

The Pediatric Inflammatory Bowel Disease Medical Home: A Proposed Model

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Care for patients with inflammatory bowel disease (IBD) can be complex and costly. Care delivery models to address these challenges and improve care quality are essential. The patient-centered medical home (PCMH), which was developed in the primary care setting, has recently been applied successfully to the adult IBD population. Following the tenets of the PCMH, this specialty medical home (SMH) emphasizes team-based care that is accessible, comprehensive, patient/family-centered, coordinated, compassionate, and continuous and has demonstrated improved patient outcomes. Children and young adults with IBD have equally complex care needs, with additional challenges not faced by the adult population such as growth, physical and psychosocial development, and transition of care from pediatric to adult providers. Thus, we advocate that the components of the PCMH are equally—if not more—important in caring for the pediatric patient population. In this article, we review what is known about the application of the PCMH model in adult IBD care, describe care delivery within the Center for Pediatric and Adolescent IBD at Nationwide Children's Hospital as an example of a pediatric IBD medical home, and propose a research agenda to further the development and dissemination of comprehensive care delivery for children and adolescents with IBD.

Key Words: patient centered medical home, multidisciplinary, comprehensive care, Crohn's disease, ulcerative colitis

Introduction

Inflammatory bowel diseases (IBDs), including Crohn's disease (CD) and ulcerative colitis (UC), are chronic inflammatory conditions of the gastrointestinal (GI) tract that affect over 3 million people in the United States.¹ Nearly a quarter of patients are diagnosed under 20 years of age.² These diseases require life-long surveillance and management, with multidisciplinary care as the gold standard. Inflammatory bowel disease chronic care delivery is complex, with abundant opportunities for inefficient, poorly coordinated, omitted, or duplicated care. Several care-delivery models aiming to provide comprehensive, high-quality, cost-effective care have been described in the literature.

One comprehensive care model, initially described in pediatric primary care and later applied to adult primary care, is the patient-centered medical home (PCMH).³ In recent years, its components have been successfully extrapolated to the adult IBD population in the form of the specialty medical home (SMH).⁴ Despite advances in the development of adult IBD SMH, a description of the SMH in pediatric IBD remains limited. In this review, we aim to summarize the literature regarding the PCMH and its expansion to a SMH in adult IBD care. We then describe why a similar specialized care delivery model is necessary for children and adolescents

with IBD, using the infrastructure of the Center for Pediatric and Adolescent IBD at Nationwide Children's Hospital as a case study. We will conclude by outlining a proposed research agenda to support optimized pediatric and adolescent IBD care delivery via a pediatric IBD medical home, highlighting areas for growth, development, and dissemination.

The Adult IBD Medical Home

The term “medical home” was first used in a 1967 publication by the American Academy of Pediatrics (AAP).⁵ Decades later in the 1990s, the AAP established the principles of a medical home, emphasizing care for children with special health care needs that is “accessible, continuous, comprehensive, patient/family-centered, coordinated, compassionate, and based on trusting relationships.”³ In 2007, driven by rising health care costs and the aim to improve care quality, the American College of Physicians, American Academy of Family Physicians, American Osteopathic Association, and the AAP published a consensus statement reviewing the principals of the PCMH.⁶ This statement emphasized the patient at the center of the medical home, with the primary care provider serving as the coordinator of care within a “medical neighborhood” of subspecialists, ancil-

lary providers, and community resources.⁷ Ultimately, this medical home model aimed to improve health care quality, decrease costs, and optimize the experience for patients and providers alike.⁸

More recently, Regueiro et al have published on the conceptualization, development, and impact of a SMH for adults with IBD. Similar to the original PCMH, the impetus for creating the SMH included the increasing costs of IBD care, the growing care complexity, and concerns for care fragmentation.⁴ As is the case with many chronic diseases, the majority of IBD health care costs are driven by a small percentage of patients, with prominent drivers of cost being unplanned care (emergency department [ED] visits and hospitalizations), procedures, and the need for biologic medications.^{9–11} Comorbidities such as behavioral health disorders, chronic pain, and lower socioeconomic status are also associated with unplanned IBD care and increased health care costs.¹² Applying the PMCH model to adult patients with IBD, Regueiro et al aimed to improve the value of care delivered, as defined as the ratio improvement in health outcomes divided over the cost of that care improvement.¹³

Regueiro and colleagues explain that the construction and deployment of an SMH requires the following 4 elements: (1) a payor willing to partner with providers, (2) a specific, identifiable patient population, (3) a physician champion, and (4) prespecified program goals or measures of success.⁴ They initially focused their program on those patients who had incurred the greatest costs in the preceding years but later expanded the program to all patients with IBD and a University of Pittsburgh Medical Center (UPMC) insurance plan, approximately 55% of their total IBD population.¹⁴ A more recent publication explains how a complexity score comprising biological, psychosocial, socioeconomic, and systems-level variables was developed to help target SMH resources to patients in greatest need.¹⁵ They created health maintenance checklists, followed clinical care pathways to decrease variability in clinical care, and tracked patient progress.¹⁴ In collaboration with patient advocates, their center also created a volunteer psychosocial support program for patients hospitalized with IBD.¹⁶ Since its inception in 2015, the IBD SMH has demonstrated excellent patient recruitment and retention. Using quasiexperimental pre-post methods, Regueiro et al also demonstrated improvement in multiple patient outcomes in the year after enrollment in the SMH compared with the year prior, most notably including a 47% reduction in ED visits ($P < .0001$) and a 36% reduction in hospitalizations ($P = .008$). Median disease activity scores also significantly improved as measured by both the Harvey-Bradshaw Index and median ulcerative colitis activity index score. In addition to improved clinical outcomes, anxiety, depression, and quality of life scores also improved after SMH enrollment.¹⁷

Several other care delivery models that share elements with IBD SMH have been described, including Project Sonar, a community practice-based IBD SMH,¹⁸ and multicenter learning health systems such as IBD Qorus for adult IBD and ImproveCareNow (ICN) in pediatrics.^{19–21} Despite the growing literature in the care of adults with IBD, publications describing models of care delivery in pediatric IBD remain limited, with no prior studies describing a pediatric IBD SMH.

Nationwide Children's Hospital Center for Pediatric and Adolescent Inflammatory Bowel Disease—A Pediatric Specialty Medical Home Model

Pediatric and adult patients with IBD share numerous similarities; notably, both patient groups require comprehensive care to address physical and psychosocial needs. However, children with IBD have unique needs related to the age of disease onset. Patients diagnosed during childhood have an increased risk of having more severe disease than adults, in addition to nutritional deficiencies that can cause poor linear growth and delayed pubertal development.^{22–24} Furthermore, children with IBD have distinct needs when it comes to appropriate and safe vaccination, health maintenance activities, psychosocial interventions, and the eventual successful transition to adult care.^{25–27} It is in the context of these complexities and additional barriers that our IBD team aimed to establish our pediatric SMH aligning with the tenets of the PCMH model. By identifying and developing necessary members of our multidisciplinary team, applying standardized workflows, and using data to track progress, we have been able to deliver more comprehensive pediatric IBD care from diagnosis through transfer to adult care efficiently and effectively.

Assembling Our Multidisciplinary Team

At Nationwide Children's Hospital (NCH), we care for more than 700 pediatric and adolescent patients with IBD, with an average of 110 new diagnoses per year. Approximately 70% of patients have CD, and nearly 70% are treated with biologic therapy (Table 1). Our IBD care is delivered by a multidisciplinary team of providers, each with specific roles and responsibilities. The team includes attending physicians, 4 of whom are IBD-focused, gastroenterology fellows, a dedicated IBD nurse practitioner, psychologists, social workers, dietitians,

Table 1. Nationwide children's hospital patient characteristics.

Disease; N (%)	
Crohn's disease	501 (72)
Ulcerative colitis	168 (24)
Indeterminate colitis	28 (4)
Sex; N (%)	
Male	369 (53)
Age, years; median (SD)	
	17 (4)
Current Medications; N (%)*	
Nutritional therapy	29 (4)
Mesalamine	127 (18)
Corticosteroids	29 (4)
Immunomodulators	128 (18)
Methotrexate	66
6-mercaptopurine/azathioprine	48
Biologics	470 (67)
IV anti-TNF (Infliximab or biosimilar)	265
Adalimumab	161
Certolizumab pegol	1
Ustekinumab	15
Vedolizumab	28

N = 697 patients; *Percentages do not add up to 100 as patients may be on multiple or no medications; anti-TNF, anti-tumor necrosis factor alpha.

IBD nurse coordinators, administrative staff with expertise in insurance authorizations, pediatric surgeons with IBD expertise, a clinical pharmacist, a quality improvement (QI)/data specialist, and research coordinators. We also have a parent advocate team and close relationships with adult colleagues at the Inflammatory Bowel Disease Center at The Ohio State University Wexner Medical Center. Each team member has specific roles (Table 2), ensuring comprehensive care delivery and aiming to reduce inefficiency and redundancy. Although some team members are involved “behind the scenes” or on an as needed bases, the majority are connected with families soon after diagnosis at the New Diagnosis IBD Teaching Visit (described in further detail later on). This early introduction reflects their active and integrated role in patient care.

Supporting patients and families—gastrointestinal psychology

Similar to adults with IBD, pediatric and adolescent patients are also at increased risk for mental health disorders including depression, anxiety, and suicide.^{28–30} Depression rates of up to 25% have been noted in children with IBD,³¹ and patients with both IBD and depression are at greater risk for treatment nonadherence, which contributes to worse disease out-

comes.³² Children with IBD also face challenges related to coping with a new diagnosis, procedural anxiety, and body image concerns.^{28,31,33–36} Integrated psychological care for patients with IBD has been shown to improve outcomes and reduce health care costs,³⁷ but access to psychosocial care for children with IBD is highly variable.³⁸

Inflammatory bowel disease has the potential to impact peer and family relationships; compared with healthy peers, patients with IBD have poorer social functioning and peer relationships, especially those diagnosed in adolescence.^{34,39} Family dysfunction and increased psychosocial distress in parents can also worsen health-related quality of life for patients.^{40–42} Recent publications have highlighted gaps in psychosocial care amongst young people with IBD.^{43,44}

At NCH, GI psychology meets with patients and families soon after diagnosis, most commonly at the multidisciplinary IBD Teaching Visit. At this visit and yearly thereafter at IBD annual visits (to be described in more detail later on), a GI psychologist completes formal screening assessments (clinical interview; Beck Depression Inventory-2⁴⁵; Children’s Depression Inventory 2nd Edition⁴⁶; Pediatric Quality of Life Inventory⁴⁷; and the Generalized Anxiety Disorder 7 screener)⁴⁸ assesses psychosocial needs, pro-

Table 2. Roles within the NCH Pediatric IBD Medical Home.

Roles	Primary NCH Team Member	Potential Secondary Team Members
Provision of IBD medical care	Gastroenterologist	IBD NP
Care coordination within multidisciplinary setting		Nurse coordinator
Provision and coordination of transition care	IBD NP	Gastroenterologist Nurse coordinator Social worker Psychologist
Behavioral health screenings (anxiety, depression, quality of life)	Psychologist	Social worker
Behavioral health counseling		Gastroenterologist
Referral to ongoing behavioral health services		IBD NP
School and work accommodations	Social worker	Psychologist
Enrollment in supplemental insurance/cost savings programs/Copay assistance		Nurse coordinator IBD NP
Nutritional assessment/screening	Dietitian	Gastroenterologist
Development of personalized nutrition plan		IBD NP
Navigation of prior authorizations, medical insurance	Clinical pharmacist	Biologic navigator Administrative assistant Nurse coordinator
Data tracking and monitoring	QI/Data specialist	Gastroenterologist IBD NP
Provision of IBD education	Nurse coordinator	Gastroenterologist IBD NP Psychologist Social worker Dietitian
Support peers	Parent/patient advisors	N/A
Provide feedback on IBD center projects		
Co-produce resources/education		
Administrative tasks	Administrative staff	Nurse coordinator
Scheduling visits/tests		

IBD NP—IBD Nurse practitioner; QI—quality improvement; N/A—not applicable

vides interventions as needed, and coordinates appropriate follow-up. Specific treatment plans vary according to patient needs. Some patients see the GI psychologist in concert with the physician during routine clinic visits, reducing redundancy, streamlining assessment and intervention, and allowing for real-time access to needed services. Others have ongoing counseling sessions with the GI psychologist at times outside routine GI visits. For patients who already have an established behavioral health provider, GI psychologists offer to consult with them and provide IBD-specific suggestions to enrich the existing therapeutic relationship, and for those who are interested, GI psychologists assist patients in finding a local behavioral health provider in their community. The early and ongoing integration of GI psychology into routine IBD care reinforces the role of multidisciplinary care for patients and families, normalizes this support service as an expected part of care, and allows psychosocial challenges to be identified and addressed in a more holistic manner.

Navigating school, work, and insurance—GI social work

Inflammatory bowel disease care can be burdensome, time-consuming, expensive—and can significantly impact life for both patients and their families. Children with IBD are at increased risk for missing school due to symptoms and medical appointments, especially amongst patients with active disease.^{34,39} In addition to the direct costs of medical therapies, the appointments, testing, procedures, hospital admissions, and providing care for a child with IBD may also lead to missed work and lost revenue for parents or other family members.⁹ Communicating with schools or employers and completing the required formal documentation can be frustrating and challenging. Overcoming this challenge requires a planned mechanism to reduce family and medical team burden.

In our pediatric SMH, dedicated GI social workers assist families with these challenges by providing education and facilitating the establishment of school (ie, 504 plan) and work accommodations (ie, Family Medical Leave Act) and addressing insurance and financial needs. Our social workers also confirm enrollment in any available and applicable supplemental insurance or cost-savings programs relevant to their child's treatment. Cost-savings programs include copay assistance programs for certain medications, including biologic therapies, or state-specific supplementary insurance that may exist for children with chronic medical illnesses through Children with Medical Handicaps.

In addition to supporting families with school, work, and insurance needs, social workers are also available to provide support with psychosocial concerns. This could include potential barriers to care, such as transportation needs, or other psychosocial barriers that can interfere with patient health outcomes, such as homelessness, income instability, food insecurity, or concerns with family dynamics. Social workers are also available to help evaluate and provide support when there are concerns for medical noncompliance.

Similar to the relationship with GI psychology described previously, the NCH team model proactively connects families with social workers at diagnosis during their New Diagnosis IBD Teaching Visit. Creating this connection reinforces and normalizes our multidisciplinary care model while reducing

school and other financial barriers that may cause additional stress for the family and patient.

Optimizing nutritional needs—GI dietitians

Children and adolescents with IBD are at increased risk for malnutrition and other nutritional deficiencies during critical periods of growth and development,⁴⁹ highlighting the need for trained dietitians as part of the multidisciplinary team.

Within our pediatric IBD SMH, all patients and families are connected with specialized GI dietitians at diagnosis for an initial assessment and development of a personalized nutrition plan. This plan includes guidance on healthy diet content and goals, as well as recommendations regarding vitamin and mineral supplementation if needed. Furthermore, families receive targeted education pertaining to dietary treatments for IBD such as exclusive enteral nutrition or the Crohn's Disease Exclusion Diet or Specific Carbohydrate Diet. Planned evaluations occur at the New Diagnosis IBD Teaching Visit and IBD annual visits and can also be completed as needed during each follow-up visit.

Supporting and inspiring peers—parent and patient engagement

As implied by its name, the PCMH must have the patient and family at its core, informing care, quality improvement, education, and clinical efforts. In day-to-day clinical practice, we use an electronic medical record (EMR)-based patient portal to communicate quickly and effectively with patients and their families. Currently, nearly 100% of our patients have active patient portal accounts that include parent accounts for children younger than 13 years of age and a combination of patient and parent proxy accounts for those 13 years and older.

Our clinical team is also supported by a group of IBD parent volunteers who serve multiple roles in the IBD center. Some parents serve in the peer mentorship program at Nationwide Children's Hospital called Connecting Families. This program pairs caregivers of patients with IBD with vetted, trained parent volunteers to provide resources and support both at diagnosis and as needed throughout (<https://www.nationwidechildrens.org/family-resources-education/patient-and-family-centered-care/connecting-families>).⁵⁰ Parent mentors also serve as our Parent Advisory Committee, joining IBD QI meetings on a bimonthly basis, assisting in identifying deficiencies, and informing programming decisions made within the SMH.

Patients also engage in our IBD center locally as peer mentors in an ongoing funded research study, as well as nationally and internationally through the ICN network. Our patients have participated in the ICN Patient Advocacy Council, written blog posts about their IBD experiences, and coproduced informative materials for other patients and families.⁵¹

We have a strong partnership with our adult IBD colleagues at The Ohio State University Wexner Medical Center, with whom we collaborate on clinical care and patient/family outreach and education, including an annual IBD Education Day. This provides a venue not only for education but also for networking amongst patients, families, and community supports.

Addressing treatment challenges—clinical pharmacy

Inflammatory bowel disease care has become increasingly complex and subspecialized, with growing therapeutic op-

tions including multiple biologic therapies.⁵² Optimized IBD treatment requires much more than just selecting the most appropriate medication. First, there are a limited number of biologic medications with FDA-approved pediatric indications, resulting in frequent off-label usage. Children also often require dose escalations outside of FDA-approved dosing ranges due to differences in disease severity and differences in drug pharmacodynamics and pharmacokinetics.⁵³ As a result, successful insurance authorizations can be difficult to obtain, given the ongoing need for prior approval or appeals to prove medical necessity to the payors—a process that is challenging and time-consuming for members of the clinical team.^{54,55} Because the team is faced with these challenges, adding a clinical pharmacist as a member of our IBD team has allowed more seamless therapy selection, navigation of insurance, dose optimization, data tracking, and improvements that have simplified our processes and reduced unnecessary delays in access to therapy.

One example of our strong partnership with the clinical pharmacist was the development of a standardized workflow for all biologic medication new starts and dose adjustments. When a provider decides to initiate a patient on a biologic medication or adjust drug dose or interval, a brief templated note is placed in the electronic medical record to allow systematic communication of clinical information necessary for all prior authorizations such as indication for the therapy, prior therapies attempted, and dates of tuberculosis screening. Given that these decisions are often made outside of a routine clinical encounter and that routine documentation often contains additional data superfluous to the needs of the prior authorization team, this focused note allows streamlined communication and prevents staff from having to search for and extract information from multiple places in the EMR. These notes are then routed to the prior authorization team, composed of administrative assistants with insurance expertise, pharmacy technicians, the clinical pharmacist, and the patient's nurse. In the case that a medication type, dosing, or laboratory request is denied by a patient's insurance company, the clinical pharmacist has developed templated letters of medical necessity for common denials that include the supportive literature that can be personalized to the patient situation and then routed back to the provider for review and signature. This workflow has resulted in a more streamlined and efficient process for biologic approvals and has avoided patient care delays, as evidenced by an increase in the proportion of patients receiving subcutaneous biologic therapy within 15 days of treatment decision from 33% to 70%.⁵⁶ More recent work from our center regarding QI work to increase biosimilar initiation and reduce costs further highlights the essential role of clinical pharmacy on a multidisciplinary team.⁵⁷

Tracking progress—data specialist

At our center, all patients diagnosed with IBD are consented and entered into an active patient registry that captures uniform demographic and clinical data at every encounter, including disease phenotype, clinical activity, anthropometric data, therapies, vaccination status, relevant laboratory tests (eg, iron studies, vitamin D, calprotectin, therapeutic drug monitoring), endoscopic evaluations, adherence and psychosocial concerns, IBD-related complications (hospitalizations, surgeries), and frequency of follow-up appointments. A dedi-

cated data specialist enters data and maintains the integrity of the database, allowing our team to accurately track our patient population—a tenet of the PMCH emphasized by Regueiro and colleagues.⁴ Using this standardized data, we are able to create unique patient lists, stratify by variables of interest, efficiently complete QI projects, and measure clinical outcomes against set goals, many of which align with goals set by ICN.

Mobilizing the Team from Diagnosis Through Transition—Standardized Care Pathways and Multidisciplinary Visits

Care pathways

Our center uses standardized care pathways in the *outpatient* setting from the time of diagnosis through transfer to adult care in order to reduce variability and improve clinical outcomes.⁵⁸ Care pathways for patients newly diagnosed with CD and UC serve as educational tools to outline treatment options and potential side effects based on disease severity and extent, standardize care, and communicate with families coping with a new diagnosis. Developed with input from our Parent Advisory Committee, the pathways provide a timeline of what to expect for the first 12 months after diagnosis and beyond and guide families toward reliable educational resources for patients and families. Figure 1 summarizes a typical patient's journey through our SMH from diagnosis through transfer in care and demonstrates touch points with the multidisciplinary team throughout.

We have also developed care pathways in combination with the IBD surgical team to optimize care for common *inpatient* clinical scenarios. Evidence-based treatment pathways for acute severe colitis and intra-abdominal abscesses aim to standardize care by reducing prolonged steroid exposure, preparing for timely initiation of anti-TNF therapy, and involving the surgical team early.^{59,60} For children admitted with severe anemia and iron deficiency, a treatment pathway has been developed in collaboration with hematologist and dietitians to ensure appropriate screening, therapy, and subsequent referral and follow-up with hematology when applicable.

Our internally derived care pathways allow us to incorporate evidence-based recommendations from existing care guidelines with center-specific logistics of care delivery. This integration, easily modifiable by other pediatric IBD centers, aims to ensure a high standard of care for all patients and families across providers.

New diagnosis IBD teaching visit

Within 6 weeks of diagnosis, patients and families are scheduled for a multidisciplinary IBD Teaching Visit, an inclusive meeting designed to introduce all members of the IBD team and emphasize each member's role. The IBD nurse coordinators provide comprehensive education about IBD, including pathophysiology, treatment options, and expectations for ongoing communication and monitoring. They review the content of educational videos addressing IBD diagnosis, management, growth, nutrition, and transition, which were created by our center with the assistance of IBD patients and parents (<https://www.nationwidechildrens.org/specialties/inflammatory-bowel-disease-clinic/ibd-resources-for-families>). Families are also guided through the process of signing up for our EMR-based online patient portal. After

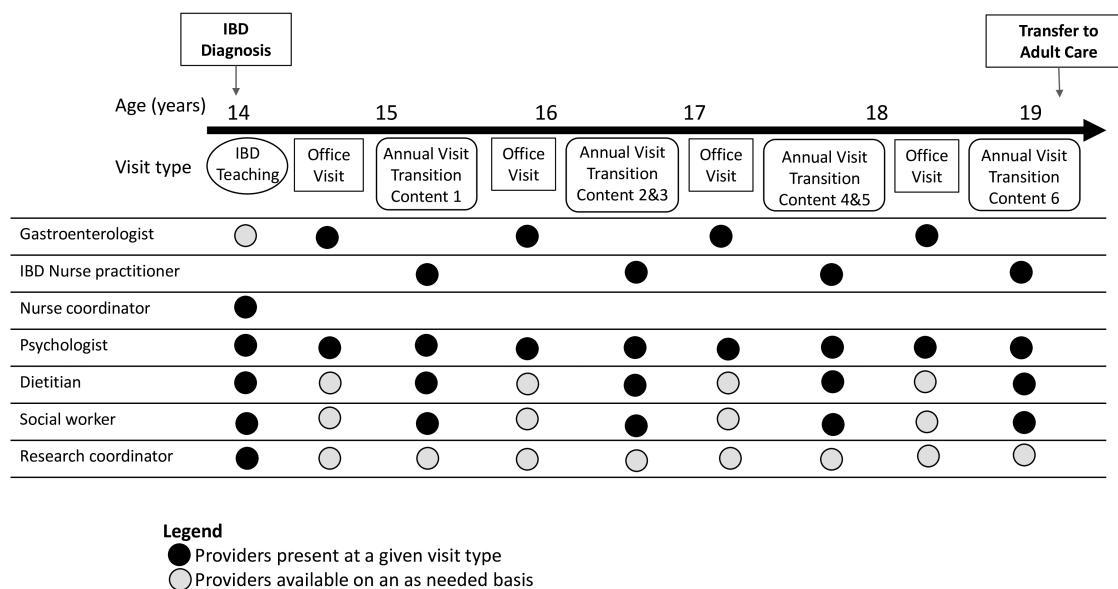


Figure 1. Example timeline of a patient journey through the Nationwide Children’s Hospital IBD Medical Home. IBD teaching day occurs within 6 weeks of diagnosis. Routine office visits with the gastroenterologist and psychologist occur at routine intervals thereafter. Multidisciplinary IBD Annual Visits take the place of a routine follow-up visit and are the venue in which our 6 module transition program is delivered.

the visit, families are offered the opportunity to be paired with an IBD parent mentor through the Connecting Families program, as mentioned previously. Initial assessments by GI psychology, social work, and dietitians occur at this visit, as well, and the visit is concluded by a quick conversation with a research coordinator to complete enrollment in our ICN IBD registry.

IBD annual visits

As a patient progresses through their IBD journey, team members are available for consultation at routine clinic visits. Starting 1 year after diagnosis, patients are scheduled for a multidisciplinary IBD Annual Visit that continues once a year until eventual transfer to adult care. The IBD annual visit is led by the IBD nurse practitioner, who completes a standard clinical visit, orders appropriate tests, and adjusts therapies as needed, in communication with a child’s primary GI provider. The patient then has the opportunity to formally reengage with the psychologist, social worker, and dietitian; the psychologist repeats formal screening assessments for anxiety, depression, and quality of life; the social worker confirms adequate insurance coverage and updates documentation for school, work, and financial accommodations; and the dietitian completes a nutritional assessment and provides individualized recommendations. Routine multidisciplinary visits allow team members to address challenges in their respective fields of expertise and provide consistent, whole-person care.

Preparing patients and families for transition to adult care— young adult IBD transition program

Young adults with IBD must obtain the knowledge and skills to care for themselves independently as they transition from pediatric to adult care.⁶¹ The period of transition and transfer is a high-risk time, with increased reports of poor adherence, loss to follow-up, and increased unplanned health care utilization.⁶¹⁻⁷¹ Young adults with IBD also have increased struggles in the transition to college compared with healthy adolescents, which may impact academic success and quality of life.^{72,73}

Starting at age 12, our Young Adult IBD Transition Program is delivered during IBD annual visits, with each team member addressing different complementary pieces of the transition process. The Transition Program content is divided into 6 modules, delivered over the course of 6 annual visits. For patients diagnosed closer to the time of transfer to adult care, content is condensed as needed. Adolescents are provided with developmentally appropriate knowledge and self-management skills to support successful transfer to adult care, and content is reinforced with discussion questions and correlating resources.

Communication within the medical home

Multidisciplinary care requires excellent communication between providers to ensure complete care delivery without redundancy. Our team uses several methods to accomplish this within the SMH. First, the establishment of specific roles has been essential (Table 2). Regular team meetings to discuss care delivery processes, identify barriers, and reassign roles as needed have allowed processes to evolve with changes in team composition and the needs of patients and families. Although unplanned, the integration of telemedicine into IBD care due to the COVID-19 pandemic has been extremely successful in improving multidisciplinary communication and care coordination, as multiple team members are present simultaneously in a given encounter.⁷⁴ Finally, the content of all multidisciplinary visits is documented in the EMR, and any items requiring follow-up or further intervention is specifically communicated back to the patient’s primary gastroenterologist via telephone or EMR. An additional area for improvement in our SMH is assessing and improving communication with a patient’s primary care provider (PCP). At present, all clinical notes are sent via fax or EMR to the patient’s PCP, relaying information regarding health maintenance, vaccinations either delivered through GI or requested to be delivered with PCP (eg, our center does not currently have the ability to administer all routine childhood vaccinations or other vaccinations specific to immunocompromised patients). In the adult IBD SMH model, all primary care tasks

are effectively assumed by the gastroenterology team. Given the unique developmental needs of pediatric and adolescent IBD patients, this relationship has not yet been established.

Using Data to Drive Change—Tracking and Monitoring

Essential components of the PCMH highlighted by Regueiro et al include standardized data tracking in order to measure progress toward prespecified goals and guide future interventions. Nationwide Children's Hospital participates in the ICN Network, a multicenter collaborative of pediatric gastroenterology groups that share performance data collected in patient registries and utilize QI methods to optimize care.^{20,21}

Monthly reports, pre-visit planning, and population management

Division-level and individualized benchmarked data are sent to all providers each month in the form of IBD center monthly reports. Current metrics focus upon maintaining clinical remission rates greater than 85%, rates of corticosteroid use less than 5%, and the proportion of patients with a documented GI visit in the past 6 months greater than 80%. Using standardized data, we set quarterly and annual IBD center goals. Review of these data allows practitioners to evaluate their performance and apply targeted interventions such as starting steroid-sparing therapies or arranging follow-up visits as needed.

Our approach to pre-visit planning (PVP) within the NCH IBD SMH is also standardized. Prior to every IBD visit, practitioners are provided with a checklist of patient-specific recommendations for evaluation, monitoring, and health maintenance activities. Reminders for routine monitoring of vitamin D, iron, and stool calprotectin or appropriately timed therapeutic drug monitoring or tuberculosis screening for patients on biologic medications are communicated. Considerations for specific clinical conditions including repeat endoscopic evaluation for mucosal healing following medical or surgical therapy or health maintenance reminders, such as referral for an IBD annual visit, are also included on checklists.

In addition to monthly reports and PVP, the multidisciplinary team engages in weekly population management meetings. These meetings serve as a venue for review and discussion of specific cohorts of IBD patients such as complex outpatients or those currently or recently admitted to the hospital. The meetings also serve as multidisciplinary forum for group consultation on complex patients or second opinions. Active quality improvement projects are also reviewed, with recent examples including efforts to expand use of exclusive enteral nutrition,⁷⁵ standardize our approach to external infusions,⁷⁶ and therapeutic drug monitoring,⁷⁷ ensure completion of repeat hepatitis B vaccination in nonimmune patients, and optimize screening for and treatment of iron deficiency anemia. The existence of an active patient registry and inclusion of our dedicated data analyst are essential to optimal use of monthly data reports, PVP, population management, and specific QI efforts.

Supporting the IBD Medical Home—Time and Talent

Although most providers involved in the care of patients with IBD likely agree that multidisciplinary care is ideal, significant barriers exist to securing the time and financial support for

such a venture. As discussed in publications by Regueiro et al regarding the adult IBD medical home, an essential component to their model was a proactive partnership with payors in a shared-savings model, in which front-end investment in interventions to support the health of the highest utilizing patients will, over time, decrease costs by improving health.^{4,14,15} Although Nationwide Children's Hospital partners with a pediatric accountable care organization called Partners For Kids, which provides care for over 400,000 children with Medicaid Managed Care in south central and southeast Ohio, this relationship has not been specifically harnessed to optimize pediatric IBD care. The current NCH IBD SMH model differs in that in lieu of a provider-payor partnership, our efforts are bolstered by institution-level support for multidisciplinary patient- and family-centered care. Some team members bill individually for services (eg, pediatric gastroenterology, psychology, clinical nutrition), but others' salaries are supported by individual departments (eg, social work, clinical pharmacy). A strategic message focusing on health equity, population health, and expanding behavioral and mental health care have allowed multiple departments to collaborate on building this medical home.

In scenarios where acquiring all members of the multidisciplinary team is not feasible, we encourage centers to partner with leadership and identify pieces of the IBD medical home that align with their institution's strategic plan. [Table 2](#) also provides suggestions for ways to utilize the strengths of existing team members and diverse member roles to address patient and family needs. Although all team members are important, in our opinion and experience, prioritization of registered dietitians and psychosocial care providers (psychology and/or social work) and integration of clinical pharmacy have been some of the most impactful on delivery of whole-person care and efficiency of treatment delivery.

The Future of the Pediatric IBD Medical Home

Caring for pediatric and adolescent patients with IBD is increasingly complex and costly, calling for comprehensive care delivery models to address medical, psychosocial, and family needs. In adult IBD care, several SMHs have demonstrated improvements in disease activity, anxiety and depression, quality of life, and unplanned care. In this article, we share the components of the multidisciplinary care model at the Center for Pediatric and Adolescent IBD at Nationwide Children's Hospital as an example of a pediatric SMH and highlight the similarities to a successful adult IBD SMH.

Building a complete multidisciplinary team is essential to delivering high-quality care. In addition to physician and nurse experts in IBD, the early and consistent incorporation of GI psychologists, social workers, dietitians, and clinical pharmacists should be prioritized. The development of clinical pathways to standardize care, collaborating with relevant subspecialties, patients, and families, is also required to ensure uniform yet personalized care for all patients, independent of the primary GI provider. Finally, routine data tracking and benchmarking, supported by a dedicated data specialist to ensure data quality and integrity, is necessary to apply quality improvement methodology to accomplish the center's goals.

Though we have seen the benefits of a multidisciplinary specialty medical home for patients, families, and providers, well-designed, prospective studies with a standard-of-care control

group that assess both disease-related and psychosocial outcomes for patients in IBD SMH programs are needed. We need to understand which components of the PCMH are most effective in pediatric IBD care and which patients would most likely benefit from the model; we can then tailor programs to address the unique needs of individual patients and families. At our center, we have been fortunate to have the availability and expertise of ancillary providers like psychologists, social workers, dietitians, and pharmacists who have all been essential in delivering high-quality care. We understand that these resources are not available to all centers but should be considered as one works to develop an IBD SMH. Future work should assess the availability of the multidisciplinary team at pediatric IBD centers across the United States.

We need to understand the impact of the IBD SMH on health care utilization and cost and then determine ways to deliver comprehensive care in multiple different payment models and resource settings. Much of the literature related to the SMH in adult IBD care focuses on relationships with payors, improved care value, and decreased total costs. Such data are nonexistent in the pediatric sphere and are desperately needed.

Finally, as we build and evolve care delivery systems, it is essential that these models are more than “patient-centered” by name alone but truly possess the qualities that invite patients and parents to meaningfully engage and contribute.⁷⁸ A recent publication highlights the role pediatric patients with IBD should have to contribute effectively through development of patient-led educational resources.⁷⁹ Only by collaborating with families throughout the planning, development, dissemination, and assessment processes will we harness the power of their experiences and coproduce health care delivery models that optimally address their needs.⁸⁰

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Conflicts of Interest

The authors have no relevant financial disclosures or conflicts of interest to acknowledge.

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