

A photograph of a male doctor in a white lab coat and a female patient sitting on a hospital bed, both looking at a tablet computer. The image is overlaid with a semi-transparent blue filter.

ADDRESSING HEALTH EQUITY

in Inflammatory Bowel Disease



Consensus Meeting Report

DECEMBER 2022

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ABOUT AIMED ALLIANCE

Aimed Alliance is a 501(c)(3) not-for-profit organization that seeks to protect and enhance the rights of health care consumers and providers.¹ At Aimed Alliance, we envision a society where consumers, in consultation with their health care providers, can make informed and individually appropriate decisions about their health care without interference from third parties.



ABOUT THE PROJECT

The COVID-19 pandemic underscored the structural inequities, practices, and policies in the United States health care system that contribute to unequal health outcomes for patients of color.² Disparities in patient outcomes, like higher COVID-19 mortality rates for Black, Hispanic, and indigenous populations, are pervasive throughout the health care system and across health conditions, including cancer and chronic conditions.³ Aimed Alliance recognizes the need to address existing inequalities in health care, and we are committed to prioritizing health equity policy in our organization's programmatic work. We strive to develop projects that can address specific health care disparities within certain conditions, treatments, and health insurance coverage policies and practices.

Aimed Alliance recognizes that health disparities exist in the inflammatory bowel disease ("IBD") patient population. Rates of IBD have continued to increase over the last several years, therefore, there is a need to identify the root causes of outcome disparities for patients with IBD and develop solutions to redress these causes. To identify sources of inequality within the IBD patient community, Aimed Alliance convened a panel of experts and others with a strong understanding of the IBD patient community, including pharmacists, patients with IBD, health care professionals, community leaders, health educators, and advocacy organizations. This group of participants was convened because they can speak to the experiences of IBD patients and share knowledge related to IBD care, minority health, and community outreach. The panel's discussion identified grassroots access problems and best practices that should be used to engage impacted communities.

This project framed the health care journey into four stages where patients could encounter barriers in care. The four categories were: (1) barriers in accessing care prior to receiving an IBD diagnosis; (2) barriers in receiving an IBD diagnosis; (3) barriers in obtaining quality treatment for IBD; and (4) barriers in maintaining IBD treatment and care.





BARRIERS IN ACCESSING CARE FOR IBD SYMPTOMS PRIOR TO AN IBD DIAGNOSIS

Historically, minority communities have had a complex relationship with the U.S. health care system. This complex relationship stems from a variety of factors including historical misconduct between government, health care providers, and minoritized health communities, as well as personal experiences of racism within the health care system.

Egregious examples of historical misconduct in United States health care include inhumane experiments conducted on enslaved people⁴; mistreatment of minority health communities by health care practices⁵; forced sterilizations of Black women⁶; and the infamous Tuskegee study that withheld syphilis treatments from 600 Black men for decades, without consent, in an effort to track progression of the disease.⁷ Similar conduct can be found as recently as the 1990s.⁸ In a university study of a genetic etiology of aggressive behavior, researchers used financial incentives to entice parents to enroll their sons in a study which included withdrawal from all medications, consumption of a low protein diet, an overnight stay without parents, withholding of water, hourly blood draws, and the administration of a drug that increases serotonin levels and is associated with aggressive behavior.⁹ The study, which only recruited Black boys, was subsequently cited for several significant human rights violations.¹⁰ This type of conduct is widely recognized as one of the root causes of medical mistrust by minority communities.”¹¹

Lived experiences also substantially impact our views on how individuals interact with the health care system. For patients of color, personal experiences of racial discrimination in the current health care system can also contribute to medical mistrust.¹² Studies have found that negative racial biases, perceptions, and attitudes held by physicians can result in discriminatory treatment, which can ultimately have a negative impact on a patient's health.¹³ A 2020 survey conducted by the Kaiser Family Foundation found that seven in ten Black Americans believe people are treated unfairly based on race or ethnicity when they seek medical care.¹⁴ The survey cites racism as the biggest driver of disparities in health outcomes, noting that the overall life expectancy for Black persons is 75.5 years, 3.4 years shorter than it is for white persons.¹⁵ Ultimately, medical mistrust is deeply personal and can vary based on an individual's personal experiences.

BLACK AMERICANS & Health Care



7/10 PEOPLE

believe they are **treated unfairly based on race** or ethnicity when they seek medical care

Life Expectancy
for Black Persons



**75.5
YEARS**

3.4 YEARS SHORTER
than it is for white persons

KEY INSIGHTS

During the panel discussion, participants identified the following barriers that impact the ability of patients with IBD to access care prior to a diagnosis: (1) mistrust of health care institutions and health care providers; (2) social and medical perceptions of IBD and cultural competencies; (3) discomfort with completing medical forms; (4) costs; and (5) referral requirements.



Mistrust of Health Care Institutions and Health Care Providers

Participants reported that some patients may not trust their health care provider; while others may trust their providers, but not larger health care institutions. In some cases, mistrust may not relate to quality of care and treatment, but from mistrust of how the health care system will use their personal health information. Participants noted that some patients, often individuals from undocumented communities, are concerned that personal information shared on their health forms will be inappropriately used for immigration or removal proceedings. This concern can be particularly present when health care services adopt a transactional approach to providing care. Ultimately, a lack of trust with the medical system may cause some individuals to abstain from seeking care unless absolutely necessary.¹⁶

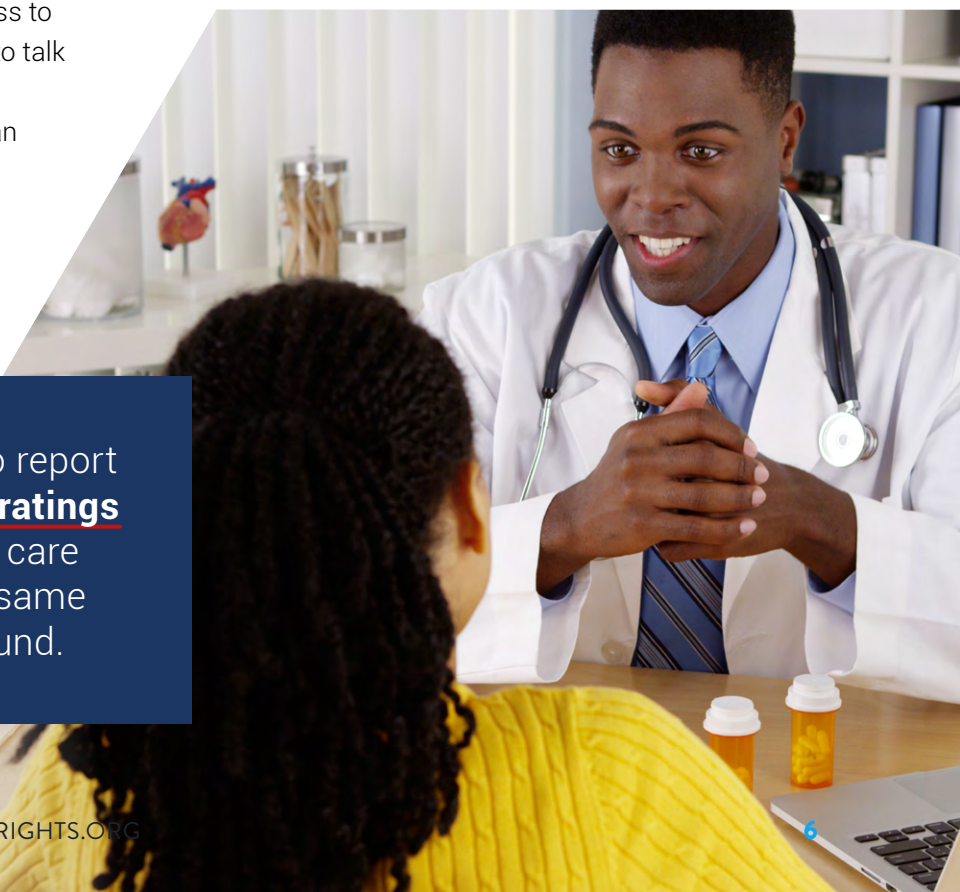
Social Perceptions of IBD and Cultural Competency

For patients with IBD, hesitancy to seek care is exacerbated by social and cultural perceptions of IBD. Participants discussed how cultural taboos surrounding intestinal health can delay access to care because some individuals are hesitant to talk about their symptoms with others. Similarly, participants identified that IBD symptoms can also be dismissed after being discussed with family members (e.g., perceived as a “sensitive stomach”), which delays patients’ efforts to seek treatments.

Participants also suggested that cultural competency is critical to resolving mistrust and overcoming cultural taboos in minority patients with IBD. In the health care context, cultural competency is defined as “the ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of patients.”¹⁷ Ensuring that culturally competent care is provided helps patients feel acknowledged and receive effective, quality care that reflects their beliefs, attitudes, values.¹⁸ Patients who feel recognized by their clinician form more trusting relationships and are more likely to seek out health care when experiencing IBD symptoms.¹⁹

To help address cultural competency between providers and patients, participants identified the benefit of patients receiving treatment by health care professionals from the same racial and ethnic backgrounds. For instance, one three-year study of over 100,000 patients found that patients were more likely to report higher patient experience ratings when treated by a health care provider who shared the same racial or ethnic background, compared to treatment by a racially/ethnically different provider.²⁰

Patients were more likely to report **higher patient experience ratings** when treated by a health care provider who shared the same racial or ethnic background.



Participants recognized that more diverse and representative health care professionals are needed, but due to the lengthy process of becoming a physician, this could take several years to achieve. Thus, in the short-term, participants acknowledged the benefit of providers, health care staff, and medical students engaging in implicit bias training to help address the current gaps in cultural competence.

The duty to build a relationship of trust extends beyond physicians. Participants expressed that it is the responsibility of all health care offices and community organizations to help foster relationships of mutual trust between patients and the health care system. Participants recognized the benefit of community within health care and suggested that the continuum of care should start with education and awareness in the community from a trusted source that provides patients with resources that empower them to be their own advocates. To help empower patient advocacy, office personnel and providers can demonstrate that patients' input on their care will be valued.

Discomfort with Medical Forms

In addition to mistrust of the medical system, patients with IBD can also experience discomfort with completing medical forms. Participants noted that this discomfort stems from both the complexity of medical forms and patient mistrust about the use of personal information. Participants reported that health literacy is a major barrier, emphasizing the value of translating medical forms and ensuring medical professionals are available to explain medical terms and the purpose for the information collection. Having an individual available to explain the forms to patients is of particular importance to patients with low health-literacy skills, intellectual disabilities, and individuals who are undocumented and concerned with how their data will be used.

Referrals and Cost

Participants reported that patients in rural communities may struggle to see a gastrointestinal specialist because visiting a specialist can require travelling several hours to receive care. Similarly, patients that do not have internet, broadband, or cellphone minutes may be difficult to reach. Participants suggested that regular visits by specialists to rural communities would be highly beneficial, reducing the undue burden on patients to travel long distances. Participants also recognized that there could be a benefit to patients being able to see a specialist without a referral; however, others recognized that visiting a specialist without a referral could cause disjointed care if patients visit multiple specialists who do not share information about patients with each other.

Participants identified that the cost of a treatment, and particularly not knowing the price of services upfront, can also limit access to care. Further, participants emphasized the need for patients to understand the total cost of obtaining treatment, such as the actual cost of the provider visit and the costs of taking a day off work, getting childcare, and traveling. One participant shared a success story of a recent community project designed to increase cost transparency and reduce the cost burden on patients. The project included placing community health workers in pharmacies to help ensure patients could afford their medications, which resulted in patients saving an average of \$70 per month.

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Additional Considerations

Participants reported that additional factors that impacted access to a diagnosis included limited access to transportation, housing insecurity, and referral requirements, can individually and collectively delay their access to medical care. Participants also reported that many primary care physicians are currently overwhelmed with meeting appointment quotas or satisfying other administrative requirements. Physicians who are overwhelmed by such responsibilities could unintentionally provide lower-quality visits for patients. Participants emphasized the need to incorporate other professionals in the provision of health care, such as by placing community health workers within provider offices to develop relationships with, and provide educational materials to, patients. Moreover, participants also noted that governmental institutions, like health departments, are often not well-equipped to provide culturally competent educational resources. Participants suggested that it could be beneficial to create partnerships with local trusted non-profits and religious institutions to develop and disseminate such materials to patients.

RECOMMENDATIONS

1. Community based programs should engage youth from underrepresented communities to create additional interest and opportunities to pursue health care careers.
2. Health care providers, personnel, and medical students should complete annual implicit bias training to ensure standards of care are applied in a culturally competent manner across racial and ethnic backgrounds.
3. Health care practices should identify an individual within their offices who can serve as the first point-of-contact with patients, be responsible for fostering relationships of trust with patients, and play an active role in helping educate patients on the importance of health history.
4. Health care providers and personnel should treat patients as experts in their health by demonstrating that the patient's input, experience, and advocacy will be valued by the health care provider.
5. Medical forms should be translated into multiple languages and developed using plain language that is easy for consumers to understand.
6. Insurers should support health care providers who want to develop a team-based approach to treat a particular condition to ensure clear communication between multiple providers.
7. Health care professionals should incorporate trusted community-based organizations, like churches and local community centers, into the continuum of care that help conduct health screenings to increase disease awareness, reduce stigma regarding digestive diseases, and empower patients to be their own advocates.
8. Pharmaceutical and health care industry partners and government agencies should financially support community organizations to develop multilingual, plain language educational resources, including, but not limited to, disease-specific fact sheets and information about permissible uses and disclosures of patient health information pursuant to federal and state patient privacy laws.
9. Dissemination of IBD materials should be conducted in a way that reduces IBD stigma (e.g., negative connotation of placing informational pamphlets in bathrooms).
10. State governments should fund pilot programs to develop programs that would allow specialists to routinely visit rural communities to increase access to specialists.



BARRIERS IN RECEIVING AN IBD DIAGNOSIS

Patients with IBD often experience delays between the onset of symptoms and the receipt of an IBD diagnosis. It can take between two and ten years and an average of three different health care providers to receive a diagnosis.²¹ As discussed above, cultural perceptions of IBD prevent some patients from visiting a doctor or specialist, allowing symptoms to progress until they are severe and emergency services are required.²² In fact, two-thirds of patients visit an emergency room or walk-in clinic, rather a specialist, for their IBD care.²³ More specifically, a study published in the *American Journal of Gastroenterology* found that Black patients experienced more than three times the number of IBD-related visits to the emergency department than white patients.²⁴ Emergency health care facilities are not appropriate substitutes for visiting a specialist because they only treat a patient's symptoms and do not provide a diagnosis or treatment plan.²⁵

Once a patient can see a primary care physician, historical misconceptions about the IBD patient population can further delay diagnosis. For decades, IBD was considered a European or "white-patient disease," causing some primary care providers to delay referrals to a specialist for patients of color. Similarly, due to the historical misunderstanding of this patient-population, some specialists may also incorrectly rule out IBD for symptomatic patients of color because these patients do not meet the right demographic for the disease.²⁶

A study published in *Digested Diseases and Sciences* revealed prominent differences in age at the time of IBD diagnosis between Asian, Hispanic, Black, and white patients, finding that Asian and Hispanic patients were more likely to get diagnosed at older ages (41 and 37 years, respectively) compared to white or Black patients (30.5 and 31.7 years, respectively).²⁷ The study, which looked at data between 1996 and 2009, proposed that such interracial differences in age at diagnosis could be due to environmental factors, such as lack of family history of IBD and first-generation immigrants moving from areas with low IBD incidence to higher incidence areas. The study suggested that physicians should be aware of these and other risk factors that may differ between racial groups.²⁸

Black patients experienced

MORE
THAN **3X**

the number of IBD-related visits
to the emergency department
than white patients.



KEY INSIGHTS

During the panel, participants identified the following barriers that impact a patient's ability to receive an IBD diagnosis (1) lack of educational resources to mitigate misunderstandings in IBD patient-population demographics; and (2) cost of receiving a diagnosis.

Educational Resources on IBD Symptoms

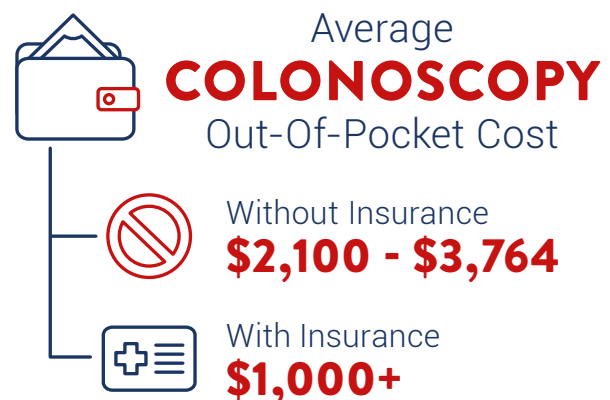
Participants reported the need for educational resources tailored to Black and Hispanic communities to help symptomatic individuals better associate their symptoms with IBD. Materials should emphasize that the disease is not linked to one demographic and underscore that a delay in treatment may lead to a more advanced diagnosis and an increased risk for developing other conditions such as colon cancer. Participants also recognized that educational resources must also extend to providers to ensure they are current on the most recent understanding of IBD patient demographics.

Costs of an IBD Diagnosis

Participants also recognized that the financial costs associated with IBD testing, including copays, coinsurance, or other cost-sharing requirements, may hinder patients from pursuing treatment and diagnosis from a specialist. Without insurance, the average cost of a colonoscopy is between \$2,100 and \$3,764. Even with insurance, out-of-pocket costs can still exceed \$1,000. To improve access to appropriate testing, participants suggested that diagnostic facilities implement policies that require health care providers to ensure patients are aware of state financial support programs and opportunities for payment plans to cover the cost of testing. They also discussed the benefit of value-based health care and its potential to reduce costs and improve health outcomes in the long-term.

RECOMMENDATIONS

1. Using evidence-based resources, health care professionals and medical students should be trained to actively understand historical biases in treatment and diagnosis of gastrointestinal disease and unintentional race-based medical bias in treating patients of color.
2. Medical schools should require practicums for medical students that require a minimum number of hours working in local and underserved communities.
3. Non-profits and health care associations should develop culturally competent educational resources tailored to Black and Hispanic communities on the prevalence of IBD and the need for prompt treatment.
4. Payers should establish policies with diagnostic facilities to ensure patients are aware of state financial-assistance programs and opportunities for payment plans to ensure cost is not a barrier to IBD diagnostic testing.





BARRIERS IN OBTAINING QUALITY TREATMENT FOR IBD

Following diagnosis, IBD patients may face barriers that delay access to treatment. Delays in treatment can lead to disease progression and increase a patient's risk of intestinal surgery.³² Further, if patients are not fully educated on their IBD diagnosis, misconceptions about the disease and its origins may cause individuals to adopt a less effective treatment approach.³³ For instance, research indicates that white patients are more likely to attribute IBD development to their diet while Hispanic patients are more likely to attribute IBD to smoking and stress.³⁴ Meanwhile Black patients are more likely to attribute IBD development to allergies or infections.³⁵

Nutritional interventions can improve symptoms and clinical courses of IBD, but some patients do not know or understand the role and benefits of nutrition in long-term IBD care.³⁶ Even when patients do understand the benefits, food insecurity or food deserts may inhibit their abilities to properly manage IBD treatment with nutritional interventions.³⁷

Beyond nutrition, understanding how different pharmaceutical interventions treat IBD is critical for patient compliance and ensuring patients can advocate for quality treatments. Currently, there are multiple treatments available for IBD including steroids (e.g., prednisone), which are used for a sudden increase in symptoms; 5-aminosalicylates (e.g., mesalamine), which are often used as the

first line of medication; immunomodulators (e.g., azathioprine), which decrease the number of activity cells that cause inflammation in the intestines; biologics (e.g., infliximab), which block the effect of the chemical, tumor necrosis factor alpha, to decrease the activity of cells that cause inflammation; and monoclonal antibodies (e.g., natalizumab), which block the ability of white blood cells that cause inflammation from reaching the intestinal lining.³⁸

Research suggests that the type and outcome of treatment can vary between patient populations. Whether such disparities are a result of gaps in health equity, unique differences in disease progression, or other factors, is a complex issue.³⁹ A study published in *Inflammatory Intestinal Diseases* reported that Asian and Hispanic patients are less likely to be treated with biologics than white patients.⁴⁰ Similarly, a 2022 survey found that 60 percent of white patients but only 15 percent of Black patients reported trying four or more treatments.⁴¹ A study published in *Inflammatory Bowel Diseases*, however, did not find disparities by race between IBD treatments, suggesting that inconsistencies in treatment may be driven by socioeconomic or other issues affecting access to care.⁴²

The cost of IBD treatment can be expensive. One study published in *Inflammatory Bowel Diseases* found that patients with IBD incurred more than twice the out-of-pocket costs than non-IBD patients.⁴³ Thus, a lack of insurance (i.e., uninsured), being underinsured, and difficulty with benefit utilization policies may prevent patients from obtaining appropriate treatment.⁴⁴ Studies have shown differences in insurance coverage and concerns about insurance coverage between racial groups. For instance, a study published in *Gastroenterology* found that white and Asian patients are more likely to have commercial insurance, whereas Hispanic patients are more likely to have Medicaid or be uninsured which can impact the type of treatments and cost-sharing available to patients.⁴⁵ The study also reported that patients on Medicaid are less likely to have small bowel resection for Crohn's Disease compared to patients on private insurance.⁴⁶ Similarly, a 2022 survey found that Black patients with IBD were more concerned with a "lack of insurance approval" than white patients.⁴⁷

KEY INSIGHTS

During the panel, participants identified the following barriers that impact a patient's ability to receive quality IBD treatments: (1) lack of resources on IBD treatment options and considerations for monitoring their condition; (2) lack of resources on how lifestyle choice can impact IBD; and (3) lack of insurance or underinsurance.

Education

To ensure prompt and proper treatment, participants suggested that patients be fully educated on their IBD diagnosis and treatment options, including the roles of nutrition intervention and pharmaceutical therapy in treating and monitoring their condition.

Understanding Treatment Options

Participants discussed the need for health care providers to unambiguously explain the risks, benefits, and alternatives associated with distinct treatment options. Patients may not understand some of the potentially dangerous side effects of treatment non-compliance or may not be aware of alternative treatments. Participants also discussed the need for health care providers to connect IBD patients with additional health care services, like diabetes screening, because adults with IBD are more likely to have other chronic conditions compared to adults without IBD.⁴⁸ Participants also shared the importance of health care providers discussing the benefits of clinical trial participation as an option for patients, rather than a last resort.

Participants also shared the importance of health care providers **discussing the benefits of clinical trial participation as an option for patients**, rather than a last resort.

The Role of Nutrition

Participants discussed several nuances on the role of nutrition in treating and managing IBD. Participants explained that while certain foods may trigger an IBD flare-up, cultural food preferences and traditions can make it more challenging for some individuals with IBD to incorporate healthy alternatives into their diet. Participants also discussed how health care providers currently have diverse perspectives on the role of nutrition in managing IBD which can create confusion among patients. Additionally, eating healthy can be more expensive than less healthy food choices. This can be particularly difficult and costly for individuals living in food deserts.

Nutritional needs for patients with IBD can also vary during times of flare-ups and remission. Therefore, patients need to be educated on how their diets might change during these intervals. Participants recognized the value of incorporating dietitians into a patient's health care team, noting that a dietitian can be particularly necessary because health care providers receive extremely limited nutrition training in medical school. This emphasizes the need for nutritionists and dietitians in gastrointestinal offices to help educate patients with IBD. One participant shared the benefit of integrating certain services and education into existing programs, noting the success of one patient advocacy organization that is integrating healthy aging programming, mental health programming, and other ad-hoc programs across six southern states.



Uninsured and Underinsured

Participants discussed multiple barriers created by the insurance market. They recognized that the nature of 12-month insurance cycle provides little incentive to health plans to offer preventative care treatment and coverage. They noted how reimbursement models based on treatments, not outcomes, place an emphasis on quantity, not quality, of services for treatment of IBD and decreases accountability for providers.⁴⁹ Participants also criticized pharmacy benefit managers for receiving large rebates in return for formulary drug placement, which can inflate drug costs for patients. For outpatient IBD medications, the average biologic-taking patient accounted for \$36,051 per member per year in 2015.⁵⁰ Participants suggested building performance measures into the Health Care Effectiveness Data and Information Set (HEDIS) and Star ratings to incentivize health plans to consider preventative care and long-term costs. Preventative care is particularly important for IBD patients using long-term immune-suppressive therapies, who may be at increased risk for infections and certain cancers;⁵¹ yet, research indicates that IBD patients do not receive preventive services at the same rate as non-IBD patients.⁵²

RECOMMENDATIONS

1. Community groups should develop and disseminate educational materials on the role of nutrition in the long-term treatment of IBD.
2. Patient advocacy organizations should develop resources to empower patients to advocate for their health and find a new health care provider if their needs are not being met.
3. Health care providers and patients should use shared decision-making to determine the most appropriate and effective treatment for a patient.
4. Patient advocacy organizations should develop culturally competent resources and materials to empower and support patients with IBD. This will help patients with the shared decision-making process.
5. Practice managers should discuss the social determinants of health (e.g., transportation, childcare, food security, etc.) with patients to help facilitate the provider-patient conversation on treatment options.
6. Health care providers must help educate patients on the treatment options available, how the treatments will alleviate any symptoms, and when patients should follow up with their health care provider if the symptoms do not resolve.
7. Patients should be educated in the stages of IBD progression, so they understand the consequences of non-compliance with medications, potential for future surgeries, and clinical trial options.





BARRIERS IN MAINTAINING IBD TREATMENT AND CARE

To properly manage IBD, patients need a trusted specialist to monitor their condition and treatment. However, finding a specialist that is willing to add a new patient to their case load can be difficult for some patients with IBD. For instance, one study published in *the American Journal of Gastroenterology* found that Black patients report increased difficulty accessing specialists for management of their IBD, compared to white patients.⁵³ Even when patients do find a specialist, however, continuity of care issues can arise due to poor communication and coordination between providers. Visiting multiple practitioners can create fragmentation between care teams, resulting in repeat tests, increased utilizations, and poor overall disease management.⁵⁴

Disease treatment may also be fragmented by the need to find a new practitioner. This often occurs when patients transition from childhood to adulthood care, switch providers, or relocate. As patients with IBD transition from childhood care to adulthood care, they may lack the requisite knowledge and health literacy skills to independently manage their care. Studies found that only 43 percent of young adult patients with IBD knew their medications and their potential side effects,⁵⁵ and only 36 percent of patients with IBD under 18-years-old had the health literacy skills required for adult-orientated IBD care.⁵⁶ Researchers have concluded that the lack of awareness may be due to socioeconomic factors and oversights from pediatric providers who presume their young adult patients have a stronger understanding of their condition than they actually have.⁵⁷

Patients may also experience delays or gaps in treatment due to benefit utilization policies and high costs of care. Delays from benefit utilization protocols, like prior authorizations, can lead to worse patient outcomes, disease progression, and lost time from work or school.⁵⁸ A study published in

Pediatrics found that prior authorization and other benefit utilization policies were associated with delays in treatment initiation by 10 to 24 days in pediatric patients with IBD.⁵⁹ As result of these delays, patients were almost 13 percent more likely to have IBD-related health care utilization within 180 days following physician biologic recommendation, and over 14 percent more likely to have corticosteroid dependence at 90 days from biologic recommendation.⁶⁰ Other financial barriers to accessing care include high-deductible health plans that have higher member cost-sharing requirements.⁶¹

When patients struggle to pay medical bills, they may delay treatment.⁶² Research published in the *American Journal of Gastroenterology* reported that Black patients with IBD were significantly less likely than to be seen regularly by a gastroenterologist or an IBD specialist, when compared to white patients.⁶³ The relationship between cost, race, and medication adherence is complex and confounded by other factors, including the nature of the disease (e.g., mistrust of the system is associated with medication non-adherence, particularly during periods of remission).⁶⁴

Gaps in treatment and poor medication adherence may cause patients to experience IBD complications and flare-ups. Studies suggest that Black patients are more likely to experience higher rates of IBD complications, including hospitalizations and mortality, when compared with non-Hispanic white and Hispanic populations.⁶⁵

Untreated and active disease IBD can impair an individual's ability to participate in the workforce.⁶⁶ A study published in the *Journal of Medical Economics* reported that patients with Crohn's disease missed nearly ten days of work per year due to medical-related absenteeism.⁶⁷ Workplace accommodations can help ensure patients with IBD can continue to work while receiving treatment during flare-ups.⁶⁸ However, many patients are unable to receive workplace accommodations. A study in the *Inflammatory Intestinal Diseases* found that 71 percent of patients surveyed needed access to a suitable toilet, yet 22 percent still reported that this was "somewhat or very difficult" to arrange this type of accommodation.⁶⁹

Patients Surveyed:

71%

Needed access to a **suitable toilet.**

22%

Reported that this was **"somewhat or very difficult"** to arrange this type of accommodation.



KEY INSIGHTS

During the panel, participants identified the following issues experienced by patients with IBD in maintaining their treatments: (1) lack of transition support for pediatric to adulthood care; and (2) lack of information on workplace protections for patients with IBD under federal law.

Pediatric to Adulthood Care

Participants noted the need for a program to bridge the gap between these transitions and ensure patients continue treatment. For example, one participant shared Medicare Part D's one-month transition fill that can be used between December and January after medication drop offs due to formulary changes or transitions between plans.⁷⁰ Participants also suggested that patients transitioning into adult care receive an informational packet or one-day training session that reviews important information about managing IBD, particularly ensuring patients are aware of different treatment options and disease progression; rights under state and federal laws, including rights under the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA); and essential insurance information, like the varying types of health insurance coverage and cost-sharing requirements, and how plan policies should be reviewed to determine medication coverage.

Federal Protections and Patient Rights

While participants recognized that patients with IBD may be eligible for some protections under federal laws such as the ADA or FMLA, participants agreed that patients with IBD may be unaware of workplace accommodations potentially available under these laws or how to apply these rights in the workplace. Participants also noted that resources must be shared by local, trusted sources using culturally competent messaging. Participants noted that in communities with individuals who are

undocumented, such as Hispanic and Caribbean communities, trusted information is often spread through word-of-mouth networks due to the lack of trust with larger institutions and fears of deportation.

RECOMMENDATIONS

1. Patients with IBD should keep a notebook that includes a roster of all their health care providers, date of most-recent visit, tests results, and other treatment information to reduce fragmentation of care when visiting multiple health care providers.
2. Employers should grant reasonable accommodations to support employees with IBD and comply with federal requirements under the ADA.
3. Employers should educate employees on their rights under the ADA and FMLA to ensure they can receive necessary workplace accommodations and time off from work to manage their IBD, when necessary.
4. Health care institutions and pharmaceutical industry members should partner with local trusted community organizations to develop culturally competent messaging, and ensure information reaches marginalized communities.
5. Medical schools should educate students on current racial disparities in the health care system, as well as particular areas where more minority providers are needed, such as gastroenterology.





CONCLUSION

Patients with IBD can face several different barriers in navigating the complex U.S. health care system. Patients of color are particularly impacted by such challenges. To address these barriers, it is critical to listen to, and learn from, the lived experiences of patients, providers, and caregivers who are impacted by them. By convening participants to share their expertise and experiences, Aimed Alliance has produced a number of recommendations to engage impacted communities and address access problems that contribute to disparities in health outcomes. Moving forward, patient advocacy groups, community leaders, and health care professionals should collaborate to implement the above-mentioned proposed solutions that will be most effective at reducing barriers to access in their communities and improving health outcomes in patients of color with IBD.



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