



## RECRUITING PARTICIPANTS FOR A RESEARCH STUDY

### Study Title: “Transition Barriers Survey: Initial Validation”

We are looking for youth AND parents/caregivers to participate!

Researchers are interested to understand the things that make it difficult for a young person living with IBD to transition from a pediatric GI doctor to an adult GI doctor.

This study involves completing some online surveys that are estimated to take **20 minutes to complete**. Participation in this study is **voluntary**. You may quit at any time.

#### You are welcome to participate in this study if you:

- ✓ Have been diagnosed with Inflammatory Bowel Disease (i.e., Crohn’s disease, ulcerative colitis, or indeterminate colitis)
- ✓ Are between the ages of 15-22 years
- ✓ Speak, read, and understand English
- ✓ Have access to the internet, through a computer, smartphone, tablet
- ✓ Have an email account
- ✓ Have a parent/caregiver who is interested in participating

PARENT/CAREGIVER: To learn more about the study and to complete the online survey, please scan the QR code or visit:  
<https://cmhredcap.cmh.edu/surveys/?s=K88JYYDF8H>



## Recruiting Patient and Caregiver Participants for a Research Study!

Is your child between the ages of 15 and 22?

Is your child diagnosed with Inflammatory Bowel Disease?

Research Study: Transition Barriers Survey: Initial Validation  
STUDY00002073

Principal Investigator: Michele Maddux, PhD

**Who is doing this research study?** This study is being carried out by researchers at Children's Mercy Hospitals, Stanford Children's, Connecticut Children's, and Children's Healthcare of Atlanta.

**What is this research study about?** The purpose of this research study is to understand the things that make it difficult for a young person living with IBD to transition from a pediatric GI doctor to an adult GI doctor.



**Why are we being asked to be in this study?** We are asking you AND your child to be part of this research study because your child has been diagnosed with Inflammatory Bowel Disease.

**What will my child and I be asked to do if we decide to be in this study?** If you and your child choose to be in the study, we will ask each of you to complete some online surveys at two times, 2-4 weeks apart. Together, this will take about 20 minutes to complete. There is no extra cost for being in the study.

**What are the benefits?** There may not be direct benefit to being in this study. By being in this study, you may help researchers learn how to better work with patients moving to adult health care.

**What are the risks?** There's a small risk of a breach of confidentiality. You and your child's confidentiality will be protected to the greatest extent possible. You and your child do not have to give any information you do not want to give.

**What identifiable information will be used for this study?**

This is a 2-part study. We will ask you and your child for an email address to send a follow-up survey in 2-4 weeks. You or your child may choose not to give an email address and only finish the first survey. We will keep this information confidential. No other identifiable information will be collected.

**How will my child's information be used in the future?**

Information from this study will not be used for future research.

**What are the alternatives to being in this study?** Instead of being in this study, you may choose not to participate. Being in this study is completely voluntary. You/your child may change your mind at any time. Your/your child's decision will not impact your child's standard care at your IBD center.

**Problems or Questions?** Please contact Michele Maddux at 816-302-3055 if you/your child have any questions about this study.

You may also call the Children's Mercy Hospitals' Pediatric Institutional Review Board (IRB) at (816) 731-7474 with questions or complaints about this study. The IRB is a committee that ensures that a research study is ethical and that the rights of study participants are protected.

Continuing with the study procedures means that you agree for you and your child to be in this study.

Please think about participating in this study.

