

# “A Guide to Gutsy Living”: Patient-Driven Development of a Pediatric Ostomy Toolkit

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As patients (J.G.D. and A.J.) who have lived with pediatric-onset inflammatory bowel disease (IBD) since 12 and 9 years of age, respectively, and who underwent ostomy surgery at 19 and 15 years of age, respectively, we experienced a lack of psychosocial education about our surgeries. This negatively impacted our ability to adjust postoperatively to having an ostomy. For example, we had to learn how to explain our ostomies to friends and how having an ostomy might impact our clothing choices. The education we received about our ostomy surgery was brief and focused only on basic skills regarding caring for an ostomy, including changing and emptying the bag, but did not address concerns we had about living with ostomies as part of our everyday lives. This educational void placed the burden on us as patients to find resources on our own, decide if the information was appropriate, and determine if it was reliable and accurate.

In this article, we describe how we, as patients, harnessed the capacity of a collaborative chronic care network<sup>1</sup> and were supported to develop a resource that patients needed.

## METHODS

### Setting

The ImproveCareNow (ICN) Network is dedicated to improving the health and health care of children and adolescents with IBD. Formed in 2007,

the network is presently composed of 107 pediatric IBD centers in the United States, Europe, and the Middle East.<sup>2,3</sup> One of ICN's central values is coproduction, in which participants (patients, families, clinicians, and researchers) work together to plan, develop, and create health care services.<sup>4</sup> Coproduction is of growing interest in the medical field, in which there is an explicit need for medical professionals to work with patients to create more effective services. In ICN, patients, clinicians, and researchers collaborate to coproduce health care services, systems improvement, and research.

The ICN Patient Advisory Council (PAC) is a national council for patients with IBD who are patient advocates and contribute to the continuous evolution and improvement of ICN by serving as leaders across the full range of ICN's activities. PAC members work to identify needs of the patient community and help patients self-organize to develop interventions, tools, and resources to improve care and outcomes of patients cared for across the network. At the time this project was conducted, the PAC was composed of 2 cochairs (J.G.D. was 1 cochair), 2 patient scholars (ie, vice chairs) (A.J. was 1 patient scholar), and 11 general members and was supported by 1 ICN staff member.

### Planning the Intervention

Our project evolved from the ongoing work of the PAC within the network. After noting a shared need in our

Ms David conceptualized and led the coproduction of the resource described in the manuscript, designed the survey tool, conducted relevant analyses, and drafted the initial manuscript; Mr Jofriet co-lead the development of the resource described in the manuscript and reviewed and revised the manuscript; Drs Seid and Margolis assisted with relevant analyses and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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own experiences living with IBD and ostomies, we, as members of the PAC, made ourselves available as mentors to clinical teams within ICN that were interested in having pediatric patients with IBD available to their patients who were facing ostomy surgery. After serving as peer mentors, we quickly realized our capacity to provide individual mentorship would be insufficient for the demand given the limited number of PAC members with ostomies and the time involved to repeatedly provide virtually identical ostomy mentorship to each individual patient. We hypothesized that a printed resource could serve as continuing education and support in lieu of a 1-time verbal mentorship session and better serve the network's patients, parents, and clinicians. For these reasons, we identified the pediatric ostomy toolkit as a high-priority project for our PAC to develop.

We started a national task force of interested patients and parents who had experiences with ostomies to develop a pediatric ostomy toolkit. The task force was composed entirely of patients and parents and consisted of 7 patients and parents (previous and current pediatric ostomates and their parents; 6 young women and 1 young man), including 5 pediatric patients with IBD and 2 female parents, and was led by 1 of our PAC co-chairs who had an ostomy. We worked together over e-mail to allow our members from across the United States to contribute. We also took advantage of the ICN Exchange ([www.icnexchange.org](http://www.icnexchange.org)), which is a resource-sharing Web site that is open to all ICN community members for sharing information, documents, and resources. It is also a place where ICN community members can post research and quality improvement (QI) questions or comments. We posted about the pediatric ostomy toolkit development and asked clinicians to recruit any interested

patients and parents to join our patient- and parent-led group and share their contact information for project communication.

### **Improvement Activities**

#### *Identification of Topics Relevant to Ostomy Education and Postoperative Adjustment*

Our self-organized group of patients and parents, all individuals either living with IBD and ostomies or parents of such an individual, reviewed IBD resource Web sites to identify current resources for pediatric patients with ostomies. We were unable to find any developmentally sensitive education resources that used appropriate images.

Our task force searched the medical literature for studies in which researchers described the needs of ostomy education. Adolescents who undergo ostomy surgery for IBD experience a broad impact on their lives, including having to cope with a range of adjustment issues related to body image and autonomy.<sup>5</sup> Clinicians who care for adolescents also face the challenge of providing supportive education that promotes psychosocial resilience. Pediatric ostomy education differs from adult ostomy education because of the need to adapt education to the developmental stages of the pediatric patient and family.<sup>6,7</sup> Helping the child be comfortable and odor-free at school and participate in normal childhood activities such as playing sports, continually encouraging the child's confidence in self-care, and the eventual transfer of responsibility from caregivers to the child are all important issues to be addressed.<sup>8</sup> Adolescents with ostomies often express concerns about the impact on clothing, acceptance from peers, returning to favored activities, traveling, and pursuing education.<sup>8</sup> After reviewing this information, we asked task force members to identify questions and topics related to living

with an ostomy, including questions members had preoperatively, immediately postoperatively, and in the extended time since their surgeries. From this prompt, our group generated a list of topics all patients and parents agreed on based on the shared concerns, insights, or questions our task force members had around ostomy surgery. For example, 1 member was an athlete and wanted the toolkit to include insights about playing a contact sport with an ostomy, whereas another had traveled abroad and sought to include her thoughts about travel advice with an ostomy. We chose to develop the toolkit to be of use across the pediatric developmental span, from a 10-year-old child to a 17-year-old adolescent, so that it would be an accessible resource both at the time of surgery as well as while the child matured. Our group chose to structure the topics as a series of general questions (eg, "How do I tell my friends about my ostomy?") and quoted responses to imitate mentoring, ensure the resource provided appropriate insights without suggesting a "right" way to cope with an ostomy, and to reiterate the resource being developed by and intended for pediatric patients with IBD.

#### *Production of the Toolkit*

With the list of generated topics, our task force worked iteratively to condense topics where possible (eg, incorporating high school and college into 1 topic) to produce a finalized topic list. Once the list of topics was finalized, our members contributed to at least 2 topics by writing down their insights regarding the question in an answer format. This approach ensured a diversity of responses that would make the toolkit representative of our collective experiences. We then designed a first draft of a toolkit, complete with images provided by members. We ensured that the toolkit was written at a fifth-grade literacy level. To help

address accessibility of the resource, we obtained a creative commons license for the pediatric ostomy toolkit. It has been made freely available for download on ICN's Web site as of July 8, 2016.<sup>9</sup>

### Toolkit Evaluation by Clinicians

To address medical accuracy, our task force took advantage of the network infrastructure to facilitate medical review by network clinicians, including nurses, doctors, and psychologists. After the creation of the toolkit, we reached out to clinicians to provide clinical review. Our task force then approached ICN clinicians and circulated the toolkit for critique to a group of clinicians who had previously referred patients for ostomy mentoring. We also brought the toolkit to the national ICN network meeting to give clinicians the opportunity to provide feedback on the toolkit in person, including a workshop session led by the chair of the task force (J.G.D.).

We then created an online survey with questions relating to the theorized utility of the ostomy toolkit, current barriers to ostomy education, and perceived levels of ostomy preparedness. Working with the ICN coordinating center and QI team, our task force recruited clinicians from the network to participate in the survey and circulated it with an electronic copy of the toolkit. By using the ICN listserv, 15 clinicians (9 physicians, 6 nurses) were recruited to review the toolkit and complete the online survey. On the basis of the quantitative and qualitative feedback, we decided to maintain the focus of the pediatric ostomy toolkit on children and adolescents and chose not to include an insert for caregivers, although all task force members agreed this feedback had merit for a future project aimed at caregivers of a child or adolescent with an ostomy. Following feedback from clinicians and additional ideas from the task force, we decided to

adjust the color scheme, add sections on "take down" surgery, and add a blank notes page.

## RESULTS

Our final 19-page, colorful toolkit included topics relating to friends, school, travel, ostomy supplies, clothing, playing sports, using humor to cope, emergency kits, educational issues (eg, 504 plans), "Gastronauts" (Gastronauts are freely available puppets with ostomies), and ostomy medical language. To demonstrate the question and answer style, we give the following examples from the travel and clothing sections of the toolkit. From the travel section, the prompt question states, "Does having an ostomy make it harder to travel?" with 1 reply from a 23-year-old woman with Crohn disease and a permanent ileostomy as follows:

*Have ostomy, will travel! . . . When I travel, I make sure to have plenty of spare supplies (especially if I'm going to an international destination) and ensure I keep them on my person (i.e., in my carry-on and not in my checked luggage if I'm flying). . . . I have a card that says I have an ostomy, but you could also get a note from your doctor so that airport security will allow you to use the special line without hassle.*

In the clothing section, the prompt question reads, "Do I have to wear different clothing with an ostomy?" with a response from a 17-year-old boy with Crohn disease and a permanent ileostomy as follows:

*Clothing for me is really easy. I only wear three types of clothes, t-shirts, athletic shorts, and athletic pants, and both the pants and the shorts have the same exact feeling and function. To incorporate my bag into my outfit is a two-step process. I first decided whether to tuck my bag into my pants or to let it hang out of my pants. My second and final step was to wear slightly too large shirts to keep everything well covered. Without a bag, I would be wearing Adult Mediums; since I have the bag, I wear Adult Large. If your outfit is more extravagant than mine, my only advice would be to wear things that are comfortable and cover up your ostomy bag.*

Other sample responses can be found in Table 1.

The pediatric ostomy toolkit was posted on the ICN Exchange platform, where it has been downloaded 85 times and viewed 106 times as of August 15, 2017. We obtained feedback on the medical information presented in the toolkit from the clinicians who reviewed it to produce an accurate resource. Clinician survey responses were extremely positive. Over 90% ( $n = 14$ ) reported fully approving the current design format of the toolkit. Qualitative feedback was extremely enthusiastic (eg, "I think you have done a fantastic job and are providing a well-needed service. Congratulations to all who took part in this. ICN and the PAC rock!," "Excellent Job. This is an awesome resource for providers to provide their patients and families," and "[G]reat job. Maybe a more formal insert for parents only?").

## DISCUSSION

We found that a collaborative network of patients, families, clinicians, and researchers provided the organizational infrastructure to enable our self-organized team of youth and parents with IBD to work together and to work with clinical teams to coproduce a resource for ostomy patients. We took advantage of the ICN community to self-mobilize patients and parents into a task force, work together as patients by using QI methods, find and consult clinicians as advisors, revise the tool, and make it immediately available to the network via an electronic platform. We developed the toolkit in response to a need perceived by patients like ourselves and built on our motivation to contribute by enabling other patients to thrive with their illnesses.

The patient-driven approach described here differs from how traditional top-down development of clinical education resources usually

takes place. The traditional model is one in which patients and families may only be consulted during or after the resource is developed. The “bottom-up” approach we describe here began with a need identified by patients and parents who then self-organized, developed the educational resource, and consulted clinicians. We drew on the support and QI education we received as full and equal participants in the network

to draft this article according to the SQUIRE guidelines.

The pediatric ostomy toolkit has potential utility both preoperatively and postoperatively for pediatric patients facing ostomy surgery. This is a unique and important quality of the pediatric ostomy toolkit that moves ostomy education away from a single time point and toward a malleable and personalized

education schedule. Additionally, the physical resource allows pediatric patients to interact with the toolkit through underlining notable lines, writing questions, and making use of the notes section of the resource. The resource allows patients like ourselves who have IBD and ostomies to return to the toolkit as needed (for example, when transitioning to college and interested in learning more about living with an ostomy in

**TABLE 1** Sample Question and Answer Format of Pediatric Ostomy Toolkit

Ostomy Toolkit Section	Responses From Primary Stakeholders	
How do I tell my friends about my ostomy?	<p>“Since I just started high school last year many of my friends don’t know that I have Crohn’s Disease or that I have an ostomy, but I have told a lot of my really close friends. For me, it was easy to tell my friends. I would just tell my friends that I would be having surgery pretty soon and they would then ask, “Why?” so then I would tell them. The friends that I did tell, I was very glad that I had because a few of them got me get well gifts and it was really nice to know that they cared. A few of my friends even called me the day after my surgery, which was really awesome to hear that they truly cared even though they didn’t fully understand what my disease was all about. My advice for telling your friends about your ostomy is to be completely honest with your friends. Don’t be afraid to tell your friends anything. Your friends will care even if you think they won’t. Although if you don’t feel comfortable talking to your friends about your ostomy, don’t stress over it. When the time is right, you’ll know. Don’t worry about telling your friends, they will care for you!”</p> <p>16-year-old girl with Crohn disease and a temporary ileostomy.</p>	<p>“Above all else, having an ostomy is very personal and you have the ability to decide who to tell and how you explain it all. Personally, I was always very open about my ostomy and can remember holding up my shirt to show friends a week or two after my surgery. I talk very positively about my ostomy, and have honestly never had a negative reaction. I typically explain my disease, the need for surgery, and that now I don’t have a large intestine and wear a cloth bag on my belly at all times. I love to educate people and raise awareness, and encourage other ostomates to only tell others when they are ready and prepared.”</p> <p>23-year-old woman with Crohn disease and a permanent ileostomy.</p>
Do I need an emergency kit?	<p>“The ostomy nurse at [hospital] helped [adolescent] get samples and 2 bags to use for emergency kits, one the size of a folder and the other more like a large pencil pouch. In the small kit, [adolescent] keeps an ostomy bag or two, scissors, tape, and a disposal bag. He can carry it with him anywhere. It’s usually in his book bag during school. He takes it to tennis matches and band competitions. When [adolescent] is at school or an all-day event, he takes a few more precautions. In addition to the small kit, he also takes a change of clothes (t-shirt, shorts, socks, and underwear), a large ziplock bag for dirty clothes, and a plastic grocery bag for discretion. He puts it all in a cinch sac, along with bottles of water. For school, he keeps a large kit in his book bag in his locker and one in the main office. That way he can go to whichever place is closer when he needs it, or he can ask someone to get his bag from the office if he is stuck somewhere and can’t get it himself. He used these kits mostly before he had an ostomy and had urgent trips to the restroom. He has not used them much since his colectomy.”</p> <p>Mother of a 17-year-old boy with Crohn disease and a permanent ileostomy.</p>	<p>“While it’s unusual to need to change my bag urgently when I’m out of the house, it’s important for my comfort and peace of mind to have an emergency kit with me at all times. I use a small pouch (about the size of a pencil case) where I keep a couple extra bags, flanges, barrier wipes, and garbage bags – it’s also an easy place to keep any pills I need to bring with me when I’m on the go. I chose a pouch that had a design I really loved, and it’s very easy to throw into my backpack or even my purse so I can bring it with me wherever I go.”</p> <p>23-year-old woman with Crohn disease and a permanent ileostomy.</p>



TABLE 1 Continued

Ostomy Toolkit Section	Responses From Primary Stakeholders	
Can I play sports with my ostomy?	<p>“Playing sports with an ostomy can be scary if you don’t have any protection. I have played soccer ever since I was 4 years old, it’s my favorite sport. I was so worried that after my surgery I wouldn’t be able to play again. Luckily I did some research and found wraps or belts to buy for sports. These belts are just like a small amount of hard plastic like material that goes over your stoma and a soft belt that goes around your waist to keep the armor on. I bought one and when I played for the first time after surgery I was nervous. I was afraid that my stoma would still get hit from either the ball or someone else, but nothing happened and I played like I didn’t even have an ostomy. I have been playing soccer for a long time now and I didn’t let my ostomy get in the way. Don’t be afraid to play sports with your ostomy, but make sure you have some sort of protection just in case you get hit with a ball. You don’t have to give up playing a sport because of an ostomy.”</p> <p>16-year-old girl with Crohn disease and a temporary ileostomy.</p>	<p>“When I started playing tennis, it was during a time when I was wearing shorts and t-shirts and I let my bag hang out of my pants and wore large t-shirts. On the first day of practice I quickly realized that the constant movement would lift up my shirt and reveal my bag to the other teammates. While, if they knew I had it, this situation would be perfectly fine, but my preference was that if they didn’t ask, I didn’t care if they didn’t know. I quickly decided that the current arrangements weren’t going to work, so I tucked my bag into my shorts to get the bag out of that way and out of sight. After practice I continued to try out this new method and decided it didn’t feel any difference than letting it hang out. What I learned from this was that during recreation, having the bag as comfortable as possible is most important, but during physical activities, I had to try different things to accommodate it to the sport. Once you find your happy spot, playing your favorite sports will feel just like playing without a bag.”</p> <p>17-year-old boy with Crohn disease and a permanent ileostomy.</p>

college). Thus, our pediatric ostomy toolkit can be used to address the psychosocial needs we have felt as patients as well as clinician-reported barriers by providing a resource filled with appropriate medical and psychosocial information, thereby extending the period of education to address surgical-time pressure and delivering developmentally sensitive information to pediatric patients and their families to acclimate them to talking about ostomies. In addition, as patients we feel strongly that having this resource available to pediatric patients with IBD who are having ostomy surgery would address many of the concerns we had around the time of our own surgeries without the need for patients and parents to independently search for reliable medical information.

Previous research on ostomy education has included encouraging clinicians to provide educational pamphlets to patients and families, demonstrating putting an appliance on a favorite toy for children, directing patients and families to online support groups,<sup>10</sup> videos to teach patients to independently change their ostomy appliances,<sup>11</sup> and guidelines for teaching adults

with ostomies how to care for their appliances.<sup>12,13</sup> In a systemic review of educational interventions for individuals with ostomies, researchers identified 7 studies (2 randomized control trials, 5 cohort studies) in which all of the educational interventions were delivered by ostomy nurses and were exclusively designed to minimize stoma-related complications.<sup>3</sup>

There have been barriers to achieving optimal ostomy education for pediatric patients, including the lack of a standardized approach to medical and psychosocial education, outdated information, and minimal information on developmentally appropriate topics (eg, school). To the best of our knowledge, our project is the first one in which patients and parents led the coproduction of a resource for pediatric patients undergoing ostomy surgery that addresses medical and psychosocial information on the basis of needs perceived by the patient community.

There are several limitations of our study, including the potentially unique voices of the patient advocates who created it and limited evaluation of the resource. It is

conceivable that the insights and topics identified by our task force do not fully represent the needs of pediatric patients with IBD and their parents. The patients and parents engaged in our task force certainly have a high level of motivation to participate. This observation is consistent with ICN’s previous ethnographic research in which a subgroup of patients was identified who would be highly motivated to contribute as an important segment of the population.<sup>14</sup> In his extensive research, von Hippel<sup>15</sup> suggests that such “lead users” may have insights into how to create innovative approaches to products and services and that such individuals anticipate the needs of others. We believe our task force represents individuals who may have well-developed insights into how to live effectively and purposefully with physical limitations given the personal experiences of all task force members. Thus, it is possible that by selecting for individuals who are willing to innovate, we have contributed knowledge and insights that may be absent in traditional educational resource development projects. The favorable reviews by clinicians and staff suggest that our insights as

patients and parents were not only medically appropriate but also useful from a clinical perspective. This question will require further study and confirmation.

Our toolkit has not yet been evaluated prospectively to assess whether using the toolkit as part of clinical care improves psychosocial outcomes for pediatric patients with IBD after surgery. We hope this will be an opportunity for future research and further engagement of patients in the “bottom-up” design and execution of research so that it answers the questions that are most meaningful to patients, parents, and clinicians alike. We firmly believe that this is a valuable approach to patient-led coproduction in pediatric chronic illness care and that the structure of our process may be a useful example for other projects.

This project provided us as patients with a number of insights about patients’ roles in coproducing medical care with clinicians in a network. We as patients came to appreciate how the network culture and processes thoughtfully encourage and respect the unique perspectives of patients and parents and set the norm that these insights are valuable. Our positive experience of initiating collaboration with clinicians served as a useful example and deepened the appreciation across ICN participants (patients, families, clinicians, and researchers) about the potential for patients and parents to contribute meaningfully to the care system and help to shape future initiatives.

The experience also helped us learn about using network communication infrastructure to address the challenges of communication across barriers of geography and time. The network’s QI capability enabled us to work efficiently and to iterate and improve the ostomy toolkit. We used what we learned about QI to build a complete first draft, approach clinicians for an evaluation of the toolkit, and integrate feedback into a revised version of the toolkit in an interactive way.

The patient-driven “bottom-up” approach we used overcomes the limited capacity of the health care delivery system, which imposes a significant constraint in the production of useful medical and psychosocial education for children and youth. In our example, we demonstrate how patient and parent-led coproduction of patient education can expand capacity and directly infuse resources back into a network as well as generate solutions to problems experienced by patient communities. In addition, the lack of psychosocial support after ostomy surgery in pediatric patients with IBD had been a significant void for our population. In our toolkit, this need is recognized and addressed.

In our patient- and parent-led toolkit project, we demonstrate how patients and families can self-organize and ask clinicians to consult to create needed resources within a network. Our approach to coproduction offers the potential to increase capacity and relevance within the

health care system. Understanding the potential and challenges of this model deserves future research. Most importantly, the implications of this project suggest that patients have the motivation and ability to work together to inform clinical pediatric practice and to increase the integration of patient perspectives into medical and psychosocial education.

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## ABBREVIATIONS

IBD: inflammatory bowel disease  
ICN: ImproveCareNow  
PAC: Patient Advisory Council  
QI: quality improvement

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