

Inflammatory Bowel Disease Shared Value Initiative



IBD



VIEWPOINTS

Laying the foundation for greater value in inflammatory bowel disease care

Executive Summary

Recent innovations have led to major change in the care of inflammatory bowel disease (IBD). Patients suffering from the chronic and debilitating disorders comprising IBD now have treatment options that can relieve their symptoms and prevent progression of the disease. In addition, new advancements on the horizon may further improve patient quality of life and reduce related financial burdens, such as lost wages due to decreased productivity. However, adoption of innovations in IBD care has been uneven to date. Furthermore, the advancement of value-based and alternative payment models, which have become common in other specialties such as oncology, has also been uneven in IBD. Enabling a more rapid and consistent uptake of innovation and shifting to a value-oriented care paradigm in the IBD space will require bridging various gaps in stakeholder perceptions of value.

In the first half of 2021, Tapestry Networks engaged a diverse group of stakeholders, including payers, self-insured employers, pharmacy benefits managers, gastroenterologists and clinical specialists, patient advocacy organizations, industry representatives, and others to address these issues. The effort culminated in a May 2021 IBD Progress Summit, during which participants explored how a multistakeholder collaboration might be able to accelerate the shift to value-based care in a more consensus-driven fashion than is currently the case.

There were several key takeaways from these conversations:

- **Participants identified three key challenges in IBD care:** limited endpoints that fail to account for functional outcomes for patients over long periods of time, a heterogeneous patient population requiring more sophisticated risk stratification, and high variation in care, which could be improved by increased standardization across the specialty and advancing holistic approaches to treatment.
- **In reflecting on these challenges, participants largely agreed that focusing on earlier, preventative intervention for IBD patients is the path to value moving forward.** Participants emphasized the importance of early, accurate diagnosis to ensure patients are best positioned for optimal outcomes. Furthermore, most recognized that primary-care physicians, general gastrointestinal practices in the community setting, well-honed IBD subspecialists, and ancillary support staff all have roles to play in enhancing care delivery

and ensuring access. Some noted that improved collaboration across these professionals could further improve the quality and value of IBD care.

- **Both specialty medical homes and digital tools could help advance value-based IBD care and the preventative focus noted above, but both are likely to require multistakeholder cooperation to achieve success and mitigate investment hurdles.** IBD medical homes are uniquely tailored to provide holistic, coordinated services to patients suffering from IBD, but they are challenging to scale and expensive to initiate. Digital tools have the potential to achieve high degrees of scale for IBD populations and are presented to payers as ready-made, turnkey solutions. However, these tools require patient engagement and, as point solutions for distinct populations within payers' broader membership, may require better integration and alignment with other value-based initiatives.
- **Establishing consensus-based guiding principles or frameworks could be a valuable next step, as could establishing multistakeholder continuous-learning platforms to accelerate adoption of critical lessons and incubate new partnerships.** Payers, clinicians, and others underscored the benefits of creating a framework or set of consensus-based building blocks to provide a foundation for those interested in piloting new approaches to value in IBD. Such a framework or building blocks would make it possible for stakeholders to leverage existing experience and expertise more efficiently. Additionally, a broad-based learning forum could help stakeholders identify opportunities to contribute to value-based initiatives and sensitize those who have not yet prioritized development of value-based IBD programs to the benefits of doing so.

Meeting participants valued the opportunity to hear diverse viewpoints on the above topics and were optimistic about the prospects for tangible progress and multistakeholder cooperation moving forward. Some especially appreciated the level of consensus on prioritizing patient interests. One payer said at the conclusion of the meeting, *"The thing that makes me hopeful is that every person here started with the patient. That was really how we started and ended every conversation, and I really enjoyed that."*

Introduction

“Autoimmune [diseases are] where cancer was 10 to 20 years ago.”

– Payer

“If you look at where we are today versus 20 years ago, it's so much better. Treatments are getting personalized. But cost-effectiveness and value need improvement. You need to define where an episode starts, where it ends, what data counts, and so forth. We've been talking to payers and coalitions about this, and we're seeing them wise up to this, especially employers who have to pay for stop-loss policies on this ... IBD is like what Janet Yellin said about stimulus policy: if you spend money in the beginning, you make it up at the end.”

– Clinician

As the Biden administration sets its health policy agenda and the COVID-19 pandemic subsides, some stakeholders are calling for fresh consideration of what's working and what's not in healthcare payment reform.¹ Across these discussions, one principle remains constant: commitment on the part of the new leadership at the Center for Medicare and Medicaid Services (CMS) to sunsetting the fee-for-service paradigm and advancing value-based payment and care delivery models.² Certain commercial payers' ongoing investment in and prioritization of value-based models indicate that value-based healthcare has caught the attention of the commercial sector as well.³

Experimentation in value-based care has accelerated in specialty areas, especially in high-cost, high-volume areas like oncology and for specialties that naturally lend themselves to bundled payments and episode models, such as joint replacements.⁴ There has also been innovation in models for autoimmune and gastrointestinal (GI) disorders. In autoimmune, some payers have focused on high-volume conditions like rheumatoid arthritis (RI).⁵ In the GI space, some approaches to better incentivize preventative care—especially through use of digital tools—have begun to emerge,⁶ but some of these have had difficulties achieving scale and offering holistic solutions for the full range of stakeholder needs.⁷

Some stakeholders believe there is potential to accelerate uptake of value-based healthcare for subspecialty conditions that experience high variability in cost and outcomes, sometimes described as “high-beta” conditions.⁸ Inflammatory bowel disease (IBD), an umbrella term for two autoimmune diseases—ulcerative colitis and Crohn's disease—impacts an estimated 3.1 million (or 1.3%) of Americans and is a high-beta condition that some believe would benefit from value-based approaches.⁹ *For more background on IBD and some of the drivers of its variability, please see the box on page 4.*

The treatment paradigm for IBD is undergoing change. In the past, IBD was managed by introducing increasingly advanced treatments until a patient's symptoms were under control. Today, however, the notion of inhibiting disease progression by preventing inflammation is gaining traction. The advanced pharmaceutical therapies that make this possible are now a cost driver of IBD care by some estimates.¹⁰ Despite their ability to reduce costly

hospitalizations and improve patient quality of life, they have not reduced overall healthcare spending, leading some stakeholders to question their cost-effectiveness.¹¹ In addition, payers have resorted to traditional utilization management techniques such as step therapy and prior authorization.

Given both the pressing need to transition to value-based care across the United States and the current treatment revolution in IBD, the time is ripe for a reconsideration of value in this subspecialty. Throughout the first half of 2021, Tapestry Networks brought IBD stakeholders together for discussions on critical IBD challenges and how a multistakeholder collaboration might address questions about the efficacy, value, cost, benefit, and sustainability of new technologies and treatment approaches. These discussions culminated in an IBD Progress Summit on May 14, 2021. *For a list of discussion contributors, please see page 18.*

Across conversations, participants considered the following questions:

- What challenges need to be addressed to arrive at consensus on value in IBD care?
- What approaches to value-based care are currently in use or under development?
- What steps could a public-private consortium take to advance value-based care in IBD?

This *ViewPoints* offers a synthesis of views that arose during the summit and in preceding conversations, along with external analysis, when relevant.

IBD: a primer

Patients with IBD experience chronic inflammation in the gastrointestinal tract that causes persistent diarrhea, abdominal pain, bleeding, weight loss, and fatigue.¹² Patient symptoms also vary and typically change over time. IBD patients may experience symptom-free periods of remission followed by a severe flare-up that results in complications.¹³ In advanced cases, IBD can permanently damage the GI tract, requiring costly hospitalization or surgical intervention.

There is no single lab test for IBD. Diagnosis begins with blood and stool tests, followed by endoscopic examination or imaging to confirm a suspected diagnosis. IBD patients skew younger, with IBD typically being diagnosed by age 30. This makes the population more relevant to commercial or employer-based payers rather than Medicare, unlike many other health conditions.

Healthcare costs for IBD are significantly higher in the first year when IBD is diagnosed, and average annual healthcare costs for IBD patients (\$22,987) are more than three times higher than non-IBD patients' annual costs (\$6,956).¹⁴ In addition to losing income as a result of lost productivity, IBD patients also experience significantly higher out-of-pocket spending. Taken together, the direct and indirect healthcare costs of IBD amount to an estimated annual economic burden of between \$14.6 and \$31.6 billion.¹⁵

Stakeholders identify challenges that complicate defining value in IBD care

Although IBD sufferers comprise a relatively small population, the “significant resource utilization and health care burden” IBD entails has prompted several stakeholders to pursue value-based frameworks and guidelines that promote “patient-centered, cost-effective IBD patient care.”¹⁶ A number of these efforts focus on defining measures of quality and promoting standardization of care, but while the various guidelines “*try to be consistent as much as possible*,” they remain piecemeal across multinational clinical and patient-oriented groups with distinct interests and constituencies.¹⁷

A shared, consensus-based framework that assesses and communicates the value of various healthcare technologies and interventions could help to align the community around good practices in IBD care.¹⁸ Differing views on factors in IBD such as quality and standardization signal that reaching universal consensus on value may be difficult at this juncture. These differences stem from current challenges in IBD care—namely, limited endpoints and evidence, a highly variable patient population that necessitates better stratification, and high variation in care—that participants flagged as priority issues.

Narrowly defined endpoints skew perceptions of value

Many of the endpoints used today in IBD—for example, inflammation and mucosal healing—focus on disease progression, but many stakeholders feel these are limited. Several underscored the challenges in agreeing on priority endpoints and outcome measures across stakeholders. Key considerations include the following:

- **Some underscored that IBD endpoints should reflect quality-of-life-related measures that capture functional outcomes.** These could include measures such as whether patients “*are back at work, their level of disability, or their psychosocial fortitude.*”
- **Participants stressed that value and cost-effectiveness should be assessed over the long term.** Some approaches, they noted, may not demonstrate cost savings for two to three years. “*The benefit of not having to go to surgery or not having further disability isn’t really felt for maybe several years,*” said one patient advocate. Additionally, as a chronic condition, IBD lacks a clear endpoint and therefore requires distinctly longer-term frameworks to assess value. “*Cancer is an expensive therapy with an endpoint ... IBD goes on forever and can progress,*” emphasized one payer.
- **Measures demonstrating and quantifying cost-effectiveness of treatment will be critical, especially for payers.** Some noted that functional endpoints are essential for showing the value of some treatments, especially advanced therapies. One said, “*When you try to really assess cost-effectiveness—when you look at the Institute for Clinical and Economic Review report—it basically says [certain] drugs aren’t cost effective and aren’t doing a great job.*” More detailed quantification of functional measures would be beneficial. One participant

emphasized, *“There is an expectation in the payer world that there should be direct offsets from spends ... You do need to quantify what the value is of quality-of-life improvements.”*

- **A primary argument against quality-of-life-related endpoints is that data on them are extremely challenging to obtain—a fact that underscores the need for a more comprehensive approach to longitudinal data collection.** *“[Lowering] absenteeism is value, [but] how do we track and manage it so we can calculate, document, capture that in an ROI discussion? We don’t have the infrastructure or mechanism to get to that,”* a payer said. Barriers include insufficient data as well as difficulties monitoring patients over time: member churn—or patients switching their insurers as they change employers—dampens incentives for payers to invest in long-term monitoring of outcomes.

Better patient risk identification is needed

The level of symptoms and inflammation IBD patients experience is highly variable and changes over time. Some patients may progress to severe disease that leads to complications; others may not. Enhanced risk stratification early on in the course of the disease and as it progresses would, in the opinion of many, benefit the field, especially since identifying high-risk IBD patients is not straightforward. A clinician emphasized, *“It’s not so easy to tell just by meeting them in the office and hearing their history.”*

More sophisticated tools or tests that identify high-risk patients are already in use in select settings. If better standardized or implemented at scale, they could offer several potential benefits:

- **Improved real-world application of therapies and streamlined clinical interventions.** Better tools and tests would be valuable given that endpoints used to assess disease progression in clinical studies for IBD are diverse, often shaped by regulatory agency requirements and guidance, and may not translate well into real-world settings.¹⁹ Moving forward, using various biomarkers, lifestyle factors, social determinants of health, and other nonclinical metrics to predict patient risk may improve clinicians’ ability to manage IBD’s heterogeneous patient population. A clinician said, *“If we can identify which patients are those at higher risk, we could really focus our efforts on those as opposed to all patients in general.”* A payer also felt risk stratification would help: *“Score these patients from a severity standpoint. When do you go from treatment A to treatment B or C?”*
- **Improved patient adoption of and adherence to recommended treatment plans.** Physician participants noted that risk assessments are often critical to winning patient buy-in for treatment when their symptoms are not yet severe, a particular challenge in IBD: *“IBD patients are afraid of biologics ... Sometimes it takes more surgeries or complications to get patient buy-in to go on treatment.”* Another reported, *“I spend a lot of time explaining to patients, ‘Here’s why you still have to take this, even when you are feeling well.’”*
- **Reduced overutilization of treatment.** Some felt that better risk stratification would not only help high-risk patients receive appropriate care, but also reduce the likelihood of overtreatment in lower-risk patients.

Some felt that payers and employers might be unlikely to support such tools, which would inhibit their widespread utilization and scale. But others were more optimistic. In response to skepticism that payers would cover testing that predicts patient risk or response to a specific drug in IBD, one payer remarked, *“I would be paying for that test all day long.”* More evidence around the utility of specific risk stratification approaches and tools would be a beneficial step in enabling endorsement of more stakeholders. *“The ideal state is that there is an evidence-based risk stratification or scoring model,”* said one payer. Contracts for value-based approaches, discussed on page 14, can also incentivize broader adoption of tools to optimize patient care.

The distinction between appropriate and inappropriate variation in patient care needs clarification

While some of the variation in IBD care can be attributed to patient adherence issues,²⁰ some appears to be the result of physician treatment decisions.²¹ Such variation is not desirable: as one participant put it, *“You see the variations in care and the cost of care against patient outcomes, and you see it might be duplicated services or waste.”*

Some participants underscored that a more consistent definition of optimal care for IBD patients could help promote standardization and align stakeholder perceptions of value. However, because IBD patients are a heterogeneous population, participants also acknowledged that treatment plans should have sufficient flexibility to provide personalized care for each patient. Determining when variation is appropriate and when it is inappropriate, some industry participants noted, is paramount. Specifically, some participants saw an opportunity to reduce variation linked to clinicians who see a lower volume of IBD patients. One physician said, *“The doctor who’s spending every day doing 15 colonoscopies and sees a handful of IBD patients can make an honest error simply because they’re not seeing enough of the disease.”*

Furthermore, comprehensive care that addresses patient’s psychosocial needs can also play a role in reducing variability in outcomes, some participants argued. They emphasized the connection between mental health and total cost of care: *“We see that when we control behavioral health, it impacts the physical manifestation of disease, and we can reduce costs.”* Indeed, one study found that patients with a mental health diagnosis had approximately twice as many ED visits and hospitalizations as other IBD patients.²²

“If I could tell which patients are not functioning well, not only clinically but also psychosocially, then I’ll enlist lower-cost providers (like dietitians, nurses, etc.) and put in resources that help patients ... It is not expensive, but could significantly lower the cost of care.”

– Clinician

Misaligned incentives drive variability in treatment and outcomes

Misaligned incentives are a long-standing problem in the US healthcare system, impacting all stakeholders and often prompting blame across the sector, as well as contributing to the above challenges. These incentives include both the fee-for-service reimbursement framework

for clinical care delivery as well as the complex, rebate-based payment system for prescription drugs. Conversations prior to and during the summit regarding the problem of misaligned incentives focused particularly on the following points:

- **Fee-for-service payment models do not reward physicians for spending more time talking to patients and assessing their potential risks, providing more comprehensive care, or actively working to prevent more serious complications.** Some participants emphasized that under today's reimbursement framework, GI specialists *"get paid three times more per minute for endoscopy versus talking,"* which can inhibit the kind of preventative care, risk assessment, and shared decision making that would benefit many IBD patients.
- **Current utilization management policies also divert clinicians' time away from patient care.** Clinicians often spend considerable time working through payers' prior-authorization and step therapy policies. Time spent navigating these policies can negatively impact clinicians' time with patients and incentivize clinicians to spend time on revenue-maximizing procedures.
- **Reimbursement for advanced therapies depends on treatment location (site of care).** Others called out the additional costs resulting from facility fees for treatment infusion, which impact the total cost of these therapies: *"[These] should be factored out if we really want to look at the cost effectiveness of the drugs, because it makes the drugs look worse,"* noted one clinician. Infusions in nonhospital settings can reduce spending associated with advanced therapies,²³ but there is also evidence that treatment administration in an infusion setting (as opposed to home-based treatment) can increase patient adherence.²⁴
- **Complex, oftentimes opaque pricing structures also make it difficult to assess value.** Some stakeholders, and in particular employers, reported frustration with the lack of clarity around rebates, which are paid to pharmacy benefits managers (PBMs) by manufacturers, with the amounts established in prenegotiated contracts. Rebate levels are kept confidential to PBMs and manufacturers, depriving employers and other payers of the ability to determine cost savings compared to list price.²⁵ Some suggested that eliminating rebates alone would not necessarily solve the problem, citing the example of manufacturers who *"tried to come in without rebates, but still priced too high."*

Against this backdrop, many participants agreed that greater collaboration among stakeholders in IBD is needed to overcome misaligned incentives and create the foundations for designing, testing, and scaling value-based care approaches, tools, and models. One participant summed it up: *"it's really easy to start to point the finger and say, 'Well, if the payers just did this, or the providers just did this' ... but if we have that mindset, we're never going to get anywhere."*

Stakeholders are testing and advancing various approaches to value-based IBD care

Today, stakeholders are beginning to experiment with approaches and tools intended to enhance the quality of IBD care while managing total cost. Many of these are nascent, but early lessons are emerging. Most participants agreed the progress is sufficient to encourage clinicians to identify patients who need intervention earlier. Treatment is more likely to be helpful if delivered sooner in a patient's course of care, and early treatment reduces costly acute and emergency interventions. One participant noted, *"We see patients and it's too late. If we had seen them five years ago, we would have changed the trajectory of their disease ... and gotten them on early biologic therapy, and they wouldn't be in our surgeon's office."* It is also hoped that preventative-based incentives will encourage long-term use of advanced therapies when appropriate and support the creation of data sets that capture preventative benefits and cost savings over time.

Participants considered how some illustrative value-based models may help realize the above vision. Conversations centered on the necessary investments and infrastructure for adoption, as well as benefits and drawbacks of each approach. Overall, participants underscored priority characteristics that future approaches should possess moving forward. Many agreed that more broad-based multistakeholder collaboration and closure of investment gaps are necessary if these approaches are to achieve their full potential.

"I don't think it matters what we call these models. I think that what matters is that we leverage the expertise of all the various stakeholders so that we actually figure out what success looks like and how do we get there."

— Industry expert

Overview of IBD value-based approaches

Collaborative-care models

- IBD specialty medical home, e.g., IBD Specialty Medical Home at UPMC²⁶**
- **Overview:** Multidisciplinary, team-based holistic IBD treatment that also addresses psychosocial needs; coordinates care to help patients navigate the system and manage their health.
 - **Value:** Coordinated care reduces low-value, redundant care linked to fragmented teams; addressing psychosocial needs reduces ED visits and hospitalizations and improves patient quality-of-life scores.²⁷
 - **Collaborations:** Payer-provider partnership required; team also coordinates non-GI care.

Collaborative-care models *cont.*

Collaborative center-of-excellence models; early concept discussed at summit

- **Overview:** Multidisciplinary team of IBD specialists establishes diagnosis and treatment plan based on patient need, including referrals to other IBD-focused clinicians as needed while collaborating with community resources.
- **Value:** Provide specialized IBD care at defined points in a patient's diagnostic and treatment journey with an aim to prevent complications and reduce variation; can promote patient access to related support (nutritionists, social workers, etc.) and other patient-focused resources.
- **Collaborations:** Variable collaboration between IBD centers and community GI practices at present; no widely accepted (i.e., by other stakeholders) formal designation of what constitutes a center of excellence or specialty center.

Digital tools and platforms

SonarMD²⁸

- **Overview:** Digital app connects with patients via text, email, and phone to collect symptoms, which the platform uses to calculate a Sonar Score.
- **Value:** Identifies patients at risk of disease progression/potential flare-ups and notifies their physician to prevent unnecessary ED visits and hospitalizations.
- **Collaborations:** Works with many physicians across a geographical region and partners with multiple payers on value-based contracts, in which SonarMD serves as the third-party risk-bearing entity.

Trellus Health²⁹

- **Overview:** Connected-care platform connects patients to multidisciplinary IBD care team (Trellus Triad) and leverages a resilience-based care coordination approach to chronic disease to reduce unplanned ED visits and hospitalizations.³⁰
- **Value:** Risk-stratifies patients, coordinates care with a network of IBD clinicians, and coaches patients to learn self-management and resilience so as to reduce unplanned ED and hospital visits and prevent inappropriate care.
- **Collaborations:** Connects self-insured employers and health plans to network of IBD trained clinicians; connects providers to at-risk patients.

Vivante Health³¹

- **Overview:** GITHrive app allows patients to schedule sessions with a dedicated nutritionist and health coach; there is also a 24/7 nurse line.
- **Value:** On-demand nurse triage aims to prevent unnecessary ED utilization and hospitalizations; health coaching improves patient self-management and adherence to treatment.
- **Collaborations:** Partners with payers and employers to provide care for any member or employee with a chronic digestive condition.

Episodic bundles

- Episodic bundle for Crohn's Disease from Signify Health**
- **Overview:** Episodic bundle delivers high-quality inpatient care for exacerbations of Crohn's disease.
 - **Value:** Shares data and insights with providers to better coordinate inpatient care and prevent common complications.
 - **Collaborations:** Signify Health acts as a convener to help payers share risk with providers.

Many prioritize models that closely align with chronic conditions

Generally, participants felt that the chronic nature of IBD merits an approach that puts preventative care at the forefront, even if the results are spread across a longer-term time horizon. A participant said, *"The specialty medical home model is more clinically aligned with chronic conditions like IBD than an episode; the latter is very precise in terms of population and is typically just for a small amount of time."* As a result, participant discussion centered on IBD medical homes and a collaborative, center-of-excellence concept, emphasizing the following key points:

- **In some respects, medical homes are a natural fit for value-based IBD care, but they come with drawbacks and opportunities to improve.** Participants noted that medical homes provide holistic services and treatment to patients, can help reduce the duration of diagnostic odysseys, and can improve connections between PCPs, GI physicians, and IBD specialists. However, to optimally implement these models, stakeholders need to invest in additional staff. Smaller GI practices may not have enough IBD patients to make such investments worthwhile, and larger ones may still struggle with hiring relevant clinicians and ancillary staff, e.g., IBD-knowledgeable psychologists. Consequently, some participants emphasized that medical homes may be difficult to scale nationwide, at least within current incentive structures
- "We started talking about if there was some way to set up ... a referral-type system where the true specialists were seeing patients at time of diagnosis and saying, 'Here are the patients who really need more hands-on [care]' ... That's one of the good ideas that was raised: how do you get newly diagnosed patients seen before they get too severe?"*

– Industry representative, reflecting on the breakout discussion
- **Some participants introduced a concept akin to centers of excellence (COEs) known in other specialties.** These focus on leveraging existing sites of care and their competencies to enhance outcomes and experiences for IBD patients. Participants said that such a model could enable large IBD centers to share their high-quality expertise more systematically with community GI practices at the optimal time in a patient's diagnostic and treatment

journey, thereby promoting local access to care. Some noted analogous examples in oncology: *“Growing up in the New Jersey suburbs, if someone got cancer, they went to Memorial Sloan Kettering. They got diagnosed and then they went back into the community setting to get their radiation and other types of treatments, but at time of diagnosis, they went and really saw a specialist.”* Telemedicine might be able to enhance such collaboration in a cost-effective manner: if established specialty medical homes, for example, could share clinicians with highly specialized IBD expertise virtually, it could address the investment challenges smaller practices face and help focus specialist attention on the patients who need it the most at specific points in time.

- **Episodic, bundled approaches for acute flare-ups are less of a priority.** Some companies, such as Signify Health, are partnering with practices and payers to help manage the costs of IBD episodes, and some of these efforts focus on managing complications associated with inpatient admissions and mitigating the potential for readmissions during an acute IBD flare-up.³² However, for participants, episode-based approaches and acute care management were a lower priority than the preventative models discussed above, which focus on more intensive intervention earlier on in the journey. One payer commented, *“This is a chronic disease we’re talking about ... We definitely want to focus on the preventative stage.”*

Digital tools appeal to some stakeholders, but still need improvement

There are digital tools available that can help with preventative interventions, monitoring, coaching, and patient education, all in aid of long-term care coordination and timely identification of potential flare-ups. Participants discussed their benefits and drawbacks:

- **Platforms, as ready-made, third-party solutions, offer payers and employers a turnkey experience.** *“Whenever something is fully baked as much as possible before it’s presented, I think it makes it so much easier to implement,”* said one payer. Leveraging a tool’s scale across practices and payers is also attractive: SonarMD *“recruits everyone so it’s easier to contract,”* a payer working with Sonar said, referring to the company’s widespread clinician relationships. Similarly, Trellus connects employers and health plans to a vetted network of “Trellus Certified” IBD experts.³³
- **Digital platforms can provide easy-to-access coaching and educational support, but not for all patients.** While some IBD medical homes provide coaching, education, and disease management support to patients, digital tools can offer these resources in a more cost-effective way that may be more convenient. This is especially true for IBD patients, who tend to be younger, digital-savvy, and therefore more open to digital health tools than patients in other specialties. But not all patients are willing or able to engage: *“We had to cohort patients into engageability categories, because it doesn’t do you any good to have a digital tool if you can’t engage that patient in their care,”* one clinician with experience in digital tool implementation reflected.

- **Others emphasized concern about patients' fatigue with these platforms, which may jeopardize the platforms' ability to generate meaningful insights that eventually improve patient care.** This was especially true for payers who may be implementing similar programs in parallel. One said, *"If you want a patient engaged with four different programs, and they have four separate coaches or guides or things to update them? Talk about engageability—trying to do that times four every day? You get nothing."*

In light of these benefits and drawbacks, participants discussed how to advance digital tools moving forward. For some, the ability to present a digital tool as coming directly from a patient's local physician office is critical. Patients are more likely to engage with their physician than they are with their insurer, treatment manufacturer, or other stakeholders. *"If the patient feels it's the practice that's communicating with them, they'll answer the questions; they'll do what they're supposed to do. But not if you're an outsider,"* commented one industry participant.

Some also recommend patient-centered design principles to encourage patients to consistently share their data in a way that generates robust, meaningful insights. *"We've done a lot of user experience research to understand engagement with a digital tool ... While convenience is a top priority, it's also important to collect information that is meaningful to the patient. If they don't care about a metric personally, they are less likely to fill it out,"* said one patient advocate.

For value-based approaches to take hold, critical investment and prioritization gaps must be addressed

Overall, value-based care approaches in IBD—both medical homes or similar models as well as digital tools—can suffer from prioritization and investment gaps that create a vicious cycle that can impede expanding their use. There are several factors that advocates of value-based IBD care need to address:

- **Payers, including self-insured employers, underscored that because the IBD population is small relative to other conditions, it is not frequently prioritized for value-based models, which require considerable resourcing and investment.** One payer framed it bluntly: *"On the list of things to do, it's not the top priority, to be perfectly honest."* Others noted that because IBD is a chronic condition, patients can have significant short- and long-term costs if the disease is not well managed. Payers also said that it is difficult (if not impossible) for them to implement models that have not been vetted with other stakeholders. Turnkey models and scalable or generalizable tools offered by third parties may be able to help mitigate this challenge. A payer partnering with Sonar said, *"What I like*

"There is always the question of how do we really prove that we can get a return on investment, and sometimes that is challenging to do up front, when there isn't sufficient data to really support that. It's always a balance between how much we really need to pilot something formally ... versus giving it an opportunity with members and seeing where it goes."

– Payer, reflecting on challenges in initiating value-based payment

is that they made it easy for us—they partnered with the provider, with three separate groups, and presented a model that was already put together. They have the partnership all set up, physicians that are willing to work with them, and all I need to do is agree to a financial model that compensates for the program.”

- **Practices also need better incentives to make investments in value-based approaches.** Some clinicians reported that many practices currently lack incentives to invest in the systems and tools that are often the backbone of value-based models, underscoring the need for tools and approaches that are generalizable, as emphasized above. Lack of robust data infrastructure, which is essential for the longitudinal data collection needed to show clear cost and quality improvements with approaches like medical homes, is especially challenging. Some payers recognized the importance of using value-based contracts to create incentives for practices to invest in relevant tools; these payers also understand that empowering practices with actionable insights is critical.

Participants noted that resources from other stakeholders will be necessary to solve the above challenges, especially for medical homes and COE-type concepts. Treatment manufacturers and specialty pharmacies could share data and insights on patient adherence—for example, patient feedback or concerns about the treatment plan, or insights on what drives nonadherence.

Consensus-based frameworks and collaborative platforms could advance value-based IBD care

Participants recognized that advancing more value-oriented approaches to IBD care would require multistakeholder effort, support, and investment. They proposed possibilities for optimal multistakeholder collaboration, recognizing that many leaders in this space already

“What it comes down to is meaningful value-based contracts. Physicians need tools to optimize those contracts. And one of those tools is not data, it's insights. Give them a contract that allows them to optimize value and tools to optimize value—not necessarily prior authorization, but take RA, for example, and methotrexate. There is a tool now that tells you if it would work. So give providers these tools, and give them the insights each quarter so they can see if the needle is moving or not. And if you do those things, physicians will clamor to use the tools available for them to optimize value.”

– Payer

“Our job is to create a model that addresses all the patients' behavior, why they aren't following along with what the doctor tells them to do. And who knows the most about why patients do not follow protocol? Drug companies—they study patient preferences and barriers to care extensively, they have this info, so they have to be involved in building team-based value-based models.”

- Subject matter expert

have their own efforts under way. Specifically, several participants opined that frameworks and platforms that are generalizable could complement and pave the way for locally based, customized efforts.

- Participants felt that a collaborative effort should focus on defining the key elements or consensus-based building blocks of a framework for value-based IBD care, which could be used to guide development of new approaches and models.** One payer said, *“We’re juggling multiple programs, multiple meetings with multiple vendors and multiple opportunities ... If there is some kind of framework that people can borrow from that minimizes the guesswork or minimizes trying to figure out what are the important components that need to be considered, I think that would be helpful. It doesn’t have to be complete. It just needs to draw the sketch of what’s important in any specialty model, whether it’s a specialty home model or a digital tool combined with an episodic-program model. I think that having a basic framework leveraging all of the expertise of this group would be a really great outcome.”* Some emphasized that such a framework should not be restrictive but instead outline elements that could be applied and customized on a local basis.

“I think [this group is valuable] to the extent that [it] can facilitate continuing to bring stakeholders together to listen to the perspective of each, to listen and understand the resources and expertise of each, and then to discuss from each perspective what are the issues we need to address, and then work to figure out where ... those resources lie within here, and do we need to bring others in, as opposed to starting with pointing fingers or throwing punches, which is not at all unusual.”

– Subject matter expert

- Participants said a framework should focus on urgent matters such as better categorization and stratification of IBD patients, improved endpoints for outcomes measurement, and reduction of inappropriate care variation.** A framework could, for example, consider guidelines for managing enhanced risk stratification and preventative interventions, drivers of variability, patient engagement, and provider coordination and referrals. One industry participant said, *“I wonder, as a next step, are there ways that we can really list out the fundamentals and the foundational basics that are required? ... Whether it’s data architecture, or identifying the key quality indicators and then the data architecture to get there, the frameworks that follow patients across plans, etc. ... We need a prioritized list of the top three, five, seven things that are fundamental that will be woven into any ... broad program and [we need to] try to figure out how to coalesce on those.”*
- Participants also underscored the value of a multistakeholder platform that could more rapidly accelerate and disseminate emerging lessons and incubate new concepts, pilots, and ways of working.** Such a platform would allow for local development of models and could help with the following issues:

- Identifying opportunities for IBD-specific programs to integrate, scale, and move beyond point solutions, possibly even beyond IBD as a stand-alone disease. One clinician reflected on his key takeaways from the discussion: *“These point solutions are not going to be the answer even if they're good, like Sonar, and do all the heavy lifting for the plan. We need to have more broader-type solutions that are focused on all the high-beta patients so that maybe there's a solution for the high-risk, high-beta patients that have IBD, that have RA, that have congestive heart failure, that have [chronic obstructive pulmonary disease], sleep apnea.”*
- Understanding how best to leverage resources and expertise across stakeholders for some of the specific challenges noted above, for example:
 - There may be opportunities for those who value clinical data (e.g., treatment manufacturers) to support practices in setting up more robust data collection systems in exchange for some degree of data access or insights.
 - Professional societies could help stakeholders align on IBD medical-home criteria or COE certification so that payers interested in setting up a value-based payment model do not need to invest resources in care delivery components and could instead focus on financial aspects.
- Sharing lessons and successes with payers and employers so as to sensitize them to the benefits of focusing on this space—a necessary effort because payers and employers often deprioritize IBD for stand-alone initiatives due to small numbers. Such a platform could also work with payers to identify and potentially endorse the most promising tools (e.g., risk calculators) to promote standardization in the field.

“Who owns this process? We all own this process. And if we really want to make progress, we all have to own it to a certain extent.”

– Industry representative

Conclusion

Participants felt that hearing the perspectives of other stakeholders helped them gain a better understanding of existing barriers to value and consider more effective solutions. Reflecting on the discussion and how it unfolded, one stakeholder expressed a sense of optimism: *“One of the things that gives me hope is watching [how] even just an hour-long conversation can go from finger pointing—payers need to do this better and providers could do this different—[to] at the end it was basically providers saying, ‘We could do this better as providers,’ and it was the payers saying, ‘We could do this better as payers.’ ... Just seeing how people's mentality evolved a little bit within these conversations gives me a lot of hope.”*

Participants were eager to use the momentum from the summit to advance tangible next steps, including those noted above. They reiterated the group's alignment on the need for

incentivizing preventative approaches, including robust risk stratification, with some underscoring the benefits of the proposed multistakeholder framework for value-based care: *“It would be extremely helpful if there was something tangible to publish above and beyond the opportunity to have a multistakeholder discussion ... Somebody could use such a publication to change how they think of IBD or how they think about approaching IBD programs, and that's where I think being able to share some very fundamental key components might be a tangible takeaway.”* Going forward, stakeholders involved in initiating the Progress Summit will be working with the IBD community to advance summit discussions with an aim to generate long-term impact in the IBD space.

About this document

ViewPoints uses a modified version of the Chatham House Rule whereby comments are not attributed to individuals, corporations, or institutions. Italicized quotations reflect comments made by participants before and during the meeting.

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