly to extremely affected (scores from 7 to 10)

Other insights:

This was the Top 2 for those who self-identified as moderate or severe, which is consistent with the fact that around 60% of moderate or severe reported to have had 3 or more flares over the last year.



There were no differences when we compared ordering between men and women. However, women scores were slightly higher than men (Women Mean= 7.55 vs Men Mean=6.58).

Top 10 Impacts

#4

Living with physical symptoms

#4 Living with physical symptoms

Impact Definition

Living with physical symptoms (digestive symptoms and pain)

Living with and managing the physical symptoms of IBD has a significant impact on your life.

Physical symptoms include digestive symptoms (urgency, diarrhoea or constipation, bleeding, cramping, bloating), pain (abdominal, joint).

Coping with these symptoms can be exhausting and limiting.

Words used: diarrhoea, pain, unbearable, severe, awful, burning cramping, itching, bloating, aches, sweating, dizzy, nausea, bleeding

Living with physical symptoms is about:

- Always feeling some kind of physical effect
- Experiencing pain that ranges from distressing to severe
- Feeling the effect of multiple symptoms at once or over time
- Daily life and compromises personal to you

People think Crohn's is just about poo and diarrhoea but for me it's all the other symptoms which really impact what I can do - the joint pain, the dryness, mouth ulcers, and flare pain, which can be so bad I sometimes can't move

It's not about any one symptom, it's about the way they all come at the same time or one after the other, it really builds up - my joints, my eyes, my skin, the itching, the sweating, the burning poo - it might seem small but try having that all at once!

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#4 Living with physical symptoms

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **living with the physical symptoms of the condition** (including digestive symptoms and pain)?

Physical symptoms include digestive symptoms and pain. Living with and managing the physical symptoms of IBD has a significant impact on your life and can be exhausting

Living with physical symptoms

7.10

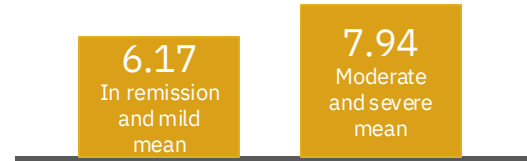
on scale of 1 (not affected at all) to 10 (extremely affected)

18.8%
extremely affected
(rating 10)

65.4%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

Those who self-identified as Moderate/Severe had higher scores compared to those that self-identified in remission or mild



This is consistent with the fact that **65% of those moderate or severe reported that their symptoms were highly disruptive to their day to day life over the last month.**

Women scores were slightly higher than men (Women Mean= 7.51 vs Men Mean=6.53).

Top 10 Impacts

#5

Feeling embarrassed
and self-conscious

#5 Feeling embarrassed and self-conscious

Impact Definition

Feeling embarrassed and self-conscious about toilet use, smells and sounds

You might feel embarrassed and self-conscious about the symptoms because of poo and toilet taboos. Fear of smells, sound, leakage, accidents, and being thought 'unhygienic'.

These feelings and fears might lead to people to not seek help, or to not tell friends/colleagues/etc that they might need time or more support.

Words used: embarrassed, paranoid, anxious, smell, odour, sound, social anxiety, fear of mess, fear of judgement

Feeling self-conscious and embarrassed is about:

- Having to think about the impact of your condition on others as well as yourself
- Worrying about smells and odours
- Feeling judged by others for things out of your control
- Feeling very aware of feeling out of control
- Shame and self-stigma
- Experiencing judgement

I'm really conscious whenever I have to use a public toilet what others might be thinking - how bad is the smell, how loud is the noise - and whether I look 'disabled enough' to use the disabled loo - I'm sure everyone's judging me and I'm desperately embarrassed every time

It's really hard to date when I feel so embarrassed about my symptoms like wind and the smell/noise - it's hard enough at a friend's house, never mind a potential romantic partner!

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#5 Feeling embarrassed and self-conscious

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **feeling self-conscious and embarrassed about toilet use, smells and sounds?**

You might feel embarrassed and self-conscious about the symptoms because of poo and toilet taboos. These feelings and fears might lead to people to not seek help or avoid talking to others

Feeling embarrassed and self-conscious

7.09

on scale of 1 (not affected at all) to 10 (extremely affected)

26.3%
extremely affected
(rating 10)

63.3%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

We found interesting differences between men and women regarding this impact. **This impact seems to affect more women's quality of life than men's.**



Scores for those self-identifying as moderate or severe were higher compared to those self-identifying as mild or in remission (Moderate/Severe Mean= 7.69 vs Mild/In Remission Mean=6.42).

Top 10 Impacts

#6

Dealing with poo

Impact Definition

Dealing with poo and coping with urgency, incontinence and accidents

Coping with urgency, accidents and incontinence is difficult. Sharing toilets with others causes additional anxiety around smells, sounds, cleanliness and comments from others.

There are also challenges with dealing with stoma or ostomy bags, leaks, odour and accidents.

Words used: leaking, smelling, running down legs, cleaning up, poo kit, doggy bag, bursting, urgency, caught out

Dealing with poo is about:

- Having to find practical solutions to potential accidents and urgencies
- Worrying about where to poo and how to clean self up
- Experiencing the reality of an accident in the moment
- Feeling embarrassed but still having to deal with the reality
- Always thinking about poo

In the past I've had some pretty embarrassing accidents; pooing myself at work and hoping no one notices until I get to a toilet - now I have an emergency 'poo kit' with wet wipes, doggy bags and cleaning spray, which helps me feel a bit more prepared

My stoma bag is always getting full and I have to make sure I'm changing it regularly and keeping it clean so I don't get sore skin. I'm so scared it's going to burst on something and poo will go everywhere

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#6 Dealing with poo

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **dealing with poo and coping with urgency, incontinence and accidents?**

Coping with urgency, accidents and incontinence is difficult, especially when sharing toilets. If you have a stoma, there can be challenges dealing with your bag, leaks, odour and accidents.

Dealing with poo

6.91

on scale of 1 (not affected at all)
to 10 (extremely affected)

22.5%
extremely affected
(rating 10)

61%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

Scores for those self-identifying as moderate or severe were higher compared to those self-identifying as mild or in remission (Moderate/Severe Mean= 7.71 vs Mild/In Remission Mean=6.03).

Top 10 Impacts

#7

Complex emotions
(e.g. frustration, worry,
grief)

Impact Definition

Complex emotions such as frustration, worry and grief

IBD can prompt a complex range of emotions, when thinking about your pre-IBD self, lost time, or your future goals and dreams.

You might feel disappointed in, frustrated or angry at your body and the reality of living with a lifelong condition, symptoms and lifestyle adjustments, and anger, fear, sadness or grief are common emotions. Uncertainty or worry about disease progression or the future can exacerbate these feelings.

Words used: grief, anger, frustration, let down, body won't let me, struggling, mental health, limited

Complex emotions is about:

- Grief for your past or future self
- Frustration at what you feel you should be able to do
- Like your body is working against you
- Feeling let down by your body
- Like your life or potential was taken away from you
- Having to re-prioritise
- Wanting someone to blame

I can't help but feel grief for the person I used to be - I used to be able to do so many things and now I just don't feel like that same energetic, productive person anymore

I feel really angry about having my future snatched away from me. It feels like my body has let me down and I feel resentful about what it can no longer do

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#7 Complex emotions

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **the complex set of emotions that come with the condition (such as frustration, worry or grief)?**

Thinking about your pre-IBD self, lost time, changes to your body or your future can be difficult. You might feel frustrated or angry at your body and the reality of living with a lifelong condition.

Complex emotions

6.83

on scale of 1 (not affected at all)
to 10 (extremely affected)

17.2%
extremely affected
(rating 10)

59%
highly to extremely
affected scoring
from 7 to 10

Other insights:

Those self-identifying as moderate or severe had higher scores compared to those self-identifying as mild or in remission (Moderate/Severe Mean=7.58 vs Mild/In Remission Mean=6).

Regarding gender differences, although women had slightly higher means, **this impact was ranked in the same order of importance in men and women.**

However, when we asked about mental health impacts (worsening anxiety, depression or other mental health conditions) we did find differences by gender. **The impact of the conditions on anxiety, depression or other mental health conditions ranked higher in men than in women.**

Top 10 Impacts

#8

Always being alert
to signs and symptoms

#8 Always being alert to signs and symptoms

Impact Definition

Always being alert to signs and symptoms

The fear of symptoms, flares or recurrence after remission makes you pay attention to any potential sign of a symptom or a flare. This can be a constant worry that takes daily attention, you feel always alert and stressed.

You might also spend time trying to identify and avoid triggers (certain foods or stressful situations) to try to minimise your risk of a flare or symptoms.

Words used: high alert, worrying, wary, any sign, dreaded, panic inside, tell-tale, warning signs, watch and wait

Always being alert to signs and symptoms is about:

- Feeling constantly on alert
- Noticing every symptom and feeling
- Not being able to relax even when not in a flare
- Reacting to symptoms
- Learning your body's own patterns and signs
- Treating symptoms as warning signs

I can't help but be on high alert - I'm always checking my poo for blood, or seeing if I have pain after a meal - and if I see any warning symptom I start to panic inside. It's constant!

Even though I'm in remission, I'm still watching and waiting for any sign of a dreaded flare up, so on one level I'm always worrying, and a bit wary of what I eat

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#8 Always being alert to signs and symptoms

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **always being alert to possible signs and symptoms of flares or triggers** ?

The fear of symptoms, flares or recurrence after remission makes you pay attention to any potential sign of a symptom or a flare. This can be a constant worry that takes daily attention.

Always alert to signs and symptoms

6.80

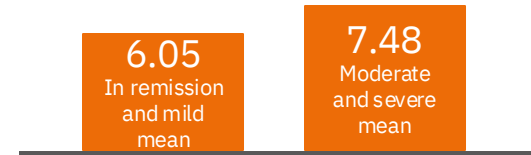
on scale of 1 (not affected at all) to 10 (extremely affected)

16%
extremely affected
(rating 10)

58.2%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

Those self-identifying as moderate or severe had higher scores compared to those self-identifying as mild or in remission (Moderate/Severe Mean=7.48 vs Mild/In Remission Mean=6.05).



This is consistent with the fact that:

- 65% of those moderate or severe reported that their symptoms were highly disruptive to their day to day life over the last month.
- Around 60% of moderate or severe reported to have had 3 or more flares over the last year.

Top 10 Impacts

#9

Having to plan and
strategise activities
and events

#9 Having to plan and strategise activities and events

Impact Definition

Having to plan and strategise activities and events

Knowing that many situations might expose you to triggers (e.g. stress, food or travel), risk lack of toilet access (e.g. transportation), require dealing with an accident (e.g. changing clothes) or a lack of access to healthcare when away from home, means trying to manage this by planning in advance of going anywhere. Researching menus, locating toilets, and planning exit strategies, while packing spare clothes, pads, or wet wipes, can be helpful. Having to plan for every eventuality means you can't enjoy spontaneity, and is an added exhaustion before any outings or trips even begin.

Words used: plan, controlled, managed, in advance, no spontaneity, prepared, caution, attention, organised

Having to plan and strategise daily life is about:

- Having to think through every possible situation
- Not being able to be spontaneous with plans
- Wanting to keep everything controlled and managed
- Thinking ahead to a greater degree than people you know
- Needing to feel organised and in control

I have to spend so much time and energy planning any time I want to leave the house - whether it's a trip to the shops or a holiday! None of my friends have to think this hard about things we do together

I've got a system now, everything is organised and controlled for any emergency, but it has to go exactly to plan for me to have time to change my stoma bag, get my medical appointments AND do normal household chores like cooking or walking my dog

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#9 Having to plan and strategise activities and events

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **having to plan and strategise for daily activities and larger life events** ?

Knowing that situations might expose you to triggers or lack toilet access means planning and researching in advance. This is true for daily activities like going to work, seeing friends, taking transport or a trip overseas.

Having to plan and strategise life

6.77

on scale of 1 (not affected at all) to 10 (extremely affected)

18.1%
extremely affected
(rating 10)

58.1%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

Those self-identifying as moderate or severe reported this impact as higher in the Top 10 than those self-identifying as mild or in remission. Those self-identifying as moderate or severe had higher scores compared to those self-identifying as mild or in remission (Moderate/Severe Mean= 7.51 vs Mild/In Remission Mean=5.95).



There were no differences between men and women on how they ranked this impact within the Top 10.

Top 10 Impacts

#10

Sleep disruption

#10 Sleep disruption

Impact Definition

Sleep disruption

A combination of pain and urgency has tangible impacts on good quality sleep. This can exacerbate any fatigue - both energy levels and ability to think clearly - and contribute to the loss of your normal routines.

You might find trying to maintain normality in the face of sleep disruption hard. Sleep disruption can create patterns of worry that start at night and impact the day.

Lack of understanding from others can make the impacts of loss of sleep worse.

Words used: terrible sleep, disrupted, messes with, affects day, vicious cycle, up and down, exhausted, zombie

Sleep disruption is about:

- Awareness of symptoms preventing good sleep
- Not being able to rely on patterns or routines
- Getting up multiple times a night (either urgency or changing bags)
- Affecting energy and attention the next day
- Feeling like a zombie

It's such a vicious cycle; I can't sleep because of the pain, but the less I sleep, the more pain I'm in - and then the next day I feel like a zombie, I'm barely there I'm so exhausted

I can't get onto a sleep schedule, because an early night means getting up several times due to urgency, but the later I leave it the more tired I am. Either way, I have a terrible night!

Note on quotes: these are constructed from real language used by a number of survey responses rather than a single response. These are designed to represent the language and stories people have shared

#10 Sleep disruption

Survey Question

As someone living with Crohn's or Colitis, how much has your quality of life been affected by **sleep disruption and the impacts of the lack of good sleep**?

A combination of pain and urgency has tangible impacts on good quality sleep. This can exacerbate any fatigue and contribute to the loss of your normal routines.

Sleep disruption

6.73

on scale of 1 (not affected at all)
to 10 (extremely affected)

19.3%
extremely affected
(rating 10)

61%
highly to extremely
affected (scores
from 7 to 10)

Other insights:

This impact was ranked higher in priorities for those living the condition as mild or in remission compared to those who self-identified as moderate or severe. This does not mean that it is not a relevant impact for those self-identifying as moderate or severe (Mean for Moderate and Severe was 7.35), it just means that these had more impacts prioritised before they considered the impact on sleep.

There were no significant differences between the means for men and women. **However, men and women differed greatly on the order they ranked this impact within the Top 10. This impact was more likely to ranked within the Top 5 by men.**

5 | Summary and next steps

Having Crohn's or Colitis has substantial and far reaching impacts on people's lives. This reality is something that people living with the conditions are forthcoming in sharing and are keen to have more understood.

It's important that Crohn's & Colitis UK, the healthcare community, researchers working in this area and the general public increase awareness and action on the impacts.

The Top 10 impacts of having Crohn's and Colitis on people's quality of life are:

1. Fatigue and energy management
2. Anxiety about toilets and accessing them
3. Living with unpredictable symptoms and flares
4. Living with physical symptoms
5. Feeling embarrassed and self-conscious
6. Dealing with poo
7. Complex emotions (e.g. frustration, worry, grief)
8. Always being alert to signs and symptoms
9. Having to plan and strategise activities and events
10. Sleep disruption

Several of the Top 10 relate to the **tangible physical impacts** of the conditions:

- Impact 1: Fatigue
- Impact 4: The physical symptoms themselves
- Impact 6: Dealing with poo
- Impact 10: Sleep

The Top 10 also highlight the **significant psychological burden of the conditions** on people's lives.

- Impact 5: Feeling embarrassed and self conscious
- Impact 7: Complex emotions
- Impact 8: Always being alert

The psychological experience and burden of the tangible impacts of the condition were also raised. For example, the mentally exhaustion and wearing down of living with constant or fluctuating fatigue.

Finally the Top 10 highlight how living with the conditions also **adds a significant mental load** for daily life as well as larger life events.

- Impact 2: Anxiety about toilets
- Impact 9: Having to plan and strategise in life

Finally, the **unpredictability of symptoms and flares** (Impact 3) means that people's experiences vary at any point in time, which makes adapting to the condition and predicting what will come next really hard.

The effects of the impacts

The Top 10, affect people's lives in very substantial and also subtle ways that are important to further understand, support and take action on.

The impacts affect people's day to day activities like work or education, socialising and how people feel in themselves.

These impacts can also affect relationships with others and also have impact on carers and on caregiving.

The Top 10 are the impacts prioritised by people living with the conditions. But it's important to also acknowledge that there are many other impacts beyond these impacts that also affect people living with the conditions. From the prioritisation survey other impacts that closely followed the Top 10 were:

- Worsening anxiety, depression and mental health due to the conditions
- Challenges finding the right treatment and medications
- Challenges of dealing with healthcare system
- Challenges and difficulties juggling commitments and priorities

The **Appendix** contains the full list of impacts from the first stage longlist and we'd encourage everyone to further explore and understand the wide range of ways the conditions affect people's lives and the lives of those around them.

This work is of strategic importance for Crohn's & Colitis UK. Who for more than 30 years, have been leading research activities that build evidence and create insight into the lived experiences, causes, and best treatments of Crohn's and Colitis.

Their research is shaped by the experiences and lives of real people, representative of the entire community, living with the conditions.

This project is part of a wider initiative programme for Crohn's & Colitis UK who want to accurately capture, measure and represent the experiences of all people living with the conditions, and the effects it has on their quality-of-life. The Top 10 impacts identified in this research will be tracked using metrics to measure quality of life over time and will feature on a public facing dashboard.

This will contribute to a major landscape review of the nation, telling the stories of impact, and highlighting areas to prioritise to drive change, and improve the lives of everyone living with Crohn's and Colitis.

Beyond these actions there are other key areas that need action from Crohn's & Colitis UK, and others:

- Deepen understanding of each of the Top 10 and co-design the improvements that are needed with people with the conditions.
- Summarise the existing research on each of the Top 10 and identify gaps in knowledge and solutions.
- Ensure patients have access to information and tools relating to the impacts of their conditions.
- Advocate for changes that will improve the quality of life of people living with the conditions. For example, campaign for the protection and improvement of public toilets.

Thank you for reading this report about the impacts of Crohn's and Colitis on people's quality of life.

Report prepared by Common Collective for Crohn's & Colitis UK

Reference: Marcus, H., Jennings, K., Bilovich, A., Nolan, F., & Bendayan, R. (2024).
Crohn's and Colitis Top 10 Impacts on Quality of Life Report.

Please get in touch if you have any questions

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6 | Appendix

Appendix

Other impacts of living with Crohn's and Colitis

There are many other impacts of living with Crohn's and Colitis.

This appendix contains the other impacts uncovered in the first stage of the project that did not make it into the Top 10.

Using data from the written text responses to the survey we extracted **42 impacts** from **298,041** words and 10 diaries using AI and human powered analysis.

Impact Definition

Worsening mental health

Having this condition can trigger or exacerbate anxiety, depression, and other mental health conditions. Sometimes your mood might be low, and you can feel worthless and isolated. The condition can also affect your self esteem and body image. Your mental health is particularly affected while waiting for diagnosis, and during periods of flare or hospitalisation.

Impact Definition

Slow diagnosis and its knock on effects

Getting properly diagnosed can take years, with the possibility of experiencing multiple tests, misdiagnoses, misinformation and delays. Whilst on the path to diagnosis you might feel frustrated or unsupported, and it may have a negative effect on the progress of the disease, timeframe for recovery or your mental health.

Impact Definition

Having to deal with healthcare systems

Having to interact with the healthcare system comes with many practical challenges, from travel to appointments, waiting time to hassles around preparing for tests. Where processes are inefficient, it creates more barriers and issues. You might experience challenges from poor care coordination to delays or administrative barriers. These impacts can both delay and worsen health outcomes, and have an impact on your energy, stress or mental health.

Impact Definition

Needing to advocate for yourself

You might find you need to self-advocate, meaning you need to research your options, coordinate care teams, or fight individual or systemic bias in workplace, education or healthcare settings.

Impact Definition

Developing resilience

You learn more about yourself and draw on your inner strength to face and overcome the challenges that come with the condition. You find ways to have pride and purpose, you learn to communicate your needs and show empathy and support of others. You feel grateful for times when you are in good health and learn to be kind to yourself when you are not. You learn problem solving skills and workarounds to help you cope the best you can. The journey towards developing this resilience can be long and arduous.

Impact Definition

Challenges juggling commitments and priorities

Choosing between all the different things you have to do whilst dealing with fluctuating energy levels means you could find it difficult to juggle work, household tasks, self-care, medical care and rest, relaxation or play. Work-life balance may feel out of reach, requiring compromises and careful choices about priorities.

Other impacts of living with Crohn's and Colitis (3 of 11)

Impact Definition

Having to follow a restricted diet

Having to miss out on particular foods and/or alcohol, make dietary changes and plan to avoid foods or drinks that trigger a flare can reduce your enjoyment of food, drinks and social activities. Worries surround foods to eat during a flare can be stressful. You might avoid eating or drinking in some situations. Your restricted diet might make it harder to get the nutrients you need.

Impact Definition

Challenges with work and career

Work life is affected both day to day and in the longer term. Not being able to work at all, or as much, or as hard as you want or need to. Your IBD can also mean you miss out on opportunities for overtime, career progression or prompt you to take early retirement. Having to ask for understanding, accommodations and adjustments can create work challenges and stressors. How well your needs are met depends on your employer's degree of supportiveness. You may also experience workplace discrimination.

Impact Definition

Challenges with treatment and medications

Finding effective treatments is challenging, difficult and time consuming. This can mean frequent tests and doctor visits. You might experience difficulties with complex medication regimens. You may need to reset expectations as you experience treatments' variable effects. Managing medication and its side effects can be problematic (e.g., issues with steroids, injections or infusions, or reduced immunity). There are risks, access issues and treatment failures.

Impact Definition

Concerns relating to fertility and having children

For those thinking about children, things can feel restrictive and complicated which might affect decisions about whether or when to have kids. You might worry about your children inheriting your disease. You might need to understand medications and their risks in pregnancy. Worries about difficulties with fertility or pregnancy can add to the stress and anxiety.

Impact Definition

Stress and concern around intimacy and sex

Sex and intimacy can be affected. You might avoid dating or sex, or disclosing your diagnosis to new partners. It may affect your libido or that of your partner. The physical symptoms of IBD may sometimes make sex not possible. You may feel worried about embarrassment or being judged or rejected by partners, both new or in long-term relationships. This can all have a knock on effect on romantic relationships and emotional connection.

Impact Definition

Continuous learning about condition and body

Your IBD diagnosis is the start of a journey of learning about the condition and your own experience of it, which can at times be overwhelming. Information is often not easy to find or tailored to your circumstances. You want to keep up with the latest treatments, developments and research, and find your place in the community. You are also learning about your condition and how your body reacts and adapts to different triggers and medications through trial and error.

Other impacts of living with Crohn's and Colitis (5 of 11)

Impact Definition

Financial worries and loss of income

The financial impacts include reduced or loss of income, reduced ability to make savings or investments or insufficient benefit payments. Worrying about money because of work insecurity and condition fluctuations can also take its toll. There can be issues getting disability status and benefits when you need them.

Impact Definition

Pressure on relationships

Relationships with your partners, family and friends can be a major source of support and comfort but they can also come under significant pressure. Relationships might be affected by missing out on time together, including everyday activities as well as special events and milestones. Finding the right words to share your experiences can be challenging, leading to misunderstandings or hurt in relationships.

Impact Definition

Constant stress and worry

Having this condition increases your mental load. The stress, uncertainty and worry about symptoms, flares, urgencies, accidents, or developing other conditions can be exhausting.

Other impacts of living with Crohn's and Colitis (6 of 11)

Impact Definition

Feeling lonely or isolated

Having to miss out on activities can lead to feeling isolated. You might miss everyday activities, socialising, special events and milestones, or holidays. Being at home and feeling unwell can make you feel distanced, let down by and separated from others. Hospital stays can be particularly disorienting or frustrating and you might also feel abandoned.

Impact Definition

Having to rely on others for care

Living with IBD can mean having to receive care from others, which can lead to changing roles and dynamics, e.g. children caring for parents. You might find asking others for support, or having to receive care difficult. You might worry about being a burden and worry about the impact on your loved ones, which can have negative impacts on mood and mental health.

Impact Definition

Caring for and worrying about stomas

Stomas and ostomy bags come with their own set of impacts. Having one comes with management, clothing and care concerns although stomas can provide relief from symptoms and allow you to manage your condition. Before getting a stoma you might worry about what it would mean to live with one.

Impact Definition

Growing up with IBD

Growing up with IBD, whether you were diagnosed in childhood or with retrospective understanding of flares and symptoms, will affect your life during your childhood and youth. This can impact long-term mental health, self-esteem and how you relate to the world.

Impact Definition

Missing out on education

Your education can be affected by having to be absent, or attending but being affected by symptoms. Not being able to study at all, or as much, or as hard as you want or need to. You may miss out on opportunities during your education, or future opportunities due to missed education. Having to ask for understanding, accommodations and adjustments can create educational challenges and how well your needs are met depends on your school, college or university's degree of supportiveness.

Impact Definition

Managing tests, hospitalisation and surgery

Having multiple procedures, regular tests, treatments and surgeries, for some, can be time consuming, inconvenient and stressful for you. They can come with disruptions, complications, stresses as well as long recovery periods. Anticipating and experiencing some tests and treatments can also add risk, anxiety about that risk, and trauma afterwards.

Other impacts of living with Crohn's and Colitis (8 of 11)

Impact Definition

Challenge of having other health conditions at the same time

Having IBD can make you vulnerable to developing other health conditions. It can also make it more difficult to cope with other physical or mental health conditions you have, in addition to your IBD. Sometimes the treatment of other conditions may worsen your IBD, which can be challenging. Some people also have fears of developing other conditions and its impact, such as COVID-19 and risk of bowel cancer.

Impact Definition

Daily life is harder

Everyday tasks become more challenging, time consuming and tiring, and you might need to develop coping strategies to maintain a sense of normalcy. Everyday activities require planning, routines are disrupted or can't be committed to, and there's a need to rest and pace yourself.

Impact Definition

Reduced access, participation and enjoyment of physical activities and exercise

Being unable to participate in sports, exercise, and physical activities at all or as fully as you'd like due to fatigue or fear of symptom triggers. This means you cannot fully access the physical and mental health benefits of sport and exercise.

Impact Definition

Missing out on social and leisure activities

Being unable to participate in social activities, hobbies or travel, at all or as fully as you'd like, due to fear of a flare, or lack of care or accommodations from others. This means you miss out on many sources of fun, relaxation or social connection, and their many benefits to your health and life experiences.

Impact Definition

Finding the right clothes

Clothing can be a challenge. It is difficult to find comfortable clothes, which may need to be loose and have accessible belts, zips and buttons. You may need clothes which facilitate stoma bags or incontinence pads without making them visible. You may find it difficult to find clothes that meet your practical needs at all, or without compromising on appearance or feeling embarrassed.

Impact Definition

Challenges in parenting / caregiving

Parents and caregivers may struggle to provide the care you need to give or would like to. You may have to balance self-care, work and family whilst being unwell. It may also be challenging to find energy for play with children. On top of the practical challenges, you may feel guilty about the gap between what you can provide, and what you feel you should be able to.

Other impacts of living with Crohn's and Colitis (10 of 11)

Impact Definition

Feeling judged or misunderstood

There is poor public knowledge and understanding. IBD is commonly misunderstood. This means people often don't understand or grasp the severity or impacts of living with the conditions. Your symptoms (such as needing to go to the toilet frequently, digestive problems and accidents) are stigmatised. Judgement and lack of understanding can lead to discrimination, negative social interactions, and choosing to withdraw from people who behave or think in stigmatising ways.

Impact Definition

The costs of healthcare, prescriptions and specialist food

Cost of treatments, travel to appointments, specialist foods and medical costs can really add up. It can be expensive seeing private healthcare providers if your needs are not met by the NHS.

Impact Definition

Lower self-esteem and body image

Your body image and confidence may be affected. There are changes in weight (e.g., loss from nutrient malabsorption and gain from steroids) and it can be difficult to maintain a healthy weight. Having scars and stoma bags can also affect your body image. Some people find that they feel embarrassment, self-consciousness and loss of their former self.

Other impacts of living with Crohn's and Colitis (11 of 11)

Impact Definition

Travel and transportation difficulties

Short and long trips can be difficult with IBD, and there are difficulties with travel due to symptom unpredictability. Both driving and public transport can have their own issues for you in terms of access to toilets, disability accommodations and places to rest. Joint pain or mobility issues can make walking even short distances challenging.

Impact Definition

Experiencing healthcare bias and discrimination

There is still some bias, misunderstanding and dismissiveness from healthcare professionals towards patients with IBD. This can lead to negative emotional impacts; you might feel upset, unheard, or hopeless, or lose trust in medical professionals - impacting both your mental health and creating tangible delays to health outcomes.

Thank you for reading this report about the impacts of Crohn's and Colitis on people's quality of life.

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