



Strategy for Patient-Oriented Research Putting Patients First

PATIENT ENGAGEMENT DR. DEBORAH MARSHALL SANDRA ZELINSKY







IMAGINE | Priority-Setting for IBD/IBS Research

Purpose/Goal:

- Inform gaps, priorities in IBD/IBS research
- Shape next proposal for CIHR funding renewal

Approach:

- Survey modified James Lind Alliance

• Team:



• Partners:

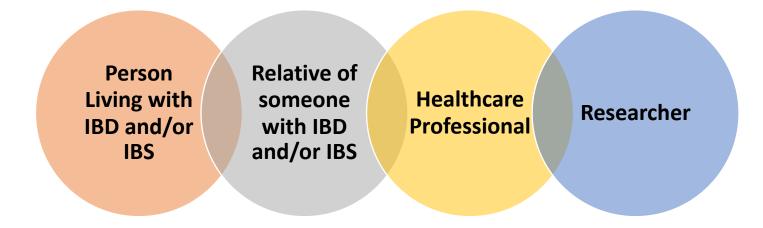






IMAGINE | Priority-Setting for IBD/IBS Research

Survey Participants:



Recruitment Target:

200 survey responses by January 2021





IMAGINE | Priority-Setting for IBD/IBS Research

Progress to Date:

- REB Approval: Not applicable
- Active Recruitment Sites: Social media
- Subjects screened/enrolled: TBD
- Sent out first survey to disseminate through Crohn's and Colitis Canada's

Question for IMAGINE Network:

• Please help us disseminate the survey!







IMAGINE | Patient Engagement Evaluation Exploratory Study

Study Purpose/Goal

- Build partnerships: SPOR SUPPORT Units, CIHR SPOR Chronic Disease Networks
- Assess and compare patient engagement

Research Question:

What factors or attributes are important to patients with IBD in considering treatment tapering?

Research Team:











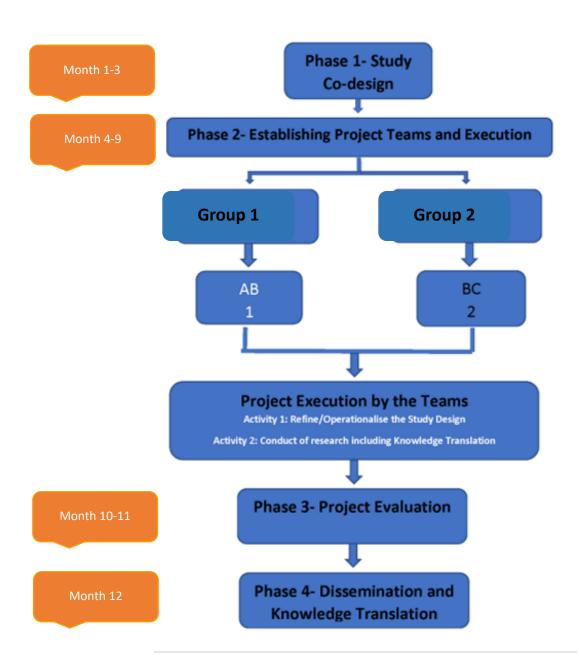




IMAGINE | Patient Engagement Evaluation Exploratory Study

Study Design: Comparative analysis

- Two groups conduct qualitative research to identify attributes and levels for a preferences study related to IBD
- Patients are coinvestigators, research partners, and participants at different levels







IMAGINE | Patient Engagement Evaluation Study

Progress to Date:

- REB Approval: Submitted awaiting approval (Oct-Nov)
- Virtual Recruitment (Dec)
 - Plan to enroll 14 group members in 2 groups
- Developing training materials (Nov-Dec)
- Planning meeting with core research team (Dec)









IMAGINE | Ulcerative Colitis Preferences Study

Objectives:

 Quantify preferences of patients with ulcerative colitis for fecal microbiota transplantation (FMT) and trade-offs regarding benefits and risks of alternative treatments

Participating Sites:

















Survey Completion Progress:

N=115 of 230 goal, aiming to finish January 2021

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IMAGINE | Patient Engagement and Capacity Building Activities

National Team

The Mob: A peer-to-peer study on the psychosocial relationship between individuals with IBD and food





Alberta Team

We've Got Guts: Exploring what resources IBD patients need after diagnosis

Patient
Engagement
Webinar (Sept)

Patient Research Partner, Kim Daley, received the McNaught and Taillon Emerging Health Leader Award and Bursary (Sept)









PATIENT ENGAGEMENT SUB-STUDIES

SANDRA ZELINSKY KWESTAN SAFARI MARCIA BRUCE



IMAGINE | Patient-Led Study

Recruitment and Retention

Improving patient participation in longitudinal research: An innovative patient-led patient-oriented qualitative research project to understand the motivations and barriers to getting and staying involved in the IMAGINE SPOR Study.



Zelinsky S¹, Daley K, Neary E², Mason K, Bellissimo G, DeNino A, MacKean G¹, Fernandes A³, Moayyedi P³, Marshall D¹



¹ University of Calgary ² Queen's University ³ McMaster University



Conclusions: Patient-Led and Patient-Oriented Research aims to create more meaningful and relevant research findings for all stakeholders. Patient Research Partners (PRPs) have been involved throughout all stages of this research project. Having PRPs from across Canada involved in the data collection helped to ensure that we recruited and captured a nation-wide representation of interview participants. We recognize that having several interviewers may have created variables in interview styles. We tried to mitigate these variables through training and the use of an interview guide. These results may not be generalizable because of the small sample size and therefore we have not captured perspectives from a large sample size. Results from this study will help to inform the development of recruitment and retention strategies for the IMAGINE SPOR Network study.

Methods

- Patient research partners from the IMAGINE-SPOR network collaborated with researchers with the aim of identifying strategies to increase recruitment and retention within the main study cohort (MAGIC).
- After undergoing training in qualitative research, PRPs co-designed and developed a semi-structured interview guide alongside academic researchers.
- 7 PRPs conducted qualitative semi-structured interviews, which were recorded electronically. PRPs took part in online meetings over the Zoom platform throughout the entirety of the study.
- All of the interviews were transcribed by a PRP, a trained medical transcriptionist Five PRPs conducted the data analysis by coding the interview content into common themes.



Results

PRPs recruited participants from B.C., AB., MB., ON., N.S., & NL. They conducted semi-structured interviews with a total of 27 participants, ages ranging from 20-75 years. Interviews were conducted between Oct. 2019- Jan. 2020.

The top four themes of key motivators to study participation that emerged were:
Convenience
Experience
Communication
Compensation



BACKGROUND

The IMAGINE SPOR Network is conducting a large longitudinal research study (MAGIC) to investigate the interactions between inflammation, diet, and mental health in patients with inflaminiritable bowel syndrome (IBS). This study aims to recruit 8000 subjects (CD, UC, IBS and healthy subjects) that must submit blood, urine and stool samples, and complete online questionnaires identify more effective recruitment and retention strategies, a group of IMAGINE PRPs led a qualitative study to better understand the motivations and barriers of healthy controls to participating studies like MAGIC.

Submitted to the Crohn's & Colitis Congress 2021





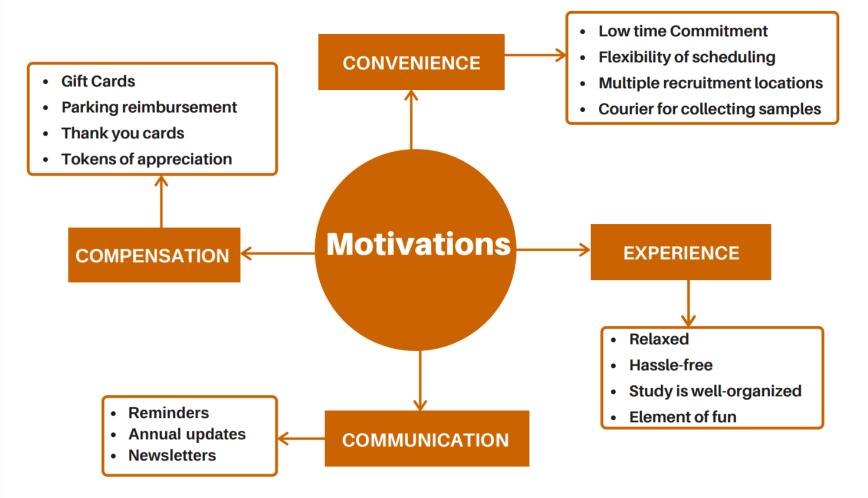




IMAGINE | Patient-Led Study

Recruitment and Retention

Results:





IMAGINE | Patient-Led Study

Recruitment and Retention

Next Steps:

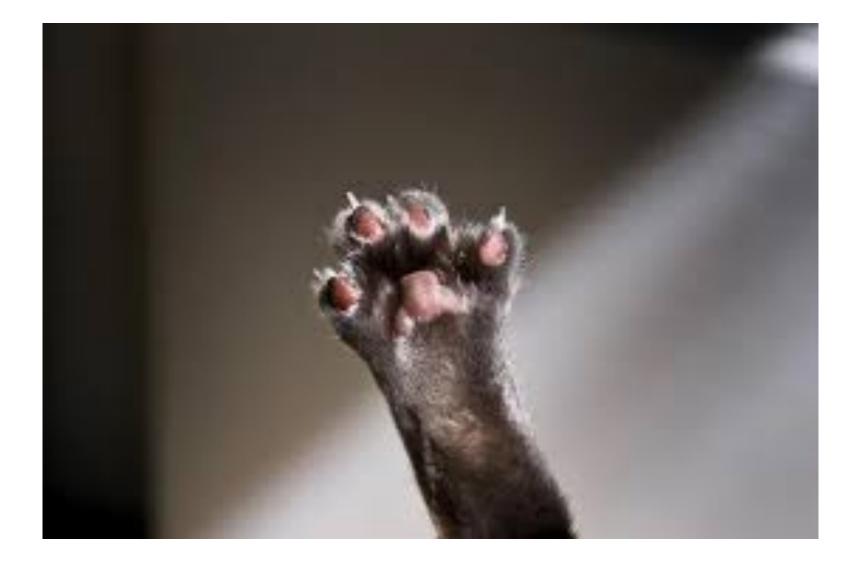
Co-develop recruitment strategies for healthy controls

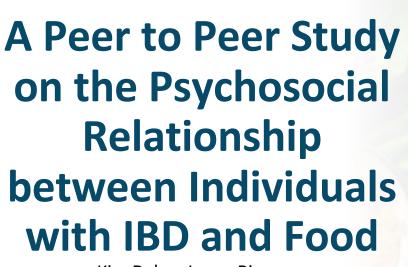
Implementation





Questions or comments?





Kim Daley, Jenna Rines, Sunny Loo, & Kwestan Safari























OUR TEAM





PaCER Methodology

SET:

Set the direction of the study together with the participants

COLLECT:

Collect and analyze data: focus groups and individual interviews

REFLECT:

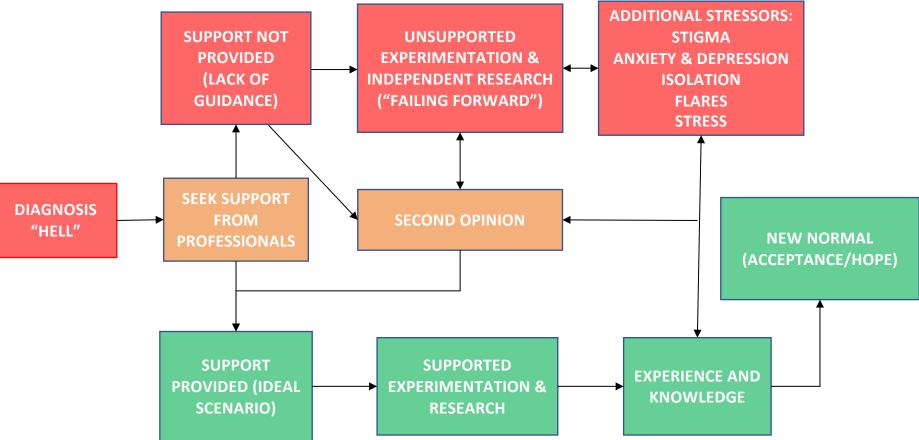
Reflect on findings together with participants



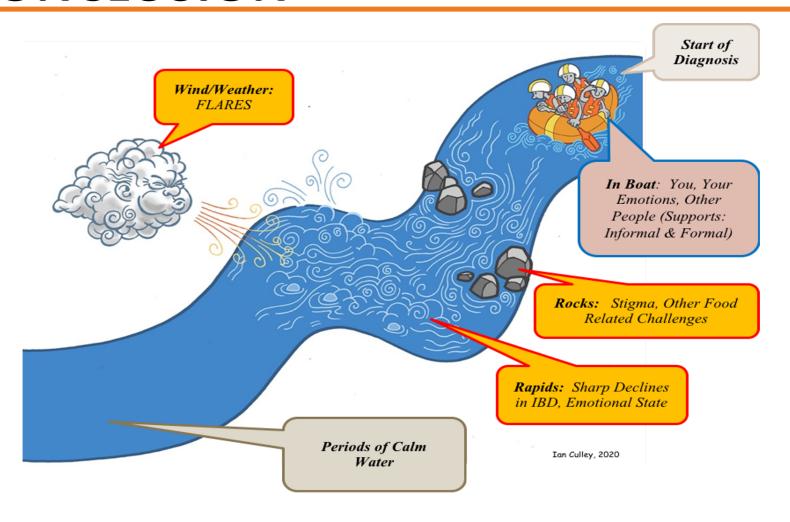




RESULTS DIAGNOSIS "HELL"



CONCLUSION





KEY RECOMMENDATIONS

- 1. Create working group of healthcare providers and IBD patients to determine guidelines supporting patients' experimentation with diet
- 2. Train healthcare providers to recognize the psychosocial significance of diet for IBD patients
- 3. Record and share IBD patient stories about their experiences with food to raise awareness (using social media, podcasts, websites, videos, webinars)
- 4. Create a centralized resource and IBD Specialist referral website
- 5. Create database of healthcare providers supportive of holistic approaches
- 6. Use telemedicine to reach IBD patients more effectively especially in areas lacking IBD specialists
- 7. Provide access to IBD case managers/coordinators to help patients navigate the health care system
- 8. Coordinate more support for IBD patients (support groups and other safe spaces)
- 9. Attend conferences (like CDDW) with these results and patient stories to share them widely
- 10. Gain support of foundations such as CCC or IMAGINE-SPOR to foster better understanding of the complexity of food relationship for IBD patients

ACKNOWLEDGEMENTS

University of Calgary

Dr. Deborah Marshall
Deirdre Walsh
Marlyn Gill
The PaCER Teaching Team
Dr. Nancy Marlett

IMAGINE

Aida Fernandes
The Imagine Team

Patient Participants









CASPHR 2020 Poster **Presentation**

Visit

https://cahspr.ca/wpcontent/uploads/2020/06/Rin es-216.pdf

or scan the QR code to view our digital poster for the CAHSPR 2020 Conference.





A patient led, peer-to-peer qualitative study on the psychosocial relationship between patients with Inflammatory Bowel Disease (IBD) and food.

Jenna Rines¹, Kim Daley¹, Sunny Loo¹, Kwestan Safari¹, Deirdre Walsh², Paul Moayyedi^{3,4}, Aida Fernandes³, Deborah Marshall^{3,5}, Nancy Marlett⁵

1: Patient and Community Engagement Research Intern; 2: Patient and Community Engagement Research Mentor; 3: The IMAGINE Chronic Disease Network; 4: McMaster University; 5: University of Calgary

BACKGROUND

als study is part of an internship within the Patient and Community Engagement Research (PaCER) program Brien Institute of Public Health, University of Calgany, Canada. The following informed our research project

- Canada has one of the highest rates of IBD in the world¹. No one diet has been identified as effective for disease management or treatment
- Many patients believe diet affects their symptoms and often make dietary changes early on at diagnosis^{2,3}.

 Food has cultural, social, psychological significance; almost all social events center around food, resulting in patient isolation from their communities due to dietary restrictions
- patient isolation from their communities due to diedary restrictions.

 Patient experiences with food have not being adequately addressed in the literature, even though 90% of patients with Crohn's Disease in one study changed their diet after receiving an IBD diagnosis^{1,6}.

Our study seeks to understand the psychosocial impact of IBD on nutrition and diet for young adults. We aim to inform healthcare practitioners, members of the IBO community, health policy makers, and others about the complex psychosocial nature of patients' relationship with flood, as well as communicate patient perspectives and ndations to improve outcomes.

RECOMMENDATIONS

How can IBD healthcare providers challenge outdated assumptions and emp they can gather scientifically-informed tools and information to help guide their dietary experimentation? ecommendations from participants included:

- Create a centralized resource/referral website with facts/contact information of specialized healthcare providers. Create a working group of healthcare providers and patients to collaborate and determine clinical guidelines that help patients experiment with diet.
- Additional training for healthcare providers regarding the psychosocial impact of food, and its significance on
- symptoms and the emotional impact to facilitate referrals to appropriate services and other practition. Record and share patient stories about their experiences with food widely to encourage increased awa issues and messages of hope amongst patients and IBD healthcare providers.
- Utilize telemedicine to reach patients and service areas that may not have access to as many IBD specialists Access to IBD case managers/coordinators that help patients navigate the health care system, make
- ndations to improve their situation, and be a non-judgmental person to listen to their stor More resources, e.g. support groups and non-judgmental spaces for patients to talk and support each other

METHODOLOGY

- Participants were recruited through social media posts by IMAGINE-SPOR. Crohn's and Colitis Canada, and other
- personal contacts.
 Inclusion criteria: 1) 18-95 years old, 2) Sufficient fluency in English to participate in interviews/focus groups, 3)
 Lives in Canada, 4) Self-identify as diagnosed with IBD.
- PaCER methodology was used to engage patients in peer-to-peer co-designed qualitative research (Figure 1):



Data analysis: Iterative questioning, narrative analysis, and open coding elements from grounded theory. Narrative interviews and focus groups were held online via encrypted videoconferencing platform

RESUITS

- terative analysis revealed four emerging categories (illustrated via numbers on Figure 2): Experimenting With Food: The ways in which people with IBD cope with the challenges of navigating which foods to eat, or the tips and tricks used to lessen food stressors or to regain control. Subcategories: a) Trial and Error, b) Not Black and White, c) Weighing Risks and Benefits, d) Developing Knowledge and Experience.
- Evolution Over Time: How their relationship with food evolves over time. Foods fluctuate between being feared/avoided and being safe, and participants gained knowledge about how certain foods make them feel. Subcategories: a) Starts with Lack of Professional Guidance, b) Experimentation and Independent Research, c) Seeking Second Opinions, and a) Acceptance and Molintaining Hope 1.
- 1) Diet Changes are Emotional: Experiencing difficult emotions was common as diets changed, especially in relation to not being able to eat 8 does that bring comfort, attending family gatherings or holiday dinners, and at times not being able to eat at all. Subcategories: a) Flores Before and After, b) Losing Comfort Foods, c) Novigoting Social/Cultural Gotherings, d) Guilt/Burden of Diet Changes on others, e) Reclaiming Joy.
- Role of Stigma: Participants' diet changes were judged, thus affecting relationships, causing social isolation worry, confusion about changing food rules, and frustration. Subcategories: a) Support System (positive or negative), b) Judgement from Others, c) Justifying Your Diet, d) Unsolicited "Cures", e) Self-Advocacy.

DISCUSSION

- Participants described:
- rucipans excrees: Hawing a complex psychosocial relationship with food. Constantly changing food tolerances and setbacks, emotional distress, social isolation, and stigma. Experiencing grief at the realization that their relationship with food had changed forever. Perceived gaps in healthcare system and dismissive attitudes (namely from Gis) regarding diet changes.
- Increasing their knowledge and experience about food on their own in order to "surviv

Our findings coincide with existing literature. Participants believed considering diet in the mar initiality contains with existing interature. Participants believed considering diet in the manage is key, yet Western medical guidelines neglect dietary counselling and resources^{5,25}. Our group reptualizes this journey with food as that of a person white water rafting (see Figure 3 below):



- The people in the raft symbolize the patient and other informal/formal medical supports to assist them
- The water symbolizes IBD: patients have little control over it and little knowledge about what lies ahead
- The water symbolises loop, patients have intered control over a rank in use knowledge about what the arready. Factors such as weather, rapids, and one's knowledge about white water artifug impact experience. The more experience a person has, the more knowledge they accumulate to be able to help them navigate future rocky waters. Acknowledging their own resilience, the person begins to accept their situation, which informs their future behaviour and outlook.

CONCLUSION

- practical clinical knowledge and structured supports available from IBD healthcare providers. Participants noted the lack of supports from their healthcare team as a significant trigger in psychosocia
- relations block the left of spages of the first intended equal to agree and in organ in proposocial challenges related to coping with changes in their diet, feelings of isolation, and emotional distress. Supports Antonovsky ¹² concept of Salutogenesis which describes the origins of health and wellness in contrast with modern Western medicine's focus on studying the causes and origins of disease (Pathogenesis). Although participants' experience of illness and distress was discussed, participants also discussed feelings of
- acceptance, and noted without promoting how they are thriving despite their illness and food challenges.
- Participant recommendations provided were Salutogenic, looking at ways to have productive conversation with retrogent recommendation provides were satistigents, cooling at ways to nave productive conversation with healthcare provides and patients allied to implement important guidelines and share stories that seek to educate and advocate to prevent future negative experiences for newly-diagnosed patients. Further patient-engaged research in this wear is recommended to build a body of practical knowledge and resources that helps patients maintain hope as they navigate food challenges.
- We also suggest specifically examining the psychosocial impact of food on specific IBD patient groups, such as those who have had surgery for their IBD, in order to capture the full range and breadth of experience.

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We would like to acknowledge and thank Marlyn Gill, the IMAGINE Chronic Disease Network, PaCER Teaching Team, Dr. Maria Santana, Dr. Humberto Jijon, and our participants and IBD community members who contributed to our research. The IMAGINE Network is supported by a grant from the Canadian Institute of Health Research SPOR Chronic Disease Network (Funding Reference Number: 1715-000-001) with funding from several partners.

University of Calgary CHREB Ethics ID: REB19-0989

















Inflammation, Microbiome & Alimentation 🔐 Gastro-Intestinal & Neuropsychiatric Effects

PaCER: Alberta IBD Team: We've Got Guts

Exploring What Resources IBD Patients Need After Diagnosis

Presenter:

Marcia Bruce



Research Team:

Marcia Bruce¹, Doug McKay¹, Sherri MacLean¹, Lindsey Rizkalla¹, Kendra Vandenhoven¹, Jeanette Van Roosmalen¹, Tatiana Kuzmyn¹, Marlyn Gill², Esther Halton², Deidre Walsh², Aida Fernandes³, Deborah Marshall ^{3,4}, Nancy Marlett ⁴



- 1: Patient and Community Engagement Research Intern
- 2: Patient and Community Engagement Research Mentor
- 3: The IMAGINE Chronic Disease Network
- 4: University of Calgary



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METHODOLOGY

- PaCER (Patient and Community Engagement Research)
 - PaCER methodology involves a series of interviews and focus groups conducted with patients by patients to complete a research study and formulate recommendations

SET Work with patient participants to set the direction of the study COLLECT Collect and analyze data from interviews and focus groups REFLECT Reflect on findings with patient participants

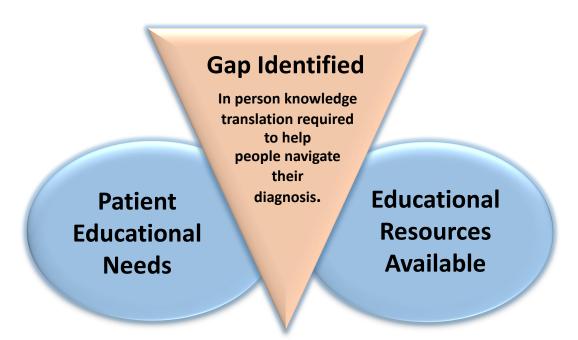
RESEARCH QUESTION

"Please describe what resources IBD patients need after diagnosis."

- Our guiding question was developed using
 - Input from our sponsor IMAGINE
 - Initial patient interviews
 - Literature review
- As interns, we sought to understand the education, information and support IBD patients were supplied with following diagnosis versus what patients felt they needed

FINDINGS

- Several quality online resources exist for patients in Alberta; however, our research concludes that online education done in isolation can lead to poorer adherence and lower certainty
- Benefits of increasing in person patient educational opportunities delivered by IBD physicians and/or IBD nurses leads to empowerment, lower anxiety and lower isolation



CONCLUSIONS

- IBD patients prioritize education as being very important to them. IBD patients value in person interventions particularly upon diagnosis and during key disease transition periods
- Highly educated patients who are actively engaged in their healthcare are more likely to be empowered increasing their medical adherence and improving their quality of life







IMAGINE | Health Care Utilization Study

Objectives:

• Estimate health care utilization and costs of IBD, IBS, and healthy control patients in Alberta, Manitoba, and Ontario linking IMAGINE and administrative health data

Progress to date:

- Established study team and created draft protocol
- Conducted preliminary analysis of IMAGINE
 IBD/IBS/Healthy cohort data to determine study sample
- Refining study protocol, study budget and timeline

Research Team:







