

# Patients' Journey Through Inflammatory Bowel Disease (IBD): A Qualitative Study

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A qualitative study to identify unmet needs and barriers in the ulcerative colitis (UC) or Crohn's disease (CD) patient journey from symptom onset through ongoing management.

## Background and Objective

Inflammatory Bowel Disease (IBD) includes the diagnoses of Crohn's disease, ulcerative colitis and indeterminate colitis. Although IBD cases are increasing in the U.S., recognition may be delayed as related symptoms may be diagnosed as less-severe afflictions.<sup>1</sup> The sensitive

and chronic nature of IBD symptoms results in long-term physical and emotional challenges.<sup>2,3</sup> This study sought to understand IBD patient experiences and mental models to enable the design of better patient pathways.

## Methods

The qualitative study utilized in-depth individual interviews of 32 patients by video or phone. A screening survey established a mix of ages, sexes, ethnicities, locations, diagnoses and levels of severity. Patients were asked open-ended questions and encouraged to share personal experiences along with 5-10 images representing their day-to-day lives with IBD.

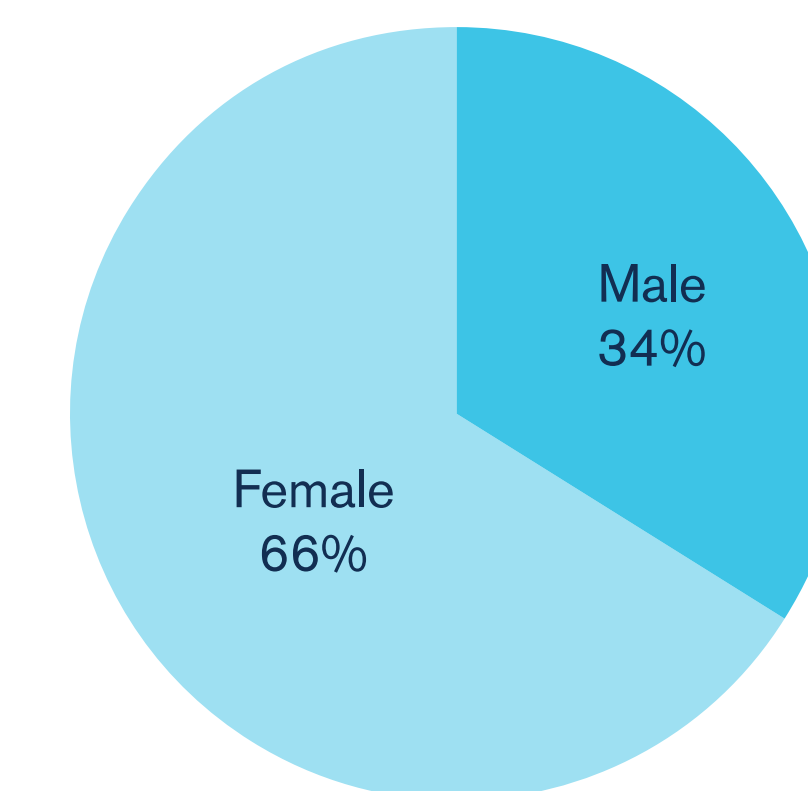
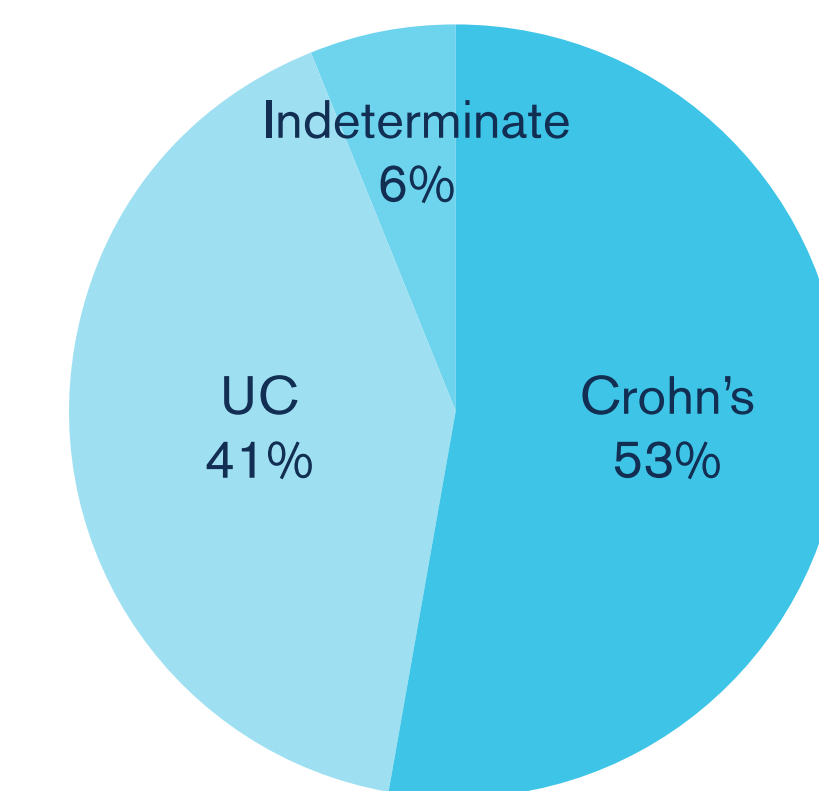
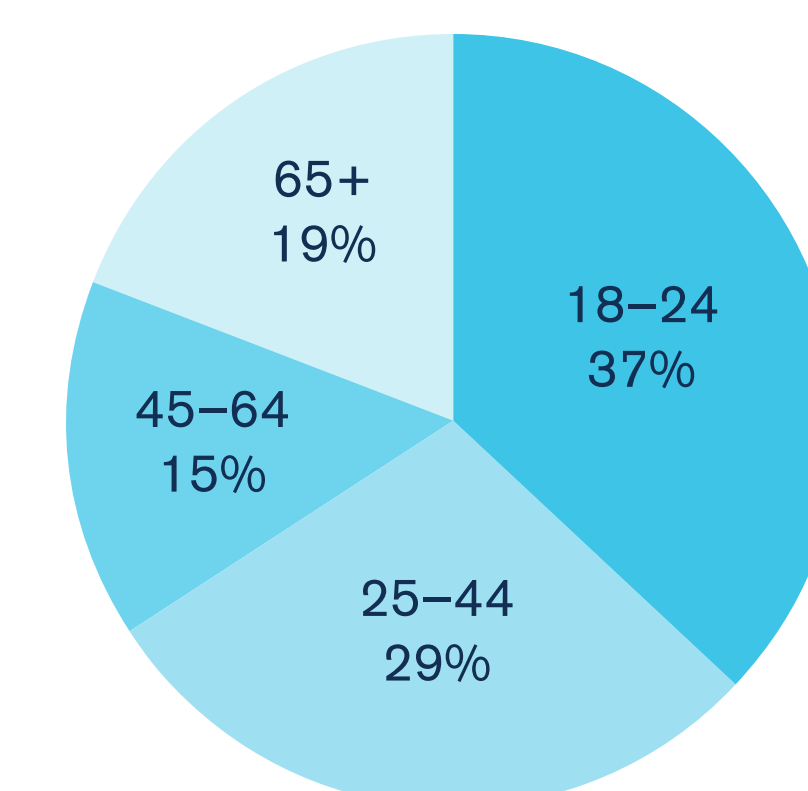
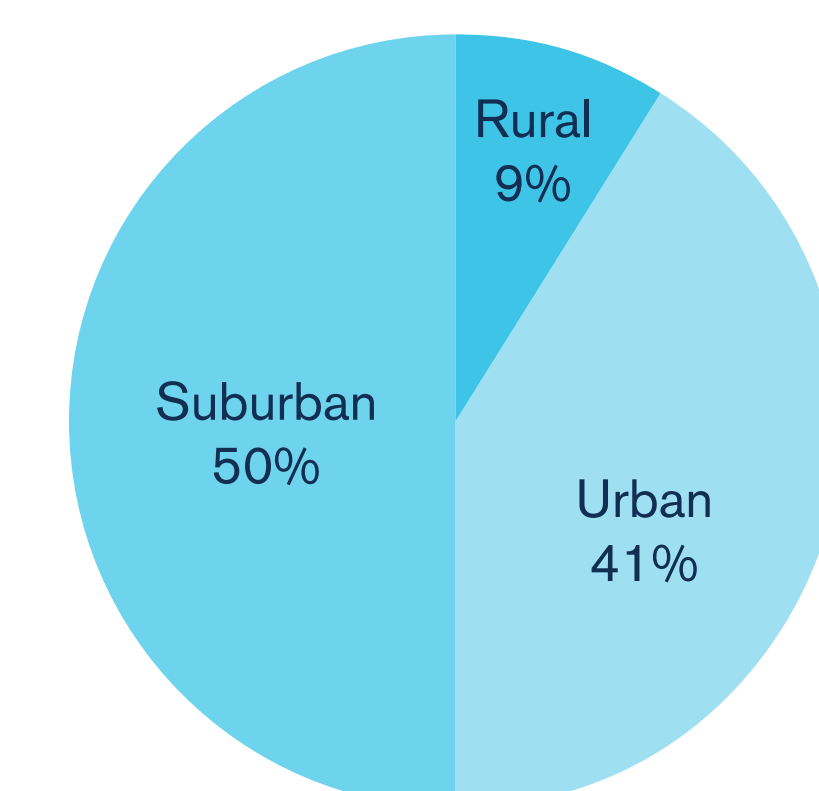
Human-Centered Design analysis methods used in the study include patient typologies (personas), forced temporal zoom (journey mapping), and affinity mapping for pattern recognition.

## Limitations

Patients volunteered to take part in the study; therefore, their perspectives may be subject to individual bias and experience. Additionally, interviews were completed during the COVID-19 pandemic. As such, responses and mindsets may be influenced by the outside stress of current events.

## Conclusions

- Increased education and training for pediatric, primary care and emergency physicians is necessary to improve and shorten the path to diagnosis. A wider variety of providers need to understand IBD and its symptoms, because a patient's first touchpoint will affect their care trajectory.
- Mental health support is a critical gap in the current journey and early intervention is essential to long-term wellness. Connecting with mental health providers and support groups may help newly diagnosed patients better cope with the emotional and physical impacts of their illness.
- Technology could be leveraged to build stronger patient-provider connections, share critical information and improve care access. Many patients would welcome telehealth for routine appointments and provider referrals to trusted online resources for information about their diagnosis.
- Patients need emotional support and a deeper understanding of the impact biologics and surgery will have on their life before committing to these treatments. Scientific explanations leave patients feeling unprepared for the resulting recovery and changes to daily life.
- Price transparency and broader promotion of drug assistance programs would dispel common myths about affordability and access for patients who are hesitant to try a biologic. Many patients feel they have limited options due to perceived drug costs.



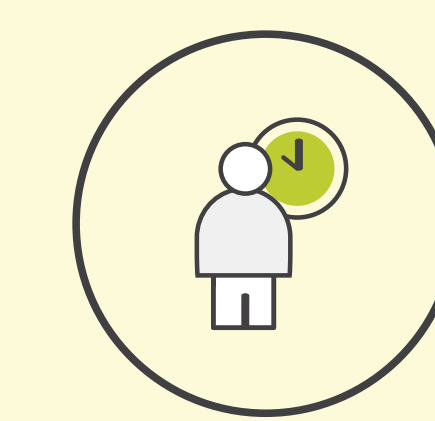
## Results



### JOURNEY OF Independence



I need to make sure I'm really sick before I will go to the ER. It needs to feel like I'm going to die.



### JOURNEY OF Acceptance



I just want to be well so bad. I want to take advantage of my good days. But my body says no.



### JOURNEY OF Recognition



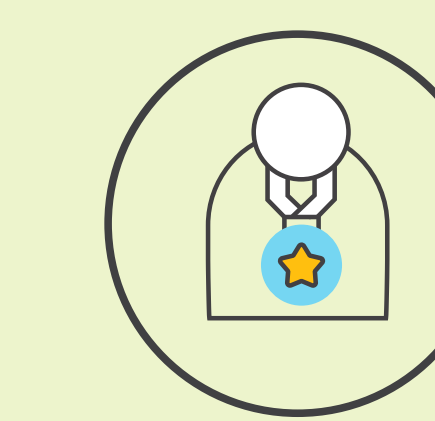
My feel good is probably someone else's not-good day. You learn to cope and adapt.



### JOURNEY OF Passion



I'm a firm believer all the work I'm doing now will one day be used to find a cure.



### JOURNEY OF Determination



People ask 'why do you push so hard?' And, some of it's like well, I'm gonna be sick either way.

## TOP NEEDS

I need a GI who is direct with treatment recommendations but respects my decisions.

I need help working through feelings about my disease and how much it has taken from me.

I need to do whatever I can to feel like myself again so I will supplement my medications with homeopathic treatments.

I need to connect with people my age who understand what it's like to be me.

I need medication and therapy because I refuse to let my physical or mental health get in the way of my goals.

## CHARACTERISTICS

Independent; doesn't believe they are as sick as others say; non-alarmist

Anxious and fearful; resigned to a "small life"; dependent on others for decisions and care

Lives life to the fullest; realistic about the disease and future; searches for information

Adaptable; wears disease proudly; finds purpose in advocacy and helping others

Fiercely motivated; never satisfied; puts achievement above their own health

## Influences

Makes decisions based on personal finances; considers care referrals from family

Relies on guidance of providers and family members to make care decisions

Listens to advice of providers and fellow patients; pursues naturopathy with doctor support

Influenced heavily by community, family and Crohn's and Colitis Foundation

Evaluates treatment against personal goals; self-educated; makes independent decisions

## Goals

Avoid surgery; enjoy family; maintain lifestyle

Feel better; socialize; get more from life and work

Avoid surgery, achieve financial stability, protect family

Improve unfair systems like Step Therapy, increase awareness

Overcome daily obstacles; achieve personal and professional goals

## Motivations: Intrinsic and Extrinsic

Trusted recommendations; maintaining independence

Support groups; financial situation; improving lifestyle

Not burdening kids; helping others; staying active

Healthcare reform; disease awareness; sense of belonging

Accomplishments; tenacity; getting everything out of life

## Key Provider Expectations

No interference in personal treatment choices

Trusted relationship and reassurance about the future

Information, plans and realistic disease progression estimates

Knowledge of newest treatment options

No judgment for decisions, however reckless

The study was sponsored by Genentech, Inc.

## REFERENCES

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- Nahon S et al. *Inflamm Bowel Dis*. 2012 Nov;18(11):2086-91
- Levenstein S et al. *Am J Gastroenterol*. 1994 Aug;89(8):1219-25

## DISCLOSURES

G. Wong, N. Reilly, J. Bhagwakar are employees of Genentech, Inc. J. Carrell, K. Woodburn, A. Breyer and F. Close are employees of Azul Seven and received funding from Genentech, Inc. T. Aswani Omprakash has speaker obligations with GNE.