



Inflammation, Microbiome & Alimentation



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:

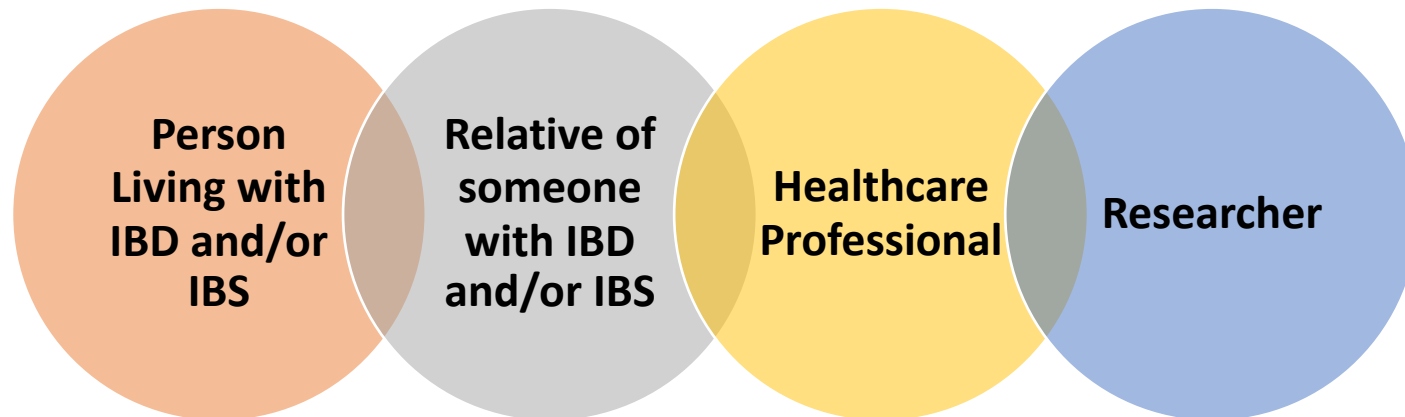


Crohn's and
Colitis Canada
Crohn et
Colite Canada



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

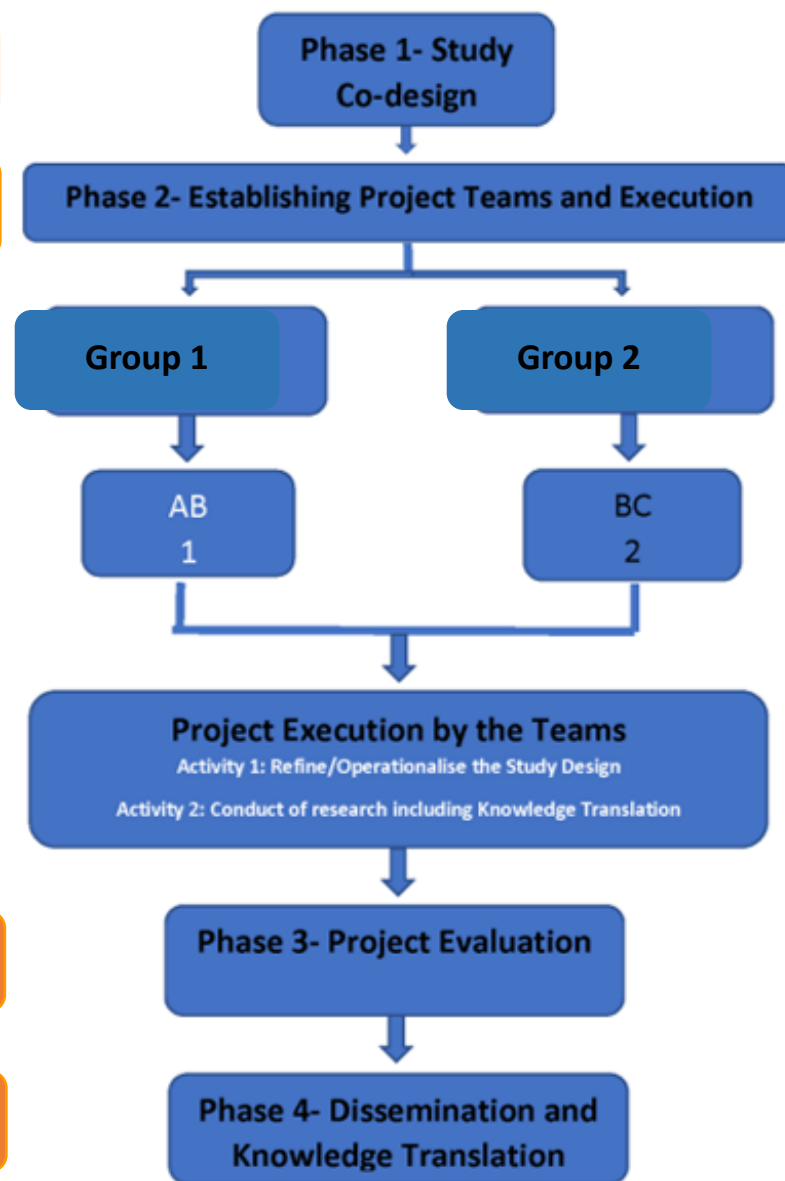
- Two groups conduct qualitative research to identify attributes and levels for a preferences study related to IBD
- Patients are co-investigators, research partners, and participants at different levels

Month 1-3

Month 4-9

Month 10-11

Month 12



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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:

Since February	Since February	Since July	Since November
 University of Manitoba	 UNIVERSITY OF CALGARY	 UNIVERSITY OF ALBERTA	 McMaster University

Survey Completion Progress:

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



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)



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PATIENT ENGAGEMENT SUB-STUDIES

SANDRA ZELINSKY
KWESTAN SAFARI
MARCIA BRUCE

IMAGINE | Patient-Led Study

Recruitment and Retention

Accepted to the
AbSPORU Virtual
Institute 2020

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

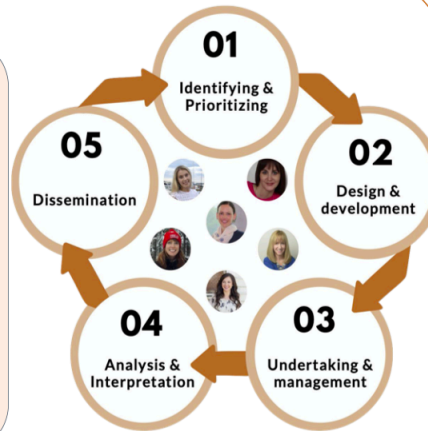


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Conclusions: Patient-Led and Patient-Oriented Research aims to create more meaningful and relevant research findings for all stakeholders. Patient Research Partners (PRPs) have been involved throughout all stages of this research project. Having PRPs 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

1. 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).
2. After undergoing training in qualitative research, PRPs co-designed and developed a semi-structured interview guide alongside academic researchers.
3. 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.
4. 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.

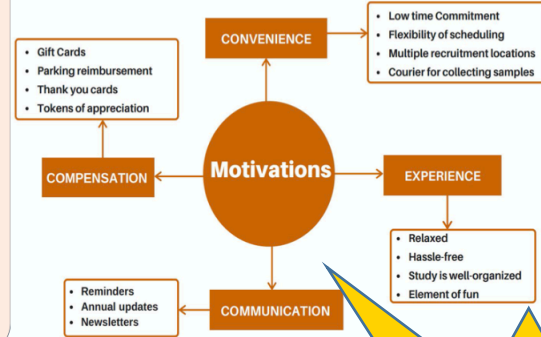


Results

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

Characteristics	Participants N=27
Age, years, mean (age range)	40 (20-75)
Sex, female, n	14
Knew someone living with IBD, n	23



BACKGROUND

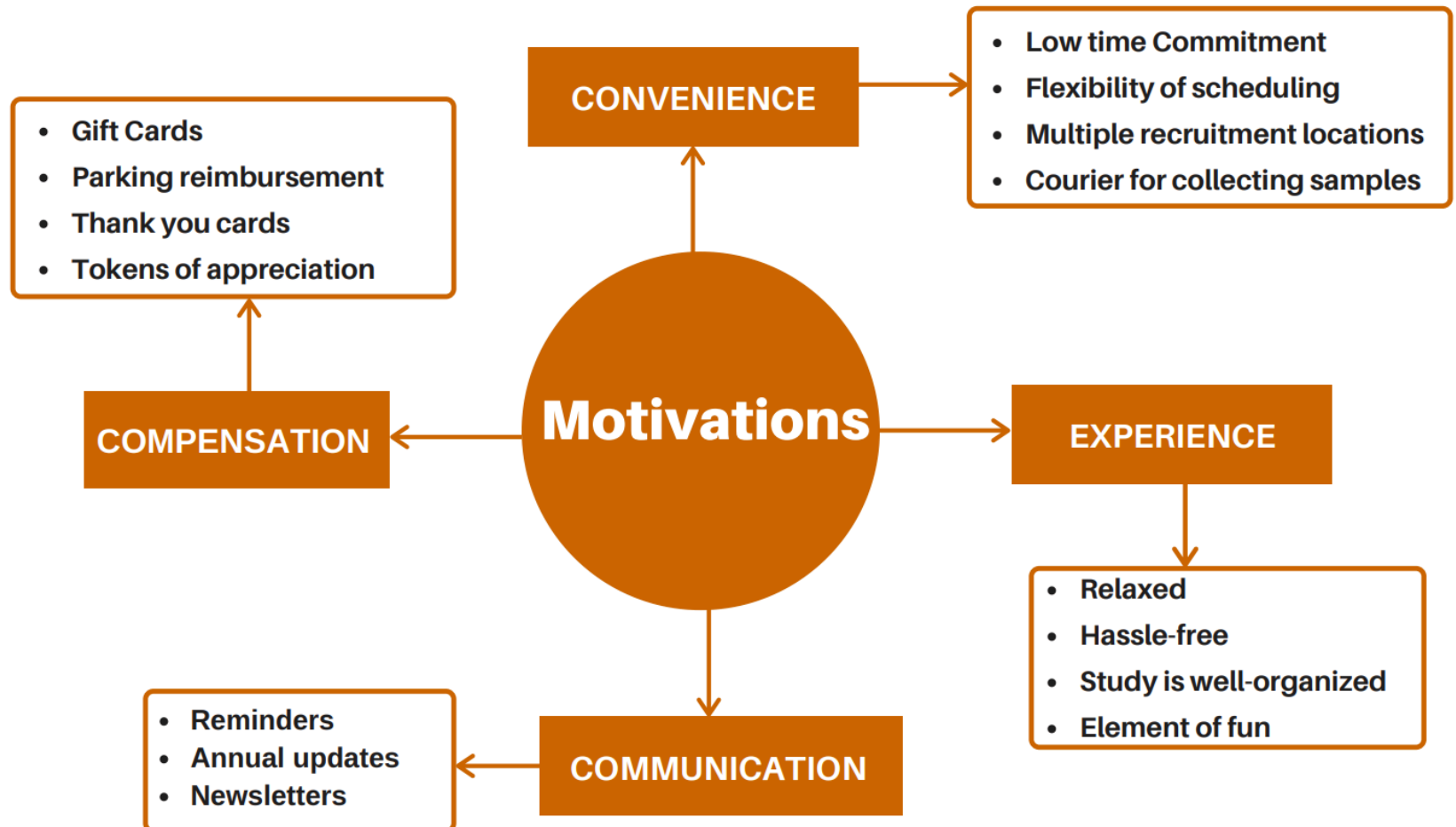
The IMAGINE SPOR Network is conducting a large longitudinal research study (MAGIC) to investigate the interactions between inflammation, diet, and mental health in patients with inflammatory bowel disease (IBD). This study aims to recruit 8000 subjects (CD, UC, IBS and healthy subjects) that must submit blood, urine and stool samples, and complete online questionnaires. To 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 in studies like MAGIC.

Submitted to the
Crohn's & Colitis
Congress 2021

IMAGINE | Patient-Led Study

Recruitment and Retention

Results:



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IMAGINE | Patient-Led Study

Recruitment and Retention

Next Steps:

- Co-develop recruitment strategies for healthy controls
- Implementation



Questions or comments?



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A Peer to Peer Study on the Psychosocial Relationship between Individuals with IBD and Food

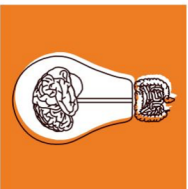
Kim Daley, Jenna Rines,
Sunny Loo, & Kwestan Safari



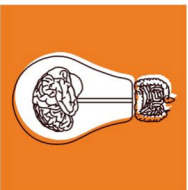
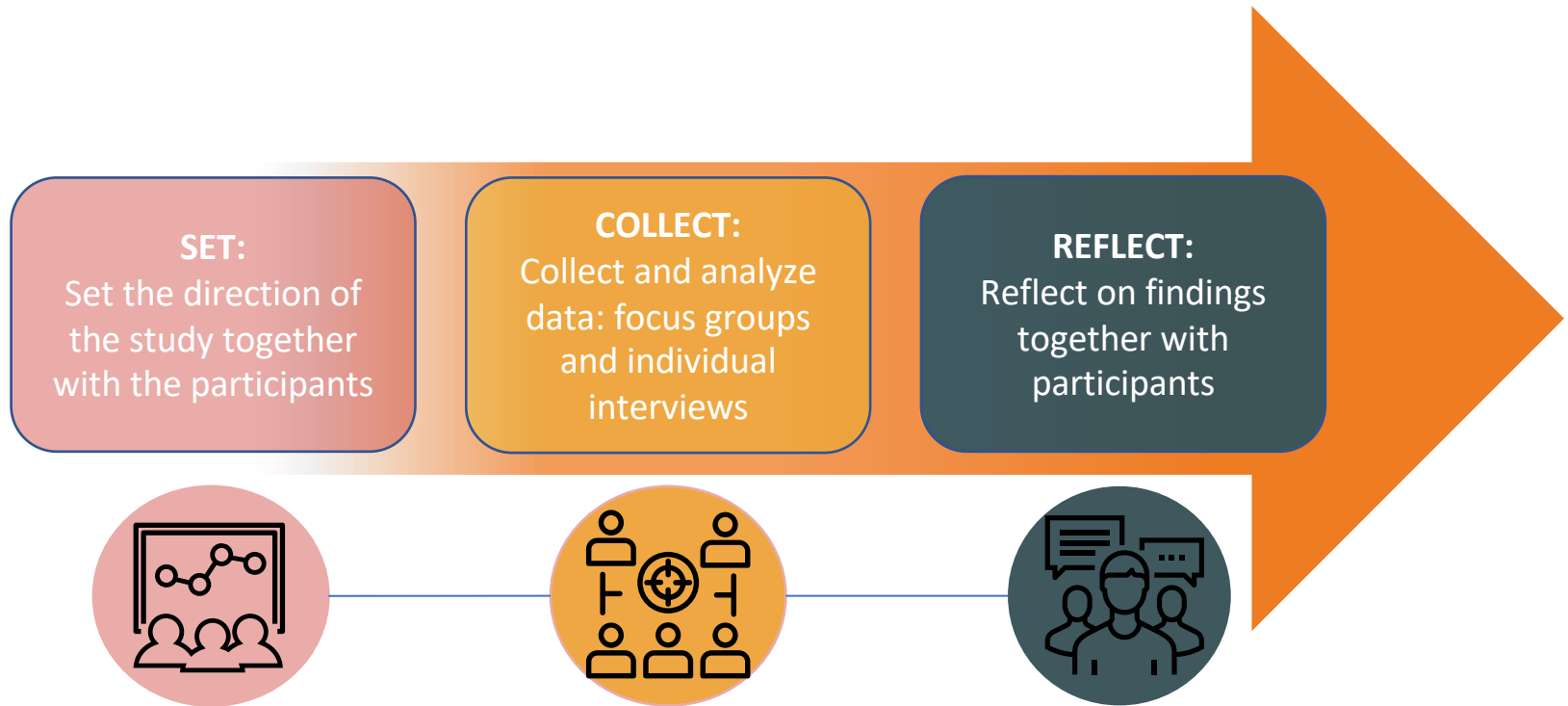
OUR TEAM



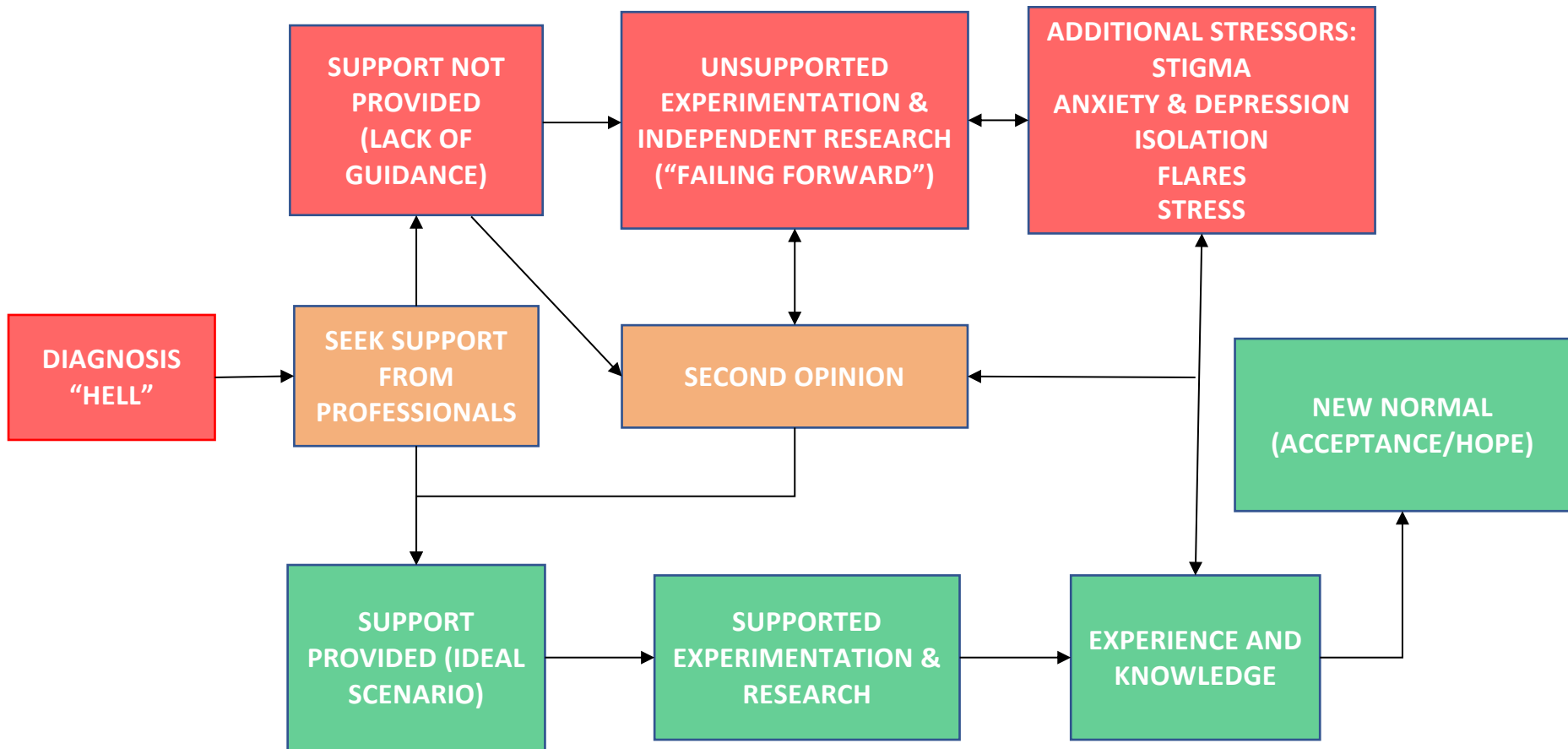
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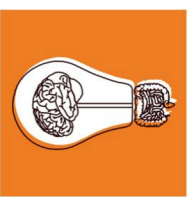
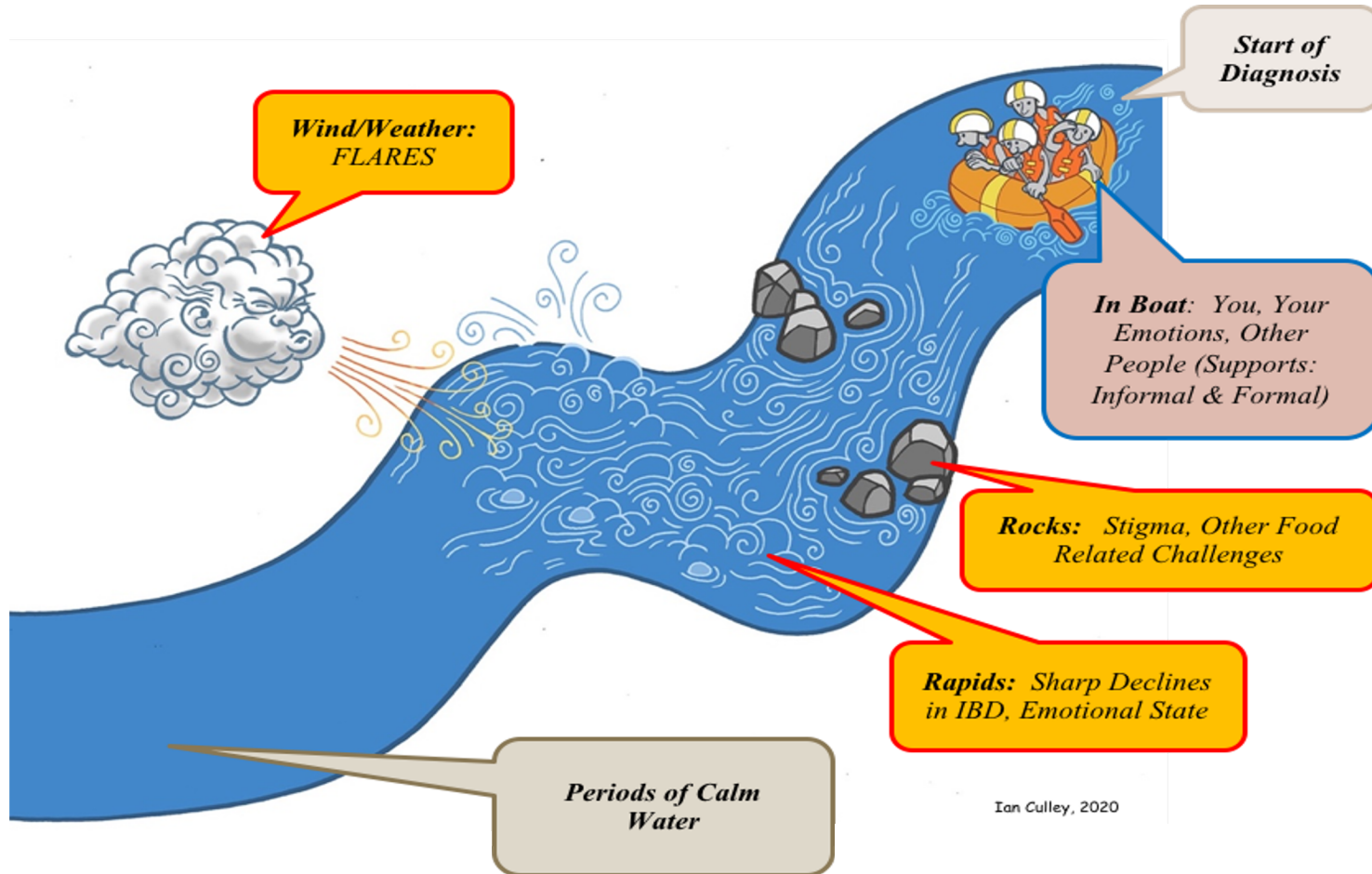
PaCER Methodology



RESULTS



CONCLUSION

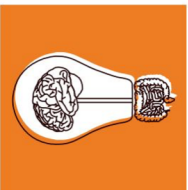


KEY RECOMMENDATIONS

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



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Marlyn Gill

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Dr. Nancy Marlett

IMAGINE

Aida Fernandes

The Imagine Team

Patient Participants



SPO
Putting Patients First 



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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 Marlett⁴

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



UNIVERSITY OF CALGARY
O'Brien Institute for Public Health



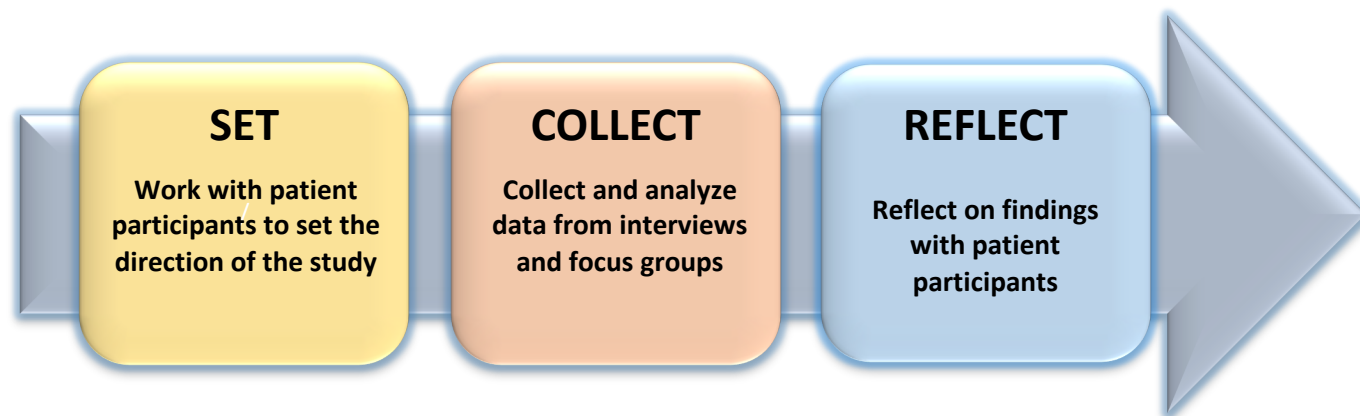
**Alberta Health
Services**

Population, Public
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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



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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

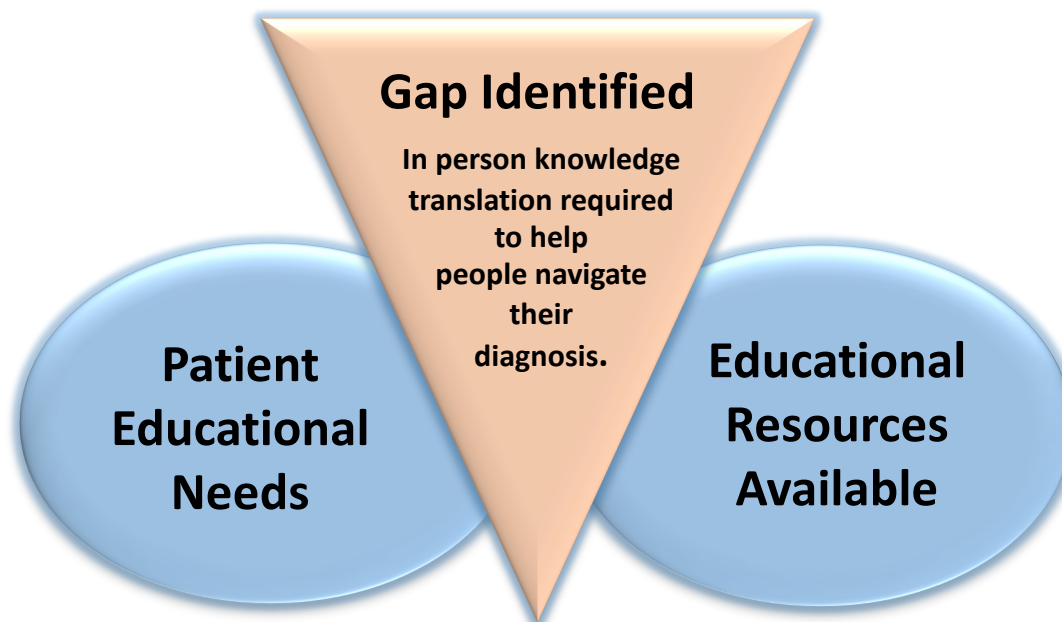




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FINDINGS

- 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





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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:



University
of Manitoba



uOttawa

