P003
INFLAMMATORY BOWEL DISEASE PATIENTS’ PERSPECTIVES OF CLINICAL TRIALS
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Background: Despite recent progress in treatment for inflammatory bowel diseases (IBD), there is a need for therapies with long-term efficacy and improved safety. Clinical trials in IBD face challenges with patient recruitment because of study designs, incomplete or overlapping trials, and a limited number of eligible patients. We sought to better understand patients’ motivations, awareness of, and experience with IBD clinical trials.

Methods: We conducted an international survey of adult patients with IBD consisting of 2 components. The quantitative component, a 15-minute online survey, was completed by all patients. A qualitative component, a 30-minute telephone interview, was completed by a subset of patients from the United States (US). All percentages indicate results from the online survey.

Results: 226 participants (mean age, 41.9 y) completed the online survey. Survey respondents included patients with ulcerative colitis (52%) and Crohn’s disease (48%) from the US (n=100, 21 of whom underwent a phone interview), Brazil (n=26), Canada (n=25), France (n=25), Germany (n=25), and Spain (n=25). Ninety-six percent of respondents reported at least a basic understanding of clinical trials, and 34 (15%) were current or past clinical trial participants.

Patients reported learning about trials through 1 or more sources (could select as many as applied); health care providers (42%), pharmaceutical manufacturer websites (31%), social media (30%), online support groups (28%), and foundations (18%-23%). In the survey, patients rated conversations with health care providers most helpful, but patients who were interviewed revealed that most physicians often do not initiate conversations about clinical trials, and patients typically do not ask.

Primary motivators for trial participation (rated from “does not encourage me at all” to “encourages me very much”) included altruistic goals of advancing medicine (67%), potentially mitigating risks of uncontrolled IBD such as colon cancer (59%), and access to treatment options that could improve quality of life (59%) or would otherwise be unaffordable (52%). Major barriers to participation (rated from “does not discourage me at all” to “discourages me very much”) included invasive screening and monitoring (35%), concern over receiving placebo (35%), or suboptimal treatment (33%), and concerns about posttrial access to study medication (27%).

The majority (68%) reported that being in a clinical trial means being a “guinea pig” for an experimental treatment.

Conclusion: Opportunities to improve patients’ clinical trial experience in IBD include better communication with health care providers and improved patient education about clinical trial design and ethics. Ultimately, a better understanding of the patient perspective will be important for more informed patients and potentially higher recruitment and enrollment.

P017
INFLAMMATORY BOWEL DISEASE: YOUTH BELIEFS AND BARRIERS TO TRANSITION
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Introduction: Transitioning from pediatric to adult care remains a vulnerable time for all youth, especially those with inflammatory bowel disease (IBD). While the medical community recognizes this, it is still an understudied phenomenon and youth are generally not prepared to transition. Our mixed methods study is unique in that it comprehensively assesses youth/caregiver understanding and priorities through interviews and surveys surrounding the transition process for youth with IBD.

Methods: This is a prospective chart review. English speaking youth with IBD ages 12-25 and their caregivers at a tertiary care center were given the Transition Barriers and Beliefs scale (TBAB). Data were analyzed by descriptive statistics and frequencies. A subgroup of youth/caregiver dyads from the above sample were asked a semi-structured set of questions. The answers were audio recorded and transcribed.

Results: 70% of caregivers reported they are not discussing transition with their youth.

Conclusion: Discussion around transition in IBD care is not happening at home or with providers. Accordingly, most youth and their families have no plan for this process. Our data agree with other research indicating that youth and their caregivers view transition more as an event and less as a process (e.g., transition discussions and transfer to adult care around the same age 17 to 18). This is highlighted by the finding that youth/caregiver dyads reported that seeing the physician alone should happen just before transition. As a whole, our data indicate that youth and their families are underprepared to transition care, with a majority expressing the expectation that similar support services will be offered in adult care. This leaves them vulnerable to a lapse in medical care, unmanaged flares, and negative consequences of drug holidays. Interestingly, youth and their families are worried about the transition from pediatric to adult IBD care and are interested in receiving this information in person, reinforcing that this information should be incorporated into routine care and is best received from their IBD providers.