

Supplemental Material – Survey 1

Research Priorities in Pediatric Inflammatory Bowel Disease (IBD): A national Survey

My name is x. I am x years old and live xxx in Canada. I was diagnosed with Crohn's Disease in x, when I was x years old. During the past four years, I have been on various combinations of all the treatments that are available. I have been through the rough times that many of you have experienced during flare ups. When going through all of the treatment changes, flare ups, and the symptoms that triggered them, I always had questions. Sometimes my questions were about my symptoms or why I felt a certain way. Sometimes my parents or doctor could answer them, but not always. As a patient, I know that there are many questions that we as IBD patients would like answers to. Research can help us find these answers. I hope that you will take the time to answer this survey, and tell us—patients, parents, clinicians (nurses, dietitians, physicians and others who care for people with IBD) and researchers who are working together on this project—about your thoughts. Thank-you.

Children and teenagers who have IBD, their parents, and those who provide care for them often have a lot of questions about how to prevent and manage the disease. Many of these questions have not been adequately answered by research.

The purpose of this survey is to hear from you:

- children and teenagers with IBD
- parents/caregivers of children/teens with IBD
- and clinicians who care for those with IBD

We want you to tell us your important pediatric IBD questions or uncertainties.

The ultimate aim of this project is to identify the top 10 research priorities in pediatric IBD. We are starting with this survey, and need to hear from people across Canada. You are living with IBD everyday or helping care for patients who have IBD. By answering these questions, you will help us focus on finding answers to questions that matter most to patients, families and clinicians.

The final top 10 will be available on the website of the Canadian Children IBD Network: a joint partnership of CIHR and the CH.I.L.D. Foundation. (<http://www.cidscann.ca>)

We will not be collecting any information that would allow us to identify you personally. This study has been approved by the IWK Research Ethics board. If you have any study related questions, please contact: xxx.

If you are answering this survey on paper, please return this to your clinic nurse, or by mail to:
xxx

YOUR UNANSWERED QUESTIONS

This survey is written as if you are a patient. However, if you are a parent or caregiver please consider the answers to these questions in relation to the child/teen who has IBD. If you are a clinician, please consider the questions from the perspective of someone who cares for pediatric patients with IBD.

Please do your best to think about and answer the following questions. **You may answer all the questions, or leave some blank.** Please do not repeat your answers, even if they fall under more than one question.

1. What issues relevant to IBD in children and teenagers are you uncertain about and do you think need further research? This may include questions about what causes IBD, how IBD is diagnosed, how it is treated, etc. Please submit as many questions as you like.

Sometimes it is hard to think of things with a very open-ended question like Question 1. The next series of questions (Questions 2 to 9) are intended to help you remember questions you think need answers through research.

1. Do you have questions about the prevention or causes of IBD?
2. Do you have any questions about the role of diet/nutrition in preventing, causing or treating IBD?
3. Do you have questions about any of the medical tests (e.g., colonoscopy, MRE—magnetic resonance enterography) that you had to go through or may have to go through in the future? This might include questions about how your doctor knew you were getting better or how often/why you needed these tests.
4. Do you have questions about your disease management or prognosis (how your disease will change over your life)? This might include questions about how you were informed about your disease, or the disease education you have received.
5. Do you have any questions about treatment (e.g., drugs, alternative therapies, surgery) that you would like to have answers to? Please be as specific as possible.
6. Do you have any questions about physical symptoms (things like being tired, feeling pain)? Are there symptoms that really bother you, or make it hard for you to do things you enjoy (e.g., playing sports, going to school)?
7. Do you have questions related to feelings and emotions that may go along with having IBD (feeling sad, worried or anxious)? These emotions may relate to how you feel about yourself, or about how IBD affects your family or the way your family interacts.
8. Do you have questions about issues that might be a problem for you in the future (such as having children, dating, or starting university)?

Demographic Questions

These questions will help us understand who has responded to our survey. If you would prefer not to answer, please leave them blank.

1. Which of these categories best describes you:
I am a person who was diagnosed with IBD before age 18 years.
I am a romantic partner or relative (aunt, brother/sister) of someone with IBD.

I am the parent of a child who developed IBD before age 18.

I am a healthcare professional (e.g., doctor, dietitian, social worker) who works with pediatric patients who have IBD. Please identify your profession:

Nurse

Physician

Dietitian

Social Worker

Psychologist

Other: _____

Other (please describe)_____

2. What is your age?
3. What is your gender?
4. What country do you live in?
5. What province are you from (Canada)?
6. What are the first 3 digits of your postal code? This will help us to know how far you live from an urban centre (e.g., Toronto), and how easy it is for you to access pediatric IBD care.
7. What ethnic group do you identify with?
 - White
 - Aboriginal
 - East Asian
 - South Asian
 - Black
 - Mixed
 - Prefer not to say

Branching logic for questions below

(if person is partner, relative, or parent they will be asked about the person who has IBD)

8. What is the current age of your child who developed IBD? _____(drop down)
9. How long has your child had IBD?
 - Newly Diagnosed (within the last month)
 - Less than 6 months ago
 - 6-12 months ago
 - Over a year ago: specify how long ago_____
10. What is the gender of your child? (male/female)
11. How old was your child when he/she was first diagnosed? _____(drop down)
12. What type of IBD does your child have?
 - Crohn's disease
 - Ulcerative Colitis
 - Indeterminate Colitis
 - I don't know
13. What ethnic group does the child you know who has IBD identify with?
 - White
 - Aboriginal
 - East Asian

South Asian
Black
Mixed
Prefer not to say

(if the person answering is the one with IBD)

8. How old were you when you were first diagnosed? _____
9. What type of IBD do you have?
Crohn's disease
Ulcerative Colitis
Indeterminate Colitis
I don't know

(if the person answering is a healthcare professional [e.g., doctor, dietitian, social worker] who works with pediatric patients who have IBD)

[we will already have their profession]

8. How long have you cared for pediatric patients with IBD?
9. Where do you practice?
Pediatric tertiary care centre
Community hospital
Private office/practice
10. Are you a researcher involved in pediatric IBD research? Yes/no

Supplemental Material – Survey 2

Pediatric IBD: Top 20 Research Questions

Please take the time to read the following message from one of our Research Team Members:

My name is x. I am x years old and live x. I was diagnosed with Crohn's Disease in x, when I was X years old. As a patient, I know that there are many questions that we as IBD patients would like answers to. Research can help us find these answers.

I hope that you will take the time to answer this survey, and tell us--patients, parents, clinicians (nurses, dietitians, physicians and others who care for people with IBD) and researchers who are working together on this project--about what questions you would like to see answered by researchers. This is your chance to vote on the top 20 questions.

In the next step, a large group of us will come together and decide on the top 10 unanswered research questions in pediatric IBD. Keep an eye out for the results!

Thank-you.

The final top 10 will be available on the website of the Canadian Children IBD Network: a joint [partnership of CIHR and the CH.I.L.D. Foundation. \(http://www.cidscann.ca\).](http://www.cidscann.ca)

We will not be collecting any information that would allow us to identify you personally.

This study has been approved by the IWK Research Ethics board. If you have any study related questions, please contact: x.

These questions will help us understand who has responded to our survey. If you would prefer not to answer, please leave them blank.

Which of these categories best describes you:

I am a person who developed IBD before age 18 years.

I am a romantic partner or relative (e.g. aunt, brother/sister) of someone who developed IBD before age 18 years.

I am the parent of a child who developed IBD before age 18 years.

I am a healthcare professional (e.g., doctor, dietitian, social worker) who works with pediatric patients who have IBD.

Other

Please specify

Please identify your profession:

Nurse

Physician

Dietitian

Social Worker

Psychologist

Other

Please specify

What is your age?

(Drop-down menu)

What gender do you identify with?

Male
Female

What country do you live in?

Canada
Other

Please specify

What province or territory are you from?

British Columbia
Alberta
Saskatchewan
Manitoba
Ontario
Quebec
New Brunswick
Nova Scotia
Newfoundland
Prince Edward Island
Yukon
Northwest Territories
Nunavut

What are the first 3 digits of your postal code? This will help us to know how far you live from an urban centre (e.g., Toronto), and how easy it is for you to access pediatric IBD care. _____

What ethnic group do you identify with?

White
Aboriginal
East Asian
South Asian
Black
Latino
Mixed
Prefer not to say
Other

Please specify:

(If a caregiver, relative)

What is the current age of your child (or family member/partner) who developed IBD?

(drop-down menu)

How long has your child (or family member/partner) had IBD?

Newly Diagnosed (within the last month)
Less than 6 months ago
6-12 months ago
Over a year ago

Specify how long ago

What gender does your child (or family member/partner) who has IBD identify with?

Male
Female

How old was your child (or family member/partner) when he/she was first diagnosed?

What type of IBD does your child (or family member/partner) have?

Crohn's disease
Ulcerative Colitis
Indeterminate Colitis
I don't know

What ethnic group does the child (or family member or partner) you know who has IBD identify with?

White
Aboriginal
East Asian
South Asian
Black
Latino
Mixed
Prefer not to say
Other

Please specify: _____

(If a patient)

How old were you when you were first diagnosed?

What type of IBD do you have?

Crohn's disease
Ulcerative Colitis
Indeterminate Colitis
I don't know

(If a clinician)

How long have you cared for pediatric patients with IBD (in years)?

Where do you practice?

Pediatric tertiary care centre
Community hospital
Private office/practice

Are you a researcher involved in pediatric IBD research?

Yes
No

Did you complete our first survey (where we asked people to tell us about their unanswered research questions in pediatric IBD)?

Yes
No

Below is the list of unique questions identified by Canadian pediatric patients with IBD, their parents or family members, and clinicians who work with with pediatric IBD patients. The Steering Committee for this project, made up of pediatric patients, parents, and clinicians has worked on reducing the list of over 350 questions submitted, to this list of questions. Also included are questions that have been suggested for future research from clinical practice guidelines. All questions have not been answered by current research.

Please choose your top 20 questions by checking off the box under "Include in top 20" in this list. Check off ONLY 20 questions, and leave all others blank.

Factors to consider when choosing your top questions, are:

-Your personal experience with (or caring for a person with) the disease

-Whether the question was reported by more people

-Whether the question was reported by both clinicians and patients

The top 20 questions will then appear on the next page, where you will rank them in order of importance, from 1-20.

Include in top 20

How can we accurately diagnose IBD without invasive tests like endoscopy? Patients: 5, Clinicians: 0, Total: 5

☐

Are there ways that patients can be identified as having/being susceptible to IBD before symptoms and/or inflammation occur? Patients: 15, Clinicians: 7, Total 22

☐

How can we increase the knowledge and/or awareness around pediatric IBD so that diagnosis is not delayed? Patients: 14, Clinicians: 0, Total: 14

☐

How does an early diagnosis of IBD in childhood/teenagers impact the lifelong course (prognosis) of the disease? Patients: 16, Clinicians: 1, Total: 17

☐

What is the impact of access to psychological/mental health support in the management of pediatric IBD? Patients: 2, Clinicians: 1, Total: 3	<input type="checkbox"/>
What is the optimal approach to diagnosis (education, psychological support, diagnostic tests) in pediatric patients with IBD? Patients: 0 Clinicians: 6, 6	<input type="checkbox"/>
What is the best approach to following a patient's disease status? Patients: 2, Clinicians: 1, Total 3	<input type="checkbox"/>
How can a multidisciplinary team (ie: dietitians, psychologists, social workers) optimally function to provide better care? Patients: 3, Clinicians: 1, Total: 4	<input type="checkbox"/>
What can be done to reduce the wait list for diagnostic tests for patients with IBD (ie MRE)? Patients: 2 Clinicians: 0, Total: 2	<input type="checkbox"/>
How can we better define the role of, and improve access to, newer non-invasive, less costly, biomarkers of IBD endoscopic activity? Patients: 11, Clinicians: 4, Total: 15	<input type="checkbox"/>
What is the best way to advocate for increased employment benefits in patients with chronic disease (ie: IBD)? Patients: 2 Clinicians: 0, Total: 2	<input type="checkbox"/>
What is the best approach to transitioning a pediatric patient to adult care? Patients: 0, Clinicans: 2, Total: 2	<input type="checkbox"/>
What are the causes of IBD (Crohn's disease, ulcerative colitis)? Patients: 49, Clinicians: 6, Total: 55	<input type="checkbox"/>
What triggers IBD in a susceptible person? Patients: 13, Clinicians: 0, Total: 13	<input type="checkbox"/>

Does stress play a role in the cause of IBD? Patients: 11, Clinicians: 1, Total: 12	<input type="checkbox"/>
Do environmental factors play a role in the cause of IBD? Patients: 7, Clinicians: 1, Total: 8	<input type="checkbox"/>
Do genetics play a role in the cause of IBD? Patients: 26, Clinicians: 1, Total: 27	<input type="checkbox"/>
Can we identify genetic patterns that could predict the type of IBD? Patients: 1, Clinicians: 1, Total: 2	<input type="checkbox"/>
Does diet play a role in the cause of IBD? Patients: 6, Clinicians: 1, Total: 7	<input type="checkbox"/>
Do antibiotics play a role in the cause of IBD? Patients: 4, Clinicians: 0, Total: 4	<input type="checkbox"/>
Does weather and/or pollution play a role in the cause of IBD? Patients: 3 Clinicians: 0, Total: 3	<input type="checkbox"/>
How does diet impact IBD? Patients: 45, Clinicians: 14, Total: 59	<input type="checkbox"/>
Is there a diet best suited for those with IBD? Patients: 47, Clinicians: 13, Total: 60	<input type="checkbox"/>
Can diet trigger IBD flares? Patients: 10, Clinicians: 3, Total: 13	<input type="checkbox"/>
Do pesticides/chemical additives impact the development of IBD? Patients: 2, Clinicians: 1, Total: 3	<input type="checkbox"/>
What is the role of probiotics in the management of pediatric IBD patients? Patients: 5, Clinicians: 0, Total: 5	<input type="checkbox"/>
What is the role of prebiotics in IBD? Patients: 2, Clinicians: 0, Total: 2	<input type="checkbox"/>
Is the best diet different from person to person? Patients: 2, Clinicians: 0, Total 2	<input type="checkbox"/>

Can IBD be prevented? Patients: 84, Clinicians: 13, Total: 97	<input type="checkbox"/>
How can surgery in IBD be avoided? Patients: 3, Clinicians: 0, Total: 3	<input type="checkbox"/>
Can diet prevent the development of IBD? Patients: 26, Clinicians: 3, Total: 29	<input type="checkbox"/>
Why does IBD differ from patient to patient? (ie: therapies, phenotypes, symptoms, etc) Patients: 13, Clinicians: 2, Total: 15	<input type="checkbox"/>
How do patients research IBD topics based on their individual IBD needs? Patients: 6, Clinicians: 0, Total: 6	<input type="checkbox"/>
What affects the onset of IBD? Patients: 5 Clinicians: 0, Total: 5	<input type="checkbox"/>
How do we effectively educate about living with IBD? Patients: 0 Clinicians: 2, Total: 2	<input type="checkbox"/>
Once diagnosed, how often is it appropriate to re-scope? (ie in remission, flaring?) Patients: 10, Clinicians: 12, Total: 22	<input type="checkbox"/>
What is the best test for determining whether a patient is flaring? Patients: 2, Clinicians: 0, Total: 2	<input type="checkbox"/>
Are there long term side effects from IBD testing? Patients: 2 Clinicians: 0, Total: 2	<input type="checkbox"/>
What skills or psychosocial counselling have been helpful in supporting children and teens with IBD? Patients: 7 Clinicians: 0, Total: 7	<input type="checkbox"/>
What is the relationship between IBD and mental health (ie Anxiety, Depression)? Patients: 15, Clinicians: 1, Total: 16	<input type="checkbox"/>

What are the outcomes of current mental health management? Patients: 0, Clinicians: 2, Total: 2

☐

What are the clinical outcomes of people that receive psychosocial support? Patients: 3, Clinicians: 1, Total: 4

☐

Do IBD medications effect a patient's behaviours and emotions? Patients: 3 Clinicians: 0, Total: 3

☐

How is body image affected by IBD? Patients: 6, Clinicians: 0, Total: 6

☐

How does a child being diagnosed with IBD affect how the family functions, for example emotional impact on parents? Patients: 3, Clinicians: 0, Total: 3

☐

What are the psychosocial implications of tube feeds, and how can we support children/teens with them? Patients: 2, Clinicians: 0, Total: 2

☐

How does the diagnosis of IBD change and affect the day to day management of life? (ie coping at school) Patients: 2, Clinicians: 1, Total: 3

☐

How does stress effect IBD? (exams, university, life stress etc.) Patients: 2, Clinicians: 0, Total: 2

☐

What supports are helpful for parents at the time of diagnosis and during treatment? Patients: 1, Clinicians: 1, Total: 2

☐

When is an appropriate time to deal with mental health issues during the treatment plan? Patients: 2 Clinicians: 1, Total: 3

☐

How do I help my child prepare emotionally for diagnostic procedures? Patients: 2, Clinicians: 0, Total: 2	<input type="checkbox"/>
As an individual with IBD are you at an increased risk of developing other autoimmune diseases (ie celiac disease)? Patients: 2, Clinicians: 1, Total: 3	<input type="checkbox"/>
Is there an association with ADHD and IBD or the medications that are used to treat ADHD? Patients: 2, Clinicians: 0, Total: 2	<input type="checkbox"/>
What effect do hormonal changes (ie: menstruation) have on IBD and the medications used? Patients: 2, Clinicians: 0, Total: 2	<input type="checkbox"/>
What is the long term effect of medication used to treat flare ups and maintain remission once remission is achieved? Patients: 5, Clinicians: 1, Total: 6	<input type="checkbox"/>
What factors improve quality of life in people living with IBD? Patients: 1 Clinicians: 1, Total: 2	<input type="checkbox"/>
What are the long term effects of IBD on daily life such as school, work, etc.? Patients: 6, Clinicians: 0, Total: 6	<input type="checkbox"/>
What long term side effects will happen from treatments such as azathioprine, methotrexate and biologics? Patients: 26 Clinicians: 2, Total: 28	<input type="checkbox"/>
Is it possible to stop treatment after a long period of remission? Patients: 4, Clinicians: 2, Total: 6	<input type="checkbox"/>
Do treatments differ in children than in adults? Patients: 2 Clinicians: 0, Total: 2	<input type="checkbox"/>
Is there a role for alternative treatment such as holistic supplements, vitamins, naturopathic remedies? Patients: 12 Clinicians: 0, Total: 12	<input type="checkbox"/>

What is the role of fecal microbial transplant in IBD? Patients: 2 Clinicians: 1, Total: 3	<input type="checkbox"/>
Could medical marijuana be used to treat IBD? Patients: 2, Clinicians: 0, Total: 2	<input type="checkbox"/>
How can we best tailor therapy to maximize benefit for each individual patient? Patients: 0, Clinicians: 2, Total: 2	<input type="checkbox"/>
With new emerging biologic therapies, can they, and how might they be combined to achieve maximal benefit? Patients: 0 Clinicians: 2, Total: 2	<input type="checkbox"/>
What are the benefits and success rates of steroids vs enteral nutrition? Patients: 1, Clinicians: 1, Total: 2	<input type="checkbox"/>
Other than medication, what are some ways to manage IBD symptoms, including pain, during a flare? Patients: 9 Clinicians: 1, Total: 10	<input type="checkbox"/>
What are the long term effects of IBD on everyday life eg: fatigue, ability to function in full time employment, symptoms, etc.? Patients: 2 Clinicians: 0, Total: 2	<input type="checkbox"/>
Why are children with IBD tired and low in energy (even without other IBD symptoms)? Patients: 3, Clinicians: 0, Total: 3	<input type="checkbox"/>
What triggers flare ups in IBD? Patients: 16 Clinicians: 0, Total: 16	<input type="checkbox"/>
Why does North America, especially Canada, have such high incidence and prevalence rates of IBD? Patients: 8 Clinicians: 1, Total: 9	<input type="checkbox"/>
Why are we seeing such a sharp increase in IBD particularly in young children? Patients: 8 Clinicians: 0, Total: 8	<input type="checkbox"/>

Will it be possible to cure IBD (through drug, nutrition, and/or gene therapy)? Patients: 27, Clinicians: 0, Total: 27 ☐

How do we best monitor for infections during anti-TNF α treatment? Suggested from clinical practice guidelines ☐

What are optimal vaccination strategies in IBD? Suggested from clinical practice guidelines ☐

What is the optimal role of therapeutic drug monitoring (drug level and/or anti-drug antibody detection) in the management of pediatric IBD? Suggested from clinical practice guidelines ☐

How do different therapies (e.g., EEN, anti-TNF) affect body composition in pediatric IBD? Suggested from clinical practice guidelines ☐

How do we improve disease self-management in pediatric IBD? Suggested from clinical practice guidelines ☐

What is the optimal means of assessing adherence to therapy in pediatric IBD? Suggested from clinical practice guidelines ☐

What role does microbiota play in fistulizing Crohn's disease? Suggested from clinical practice guidelines ☐

Are anti-tumor necrosis factor alpha/anti-TNF drugs an effective treatment for internal fistulas? Suggested from clinical practice guidelines ☐

Is there an effective brief screener that can be used in clinical practice to identify psychosocial issues in pediatric IBD? Suggested from clinical practice guidelines

☐

What is the clinical and cost effectiveness of prednisolone compared with aminosalicylates for the induction of remission for people with moderate ulcerative colitis? Suggested from clinical practice guidelines

☐

What is the clinical and cost effectiveness of regular maintenance treatment compared with no regular treatment (but rapid standard treatment if a relapse occurs) in specific populations with mild to moderate ulcerative colitis? Suggested from clinical practice guidelines

☐

What is the clinical and cost effectiveness of regular maintenance treatment compared with no regular treatment (but rapid standard treatment if a relapse occurs) in specific populations with mild to moderate ulcerative colitis? Suggested from clinical practice guidelines

☐

Following successful medical induction of remission of Crohn's disease of the colon, is mesalazine more clinically and cost effective than no treatment? Suggested from clinical practice guidelines

☐

What is the effect on quality of life of medical treatment (immunosuppressive or biological therapy) compared with early surgery for Crohn's disease limited to the distal ileum? Suggested from clinical practice guidelines

☐

What are the information needs of people with Crohn's disease, as defined by people with the condition, and can education and support based on these needs lead to better clinical and quality of life outcomes? Suggested from clinical practice guidelines

☐

Does combined therapy of a tumour necrosis factor (TNF)?alpha inhibitor with an immunosuppressant improve clinical outcomes and reduce the risk of serious adverse events in adults and children (6-17 years) with severe, active Crohn's disease who are starting a TNF?alpha inhibitor (infliximab or adalimumab) for the induction of remission, where previous conventional therapy has failed? Suggested from clinical practice guidelines

☐

How can bowel preparation be optimized in order to improve MRE imaging and increase tolerability in pediatric patients? Suggested from clinical practice guidelines

☐

What is the mechanism of action of exclusive enteral nutrition for induction and maintenance of remission in Crohn's disease? Suggested from clinical practice guidelines

☐

What is the relationship between nutrition status and rate of infections in pediatric IBD?
Suggested from clinical practice guidelines

☐

Is there a relation between bone health and vitamin D status in children with IBD based on systematic longitudinal studies?
Suggested from clinical practice guidelines

☐

What is the vitamin D level that benefits bone health in these children based on large clinical trials? Suggested from clinical practice guidelines

☐

Does exclusive enteral nutrition and enteral supplementation benefit bone health based on clinical trials? Suggested from clinical practice guidelines

☐

What is the exercise regimen (s) that would prevent bone health compromise and improve bone health in children with IBD?
Suggested from clinical practice guidelines

☐

Would changing the therapeutic approach (IBD therapy) be beneficial in children with IBD and compromised bone health, and which approach would be most beneficial (eg, early introduction of biologics vs conventional therapy vs enteral nutrition or supplementation?
Suggested from clinical practice guidelines

☐

Is there a role for "bone-active" medications such as calcitonin and bisphosphonates in children with IBD and who would benefit?
Suggested from clinical practice guidelines

☐

What effect does the transition process, from pediatric to adult care, have on medical compliance and disease course (e.g, hospital admission, surgery, disease and drug complications)? Suggested from clinical practice guidelines

☐

Is heparin use associated with lower risk of thromboembolism in severe pediatric UC, and what are the risk factors for use of heparin in this population? Suggested from clinical practice guidelines

☐

How can we better understand the relationship between HRQOL and IBD in order to design early interventions for those at highest risk? Suggested from clinical practice guidelines

☐

What is the relationship between higher HRQOL and cost savings for the healthcare system in pediatric IBD? Suggested from clinical practice guidelines

☐

Is improving HRQOL in pediatric IBD associated with lower school absences, and better academic, social and emotional development? Suggested from clinical practice guidelines

☐

How does level of disease activity, length of disease, presence of surgical intervention and nature of medication regimen affect psychosocial adjustment in youth with IBD? Suggested from clinical practice guidelines

☐

What is the relationship between psychosocial development and disease parameters over time in pediatric IBD? Suggested from clinical practice guidelines

☐

Here are the questions you had indicated are in your top 20 on the previous page. Please rank these in order from 1-20, with 1 being the MOST important, and 20 being the LEAST important.

When making your ranking, please also consider the factors that we had mentioned on the previous page, including:

- Your personal experience with (or caring for a person with) the disease
- Whether the question was reported by more people
- Whether the question was reported by both clinicians and patients

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

(Branching listed
each individual's
top 20 questions)

Supplemental Material – Expanded description of JLA Methodology

Step 1: Form a Steering Committee

A steering committee was formed to coordinate and implement all activities (Figure 1). It consisted of current pediatric patients, adult IBD patients who had transitioned from pediatric to adult care, caregivers, and clinicians involved in direct care of pediatric IBD patients. A facilitator who had conducted a number of JLA priority setting partnerships in Canada advised the steering committee throughout this process. Steering committee membership aimed to be inclusive of gender, geography, and language (English and French first language speakers were included).

Step 2: Initial Steering Committee Meeting, Develop an Action Plan

An initial in-person day long steering committee meeting was held to introduce members, initiate discussion, understanding of the research process, and establish the principles of the partnership. This meeting was held to build rapport and enthusiasm, and to ensure that team members felt valuable regardless of age, or role (patient, caregiver, or clinician).

Step 3: Identifying treatment uncertainties.

The steering committee created an online survey (see Supplemental Material) to capture uncertainties around the treatment and management of pediatric IBD. The committee took part in a facilitated discussion to determine the broad survey topics, and to decide on the wording and order of the survey questions. The final survey included open-ended questions with prompts to cover the key treatment and management uncertainties. The survey was made age and role (ie. patient, family member, and clinician) appropriate, and was available in both English and

French. Two in-person focus groups were also held for younger pediatric patients (ages 6-12 years old) in order to ensure the views of this group were included, since they may not have been able to complete the web-based questionnaire independently. Only a small amount of identifying information was collected (age, ethnicity, province, length of time since diagnosis, role, and clinician type) in order to maximize response rate, and reduce participant burden.

Recruitment was targeted through IBD clinics across Canada, since pediatric IBD care is almost exclusively delivered in tertiary care children's hospitals. We also partnered with national IBD organizations to capitalize on their established communication networks with patients and families. This included reaching patients through social media platforms, which are being increasingly used by parents and teens to obtain information about child health (13-15). .

Step 4: Refining questions and uncertainties.

Survey responses, transcripts from focus groups, and research questions identified through a review of clinical practice guidelines were used to identify potential research questions about pediatric IBD treatment and management. The UK Duets database of treatment uncertainties (www.library.nhs.uk/duets) was not referenced in review of the literature as these uncertainties have, to our knowledge, primarily been generated by, or focused on research concerning adults. Additionally, the scope of the current project was broader than the focus of the UK Duets database which is centered around uncertainties focused on the effects of treatment. A qualitative analysis of the generated research questions was conducted using NVivo Software (16). The broad themes developed when the initial survey was created were used to guide the analysis. A single coder read through each submitted item and similar questions were categorized into the

previously determined themes. When items did not fit within the themes initially identified, a new theme was created.

The resulting list of themed questions was reviewed by the steering committee in clinician-patient/caregiver pairs to determine whether similar uncertainties could be combined into an overarching question, referred to as an “indicative question”. Indicative questions that were out of scope (e.g., questions solely related to adults with IBD) or not truly a research question (e.g., a patient stated “I hate having Crohn’s disease”) were removed. Steering committee clinician-patient/caregiver pairs reviewed uncertainties grouped into themes, and verified that these indicative questions were reflective of the group of questions from which they were created (17). Indicative questions were then divided into a list of questions which *already had a sufficient answer* in the literature (ie. “answered” questions), while the remainder formed a list of questions/uncertainties *without a sufficient answer* (ie. “unanswered” questions). JLA guidance on what a sufficient answer includes was followed (12). This was achieved by reviewing the existing literature to identify reliable, reputable systematic reviews, guidelines, and current ongoing research addressing the question. Questions were categorized as *already having a sufficient answer* if they are adequately addressed in the literature, and through consultation and review with IBD content experts.

Step 5: Research Prioritization—Top 10 uncertainties.

The unanswered questions were gathered, and a prioritization survey was developed. The survey was made publicly accessible, and recruitment took place through clinics, communication with IBD groups and partnership websites. Participants were asked to rank their top 20 questions in decreasing order of importance. Priority scores were generated to determine which questions

were most important. Individual rankings of each group were tallied for consideration in the prioritization workshop, yet the collective rank was used to decide upon the top questions.

A final face-to-face 1-day workshop, attended by steering committee members, and additional patients, caregivers and clinicians, was held in order to complete prioritization, following the JLA process (12). A nominal group technique (12, 19) was used to help participants organize their personal priorities ahead of the workshop. Participants were asked to complete a worksheet to rank-order the remaining uncertainties independently, while considering those questions that were identified by more respondents, and across the respondent groups. During the workshop, small groups of 7-8 participants broke off into separate rooms with an experienced facilitator who did not have personal or professional experience with IBD. Facilitators ensured that all group member's voices were heard and valued such that collective decision making equally included patients, caregivers, and clinicians. Two researchers that were not part of the priority setting process rotated around to each group and monitored the facilitation process to ensure groups were on track and that everyone had an equal chance to voice their opinion. Each group was provided with large cards that listed each indicative uncertainty, with the number of survey respondents for each, and samples of originally worded survey submissions. The groups deliberated to rank order the uncertainties until consensus was reached. This process was repeated with new groups, again creating a new rank-order. Finally, all group results were amalgamated, and a large group ranking took place. Deliberations continued until a final agreed-upon top 10 was identified.