

should I have IBD surgery?

shared decision-making toolkit

Attention!

The following material is intended for providers and care teams. It is not intended as a comprehensive care reference or prescribed pathway as each individual patient is unique and each care center has different local resources. Providers and families should work together to develop the best plan of care for each patient.

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should I have IBD surgery?

shared decision-making toolkit

The online *Should I have IBD Surgery?* shared decision-making tool is designed for use with patients (ages 12 and up) with Inflammatory Bowel Disease (IBD) when considering surgery.

Understanding that patients and their families need time to accept and adapt to the idea of surgery, this tool can be introduced when the patient is weeks or even months away from needing to make a decision to have surgery. Great care is needed to adapt the tool for use in more acute situations and should only be attempted with careful communication between the medical team(s) involved.

The goal of the tool is to:

- Improve patient-provider communication about future IBD surgery
- Pro-actively involve patients in their health care decisions
- Identify gaps in patient understanding about their IBD
- Identify areas where additional patient or parent support may be helpful

This toolkit provides suggestions on how to introduce the tool and includes the following components:

- Introduction
- Guide for Clinicians
- Pathway to Surgery
- **Web-based Tool** (works best with Google Chrome)
- Introduction for Patients (template)

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IBD surgery shared decision-making tool

guide for clinicians

The *SHOULD I HAVE IBD SURGERY?* web-based tool assesses readiness for IBD surgery by asking patients a series of questions about their disease, treatment options, and concerns about surgery. Confidential responses are not stored, but are compiled in a printable pdf that can be shared with their physicians to promote better communication. Reputable links to vetted sources (ImproveCareNow, Crohn's & Colitis Foundation, and United Ostomy Association of America) are provided in the tool if patients desire additional information.

This tool was funded by a grant from ImproveCareNow and designed by a collaborative team from Dayton Children's Hospital, including expertise from pediatric gastroenterology, surgery, psychology, parents, and patients.

who should use it?

The tool was designed for patients (ages 12 and up) who may benefit from future elective IBD surgery due to inadequate response to medical interventions. The shared decision-making process may take several weeks or months, therefore the tool should be introduced early to ensure excellent support and resources in this life changing decision.

what are the benefits to the patient?

This tool provides a safe space for the patient to explore their understanding of:

- The type, location, and severity of their IBD
- The recommended surgical procedure
- The pros and cons of different medical, nutritional, and surgical therapies
- Their feelings about how surgery may impact their future
- Their right to seek guidance and counsel from others
- Their responsibility to take an active role in making this decision

what are the benefits to the care team?

The tool generates a shareable PDF document with patient responses to a set of questions. These responses can help the care team identify and address:

- gaps in patient knowledge about their IBD and treatment options
- barriers to acceptance of surgery as a treatment option
- need for inclusion of additional team members (e.g.: psychology, social work, others)

The multidisciplinary care team at your facility could consist of:

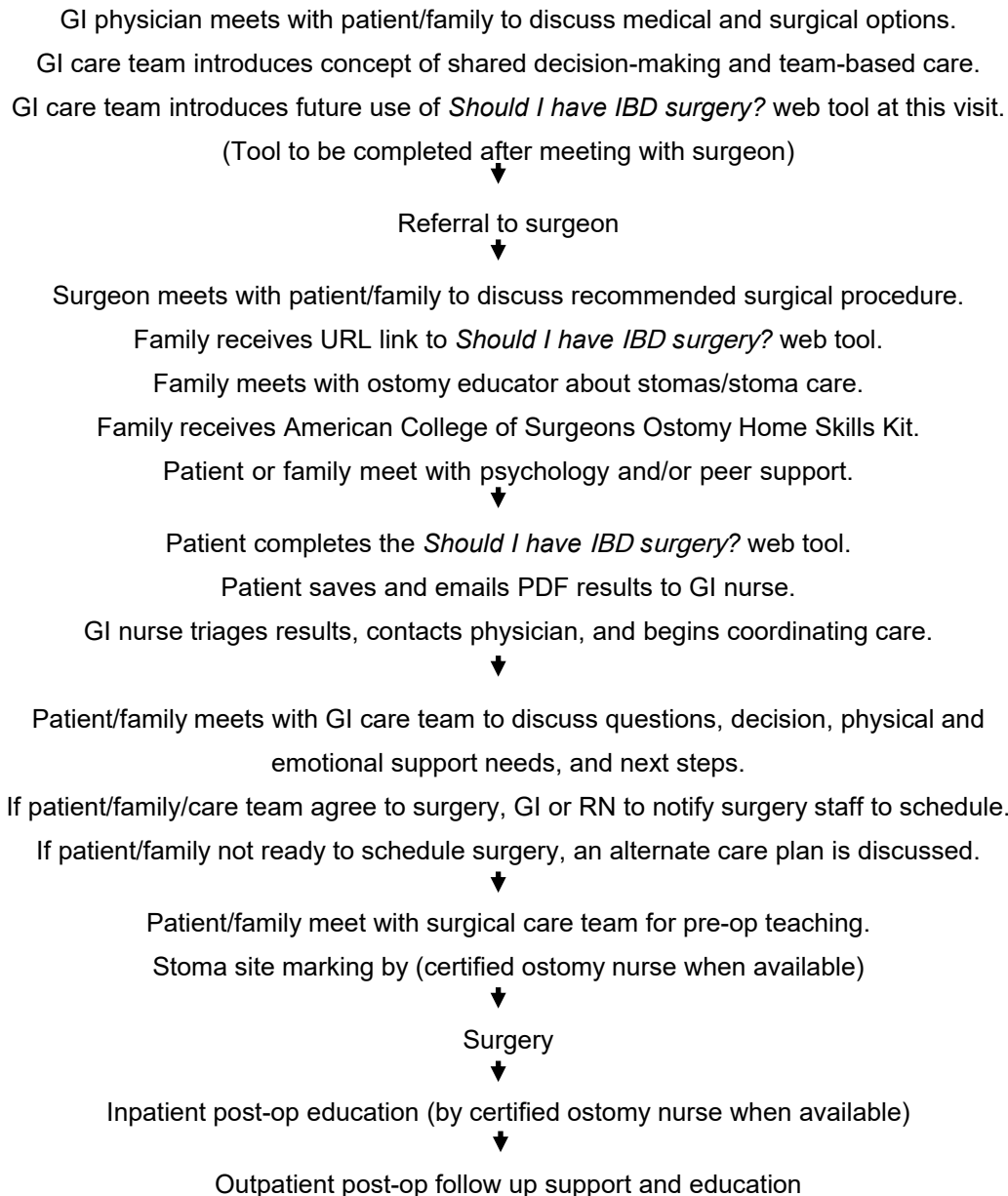
- GI physician
- Pediatric or colorectal surgeon
- Case manager
- Certified ostomy RN
- Surgical RN
- GI NP/PA/RN
- Psychologist
- Occupational therapist
- Dietitian
- Medical social worker
- Peer support
- Chaplain

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IBD surgery shared decision-making pathway to surgery

The following represents one way that the *Should I have IBD surgery?* web-based shared decision-making tool can be used in the flow of a patient's decision making. The pathway should be tailored to your patients and your medical system.



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IBD surgery shared decision-making tool: patient introduction template

should you have IBD surgery?

YOU are the most important person on your care team. Your thoughts, feelings, and concerns matter. We want you to help make the decision about whether surgery is the right treatment for you and your IBD.

The *Should I have IBD Surgery* web tool is a safe space to share what you know, what you want to know, and what matters most to you. It contains questions about your IBD, your feelings, and who you want to be on your support team. Your responses aren't stored, but you will have the option to print or save your answers. We recommend saving as a PDF and sharing with anyone who is helping you make this decision. After all, they are part of your team, too.

Just click on the link below to get started.

www.improvecarenow.com/decision_support

(The tool works best with Google Chrome.)

The website also has lots of information and links to resources. It even has some cool resources created by teens who have had IBD surgery. We hope that you will check them out!

Send PDF to _____ by __ (date) __ via _____

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