

Patient-Clinician Collaboration in the Development of an IBD Transfer Toolkit

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There is a high level of variability in inflammatory bowel disease (IBD) transition programming, practices, and policies around the country.¹ ImproveCareNow (ICN) is a learning health network devoted to improving outcomes in pediatric IBD through collaborative quality improvement.^{2,3} Among the 109 ICN centers in the United States, Europe, and the Middle East, there has been wide variation in the availability of patient resources for transition and transfer. In addition, although some ICN centers use educational materials to guide patients to become more independent and engaged in their health care (ie, transition), few are available for young people and adults getting ready to transfer into adult care. As a pediatric network dedicated to improving care quality and outcomes for children with IBD, this disparity limits our ability to successfully launch young people and adults into appropriate adult care.

As an adolescent diagnosed with IBD at age 14 (S.T.K.), I received what my family considered to be excellent guidance in anticipating the eventual transfer of my care from pediatric to adult gastroenterology. My pediatric gastroenterologist encouraged me to voice my needs, understand the basic details of my care, and be engaged in interactions with my hospital, pharmacy, and insurance company.

After transfer, however, I found that my adult care unexpectedly relied far more than my pediatric care on my voice to proactively raise and follow-up on my

health concerns. Although I had been led to expect some shift in responsibility, the differences in communication style and practices between my pediatric and adult providers surprised and discouraged me. It was not until years later, when I assumed coleadership of the Patient Advisory Council (PAC) of ICN, a platform for adolescents and young adults with IBD to actively participate in and lead national care improvement, that I realized I was not alone in feeling lost. Many young people and adults like myself feel overwhelmed, uncertain, confused, and reluctant about the process of transferring into adult care.

Here, we describe our collaborative effort, as a patient-clinician team, to develop a patient-centered resource (eg, the IBD Transfer Toolkit) for young people and adults with IBD that provides anticipatory guidance and education pertinent to transfer of care with an intent to promote self-advocacy.

PROJECT SETTING

Within ICN, the Transition Task Force was created in 2014 to identify, test, and measure the impact of quality-improvement tools and strategies related to improving the processes of transition and transfer within the ICN pediatric gastrointestinal centers.* This task force has been led by a pediatric

* Additional Transition Force Members include Sandra Kim, MD; Jeanne Tung, MD; Marc Schaefer, MD; Marc Tsou, MD; Howard Baron, MD; Diane Eskra; and Theresa Todd, MPH, MA.

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Ms Kennedy and Dr Maddux conceptualized and designed the study, designed the data collection instruments, collected data, drafted the initial manuscript, and reviewed and revised the manuscript; and both authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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gastroenterologist and a pediatric psychologist (M.H.M.) with expertise in pediatric IBD and is composed of 1 patient with IBD, who is a member of the ICN PAC (S.T.K.); 4 additional pediatric gastroenterologists; 1 ICN quality-improvement coordinator; and a research coordinator.

This project evolved from the shared experiences of PAC members, namely our desire to have a resource that compiles transfer-related information deemed essential by patients. Recognizing the need and importance of transfer planning among young people and adults with IBD, we, as a patient (S.T.K.) and a clinician (M.H.M.), partnered with the PAC to develop the Transfer Toolkit.

IDENTIFICATION OF TOPICS RELEVANT TO CARE TRANSFER

We identified content for the Transfer Toolkit from a literature search on best practice clinical guidelines for transfer planning and key patient competencies for successful transfer of care. In addition, 5 PAC members then provided free-form narratives on their transfer experiences to inform content selection, and a total of 15 PAC members provided feedback on what gaps they perceived in their current or past readiness for transfer (Table 1). Lastly, 3 posttransfer PAC members joined the Transition Task Force conference calls to advocate for

the need for a comprehensive transfer resource as well as to ask for centers to share the resources they used in their practice around transition and transfer. One PAC member reflected on her involvement as follows: “Contributing to the Transfer Toolkit was simultaneously humbling and empowering and made me recognize my privilege in working alongside others with IBD, to be listened to and respected by medical providers, and to help shape the tools and resources for pediatric patients with IBD. It’s yet another compelling example of why the patient voice is integral to the future of care.” Another PAC contributor stated while helping to develop the toolkit, “ICN empowers patients like me to make a difference in the IBD community through important contributions. As a result, the future of IBD care is more equitable, compassionate, and informed.”

PRELIMINARY TOOLKIT EVALUATION BY KEY STAKEHOLDERS

Once initial content was compiled, the toolkit was again reviewed by patients in the PAC as well as pediatric gastroenterologists who provide specialty care in pediatric IBD. The toolkit was also reviewed by the ICN Clinical Practice Committee, which is composed of 11 pediatric gastroenterologists focused on providing recommendations for model

clinical care. Review was provided on content, organization, visual aesthetics, readability, and comprehensiveness. After an additional round of revisions, S.T.K. and M.H.M. developed a short, anonymous survey in SurveyMonkey (www.surveymonkey.com) to elicit final review from the PAC and pediatric gastroenterologists in ICN on the toolkit’s clinical utility. The survey was sent to each PAC member ($n = 54$) and the physician lead(s) at each ICN center ($n = 111$) via an e-mail that included a hyperlink to the survey along with a PDF of the Transfer Toolkit.

FINAL PRODUCT

It took ~1 year to develop a final draft of the Transition Toolkit. In total, the PAC lead (S.T.K.) devoted ~4 to 6 hours of her time per month between design, analysis, conference calls, and e-mail communication with other PAC members and individual ICN centers. Our work resulted in a 10-page, color toolkit with 6 sections. These include Skills To Gain Before You Go, Considerations When Choosing a New IBD Center, Self-Advocacy, Understanding Insurance, Understanding Your Care, and Transfer Resources To Try (Table 2). The toolkit is written for an audience of 16- to 22-year-olds to account for national variation in age of transfer,

TABLE 1 Perceived Gaps in Transfer Readiness Identified by PAC Members ($n = 15$)

Label ^a	Identified Gap
A	“Advice on how to find a new doctor (pediatric doctor referral, searching online, etc)”
B	“Asking about and/or finding a dietitian, social work, other multidisciplinary services, etc”
C	“Steps to [prepare] for first adult appointment and/or checklist”
D	“Information that the doctor may ask you about”
E	“Sample scripts for talking with a doctor (eg, for difficult questions, when disagreeing, when wanting more [information])”
F	“Sample ways of [getting involved with care]: calling the pharmacy, writing down doctor’s appointment”
G	“Changes to expect (colonoscopy every year versus when in a flare, more bloodwork, etc)”
H	“Insurance transition information”
I	“Letting patients know that it is their responsibility to bring up issues with their adult GI; you need to be a self-advocate!”
J	“Patient stories: what went well, what hasn’t gone so well, struggles with transfer”
K	“Specific resources in our local community: hospitals, doctors, infusion centers, pharmacies”
L	“A list of all the [medications] I’ve been on and why they were used and/or changed . . . [and my] location of disease”
M	“List of questions to ask new adult doctor (with suggestions!)”

GI, gastroenterologist.

^a Label is intended to be used for reference in Table 2.

TABLE 2 Content Breakdown of Transfer Toolkit

Section Title	Patient-Identified Gaps Addressed (Table 1)	Content Overview	Excerpt Patient Narrative
Skills To Gain Before You Go	C, D, J, L	Skills and knowledge basics to consider organized into 3 sections: "Do I Know...?" "Do I Understand...?" and "Am I Able To...?"	"It was a little scary at first, but the more and more I went to visits on my own, the more prepared I felt to be seen by an adult provider. Over time you become a pro."
Considerations When Choosing a New IBD Center	A, B, C, J, M	Questions to consider when evaluating a possible new care center organized into 4 categories: "Will this team meet my needs?" "How can I communicate with my IBD team?" "Will the care I receive be convenient for me?" and "Will I receive the right care for me?"	"I chose a female GI to be my doctor, as I had only had my male pediatric GI and was unsure of how I would feel with a male provider as I continued to go through puberty."
Self-Advocacy	C, E, F, I, J, M	Specific guidance to encourage young adults to organize their concerns before and at appointments, ask questions, and practice essential skills	"If you don't seem to be clicking with your doctor, it is 100% valid to switch. . . . A good doc will encourage outside opinions."
Understanding Insurance	C, F, H, J	Short primer on some of the most commonly used health insurance terminology in the United States and their definitions as well as Medicaid-specific guidance	"Since I'm on my parents' insurance, I comanage my insurance with my mom. I pay my bills and communicate with my care team and the pharmacy. Meanwhile, she helps me navigate our health plan and any appeals we need to make."
Understanding Your Care	D, G, J, L	Basic standards of care to be aware of and ask about after transferring care to a new practice organized into 4 categories: "other specialists you should visit," "basic screening tests to be proactive about," "things to avoid," and "ask your IBD team about these"	"I keep a file where I list my current medication doses, a brief medical history, my questions, and a social history (which I always keep at the top of the page so the reader has to learn about who I am beyond my disease!). This structure helps me interact with my doctor and record her answers so I can later communicate that information to my family and other doctors."
Transfer Resources To Try	C, J	List of additional Web- and mobile-based transfer resources recommended by pediatric gastroenterologists and PAC members with short descriptions of their possible utility	"I would recommend using an electronic or paper journal to track your symptoms and/or nutrition. This information is invaluable for reference when at the doctor."
Notes and questions	L, M	Blank page for young people and adults to write notes and questions	n/a

GI, gastroenterologist; n/a, not applicable.

which typically occurs at age 18 or 21.² At the unanimous suggestion of patients, selections of the previously collected patient narratives with a photograph of the respective patient relevant to each section were embedded throughout the toolkit. A total of 7 PAC members as well as 26 pediatric gastroenterologists completed the final review survey.

PAC Members

On a scale of 1 (very unprepared) to 10 (very prepared), the mean level of

preparedness to transfer before reading the Transfer Toolkit was 5 ± 2.6 . The mean level of preparedness to transfer after reading the Transfer Toolkit was 8.9 ± 1.2 . Of PAC members, 100% endorsed that they would recommend the Transfer Toolkit to another patient. Free-text comments to a question on how the Transfer Toolkit might be useful to patients included, "It's a great tool to read through as one prepares for transition. It includes topics they may not have thought of on their own," and "It identifies behavioral

benchmarks for pediatric patients to reach the skills needed to transition."

Gastroenterologists

The majority of gastroenterologists endorsed that each toolkit section was important: Skills To Gain Before You Go (96%), Consideration When Choosing a New IBD Center (84.6%), Self-Advocacy (92.3%), Understanding Insurance (77.8%), Standards of Care (74.1%), Transfer Resources To Try (88.9%), and Patient Narratives (85.2%). Additional comments offered via

free text included, “The toolkit is thoughtfully done and comprehensive. If kids will read through it, they will find that we are actively trying to address many of these issues at our care center and be more engaged in our efforts to accomplish a smooth transfer,” and “Inclusion of patient comments brings a personal nature to the toolkit and may help connect to young individuals.”

RELEASE

Since October 2018, we have shared the Transfer Toolkit across ICN centers. We have uploaded a copy of the toolkit to the ICN Exchange, an online learning platform that enables sharing of and socializing regarding tools and information across ICN centers focused on improving the care of youth with IBD. It is also available for public download (https://assets.nationbuilder.com/improvecarenow/pages/268/attachments/original/1552681131/The_Transfer_Toolkit_v3.pdf?1552681131). We have maintained communication with 31 care centers (28% of the ICN network) to identify ways the toolkit is being used in clinical practice. Of these 31 centers, 11 (35%) have reported sharing the toolkit with at least 1 patient. Additionally, the public Web link has been accessed 238 times since March 2019, and there have been 114 downloads of the Transfer Toolkit. Most centers presently using the toolkit are sharing it with patients in print format. One has shared it in digital form through a patient and/or family e-mail list, and it could be shared in clinics on tablets. There has also been care center variation in the provider championing the toolkit, when it is shared, and whether it is introduced in its entirety or in parts. Primary reasons given for not using the toolkit have included understaffing, competing clinical demands, and the desire to first build a larger transition framework.

FUTURE DIRECTIONS AND NEXT STEPS

The ICN network brings patients and pediatric gastroenterologists together seamlessly to improve the lives of young patients with IBD. This allowed us to tap directly into the unique insight of patients and gastroenterologists across a large geographic area and develop a tool in direct response to the needs of patients. Our hope is that the Transfer Toolkit will become a go-to resource for young people and adults transferring into adult care. We anticipate that the Transfer Toolkit could be used in other pediatric patient populations in which effective self-management and transfer to adult care would be anticipated to improve outcomes.

In isolation, the Transfer Toolkit may not result in substantial change in the transfer success of patients with IBD moving to adult care. Rather, we encourage the toolkit to be considered as 1 piece of a multidimensional care process. In the future, we plan to evaluate the toolkit’s impact on patient health and psychosocial outcomes. We are specifically interested in evaluating changes in patient self-efficacy, self-advocacy, and perceived readiness to transfer as well as successful initiation and maintenance of adult care. The feasibility of implementing the toolkit in clinical practice across ICN centers with varying levels of transfer programming will also be evaluated from the perspective of patients as well as clinicians.

Some limitations of this project must be considered. The sample size across both patients with IBD and pediatric gastroenterologists was small; however, saturation was obtained within the sample of respondents, which suggests that feedback obtained from additional respondents would likely produce little to no change to the current toolkit. Because ICN is a pediatric network, no adult gastroenterologists were involved in

the creation of the toolkit; however, several pediatric gastroenterologists shared the toolkit with their adult gastroenterology colleagues and received positive reviews. In the future, we do plan to solicit input and feedback from adult gastroenterologists. The generalizability of the Transfer Toolkit is also limited by language because it is currently only available in English. Given interest from European ICN centers, we intend to initiate future collaborative efforts to translate the toolkit into different languages. This process will additionally address international insurance recommendations.

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ABBREVIATIONS

IBD: inflammatory bowel disease
ICN: ImproveCareNow
PAC: Patient Advisory Council

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