Strategy for Patient Oriented Research (SPOR) Update

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Canada Future Directions in IBD, Saturday, November 7, 2020

Outline

1. Overview of patient-oriented research (POR)
2. IMAGINE SPOR - Patient-oriented research in digestive health
   - POR projects that engage patients as partners
   - Patient-identified priorities
   - Capacity building for patient engagement in research
     - Patient research partners (PRPs)
     - Patient and Community Engagement Research Program (PaCER) training

Strategy for Patient-Oriented Research

…is about ensuring that

the right patient

receives

the right intervention

at

the right time

> *"By 2025, health outcomes in Canada will be demonstrably improved and the health care experience for patients enhanced through the integration of evidence at all levels of the health care system."*

https://cihr-irsc.gc.ca/e/documents/P-O_Research_Strategy-eng.pdf

CIHR SPOR Chronic Disease Networks

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CHILD-BRIGHT Network

ACCESS OPEN MINDS ESPRITS OUVERTS

CPN CHRONIC PAIN NETWORK

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

Can-SOLVE CKD Network

Diabetes Action Canada

Réseau sur les innovations en soins de santé de première ligne et intégrés

Primary and Integrated Health Care Innovations Network

Some SPOR Milestones

August 2011: SPOR launch

June 2014: SPOR Engagement Framework

August 2015: SPOR Capacity Development Framework

September 2017: SPOR Evidence Alliance (SEA)

2020: SPOR Patient Engagement Framework Update

August 2020: Canadian Data Platform (CDP) and Data Access Support Hub (DASH) led by Health Data Research Network Canada (HDRN Canada)

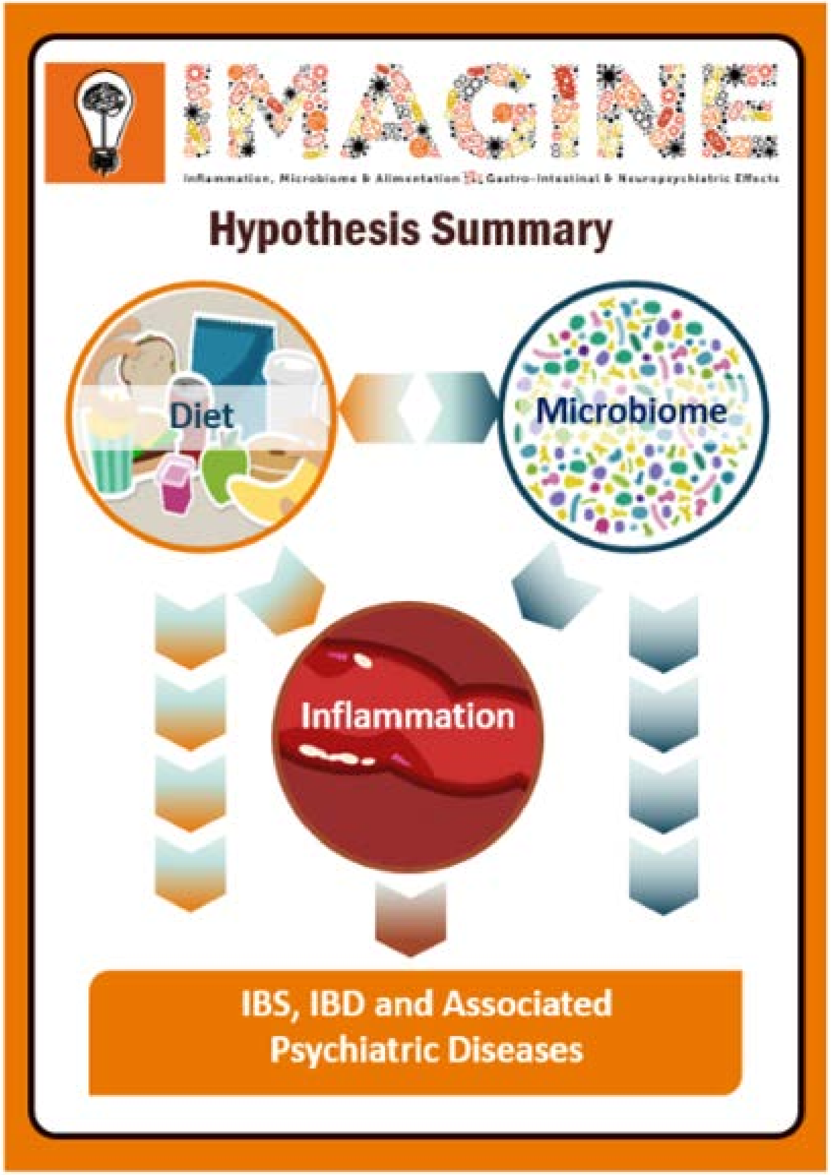
Dates vary by province: SPOR SUPPORT (*Support* for People and Patient-Oriented Research and Trials) Units

Who We Are

- One of five chronic disease networks in CIHR's SPOR initiative
- Investigating the interactions between inflammation, microbiome, diet and mental health in patients with inflammatory bowel disease (IBD) and irritable bowel syndrome (IBS)
- Research network of 17 hospitals/universities comprised of researchers, patients, and clinicians across Canada

Our Mission

Transform the management of IBD and IBS and associated mental health issues with these disorders.



What is Patient-Oriented Research (POR)?

Conducted by multidisciplinary teams in partnership with relevant stakeholders and aims to apply the knowledge generated to improve healthcare systems and practices.

Engages patients in "meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation."

-*CIHR SPOR* (https://cihr-irsc.gc.ca/e/48413.html)

Why Patient-Oriented Research?

- Achieve ***benefits that matter to patients***
- Improved health and access to the healthcare system
- Quality of life that is tied to patient-oriented outcomes
- The right treatment at the right time
- Being an active, informed partner in health care
- Contribute to improving the cost effectiveness of the health care system

Patients are at the heart of SPOR

Patients have expertise through their lived experience

Patients must be involved as much and as meaningfully as possible to make health research more responsive to patient needs

- https://cihr-irsc.gc.ca/e/48413.html

IMAGINE

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

IMAGINE SPOR
Patient Research Partners

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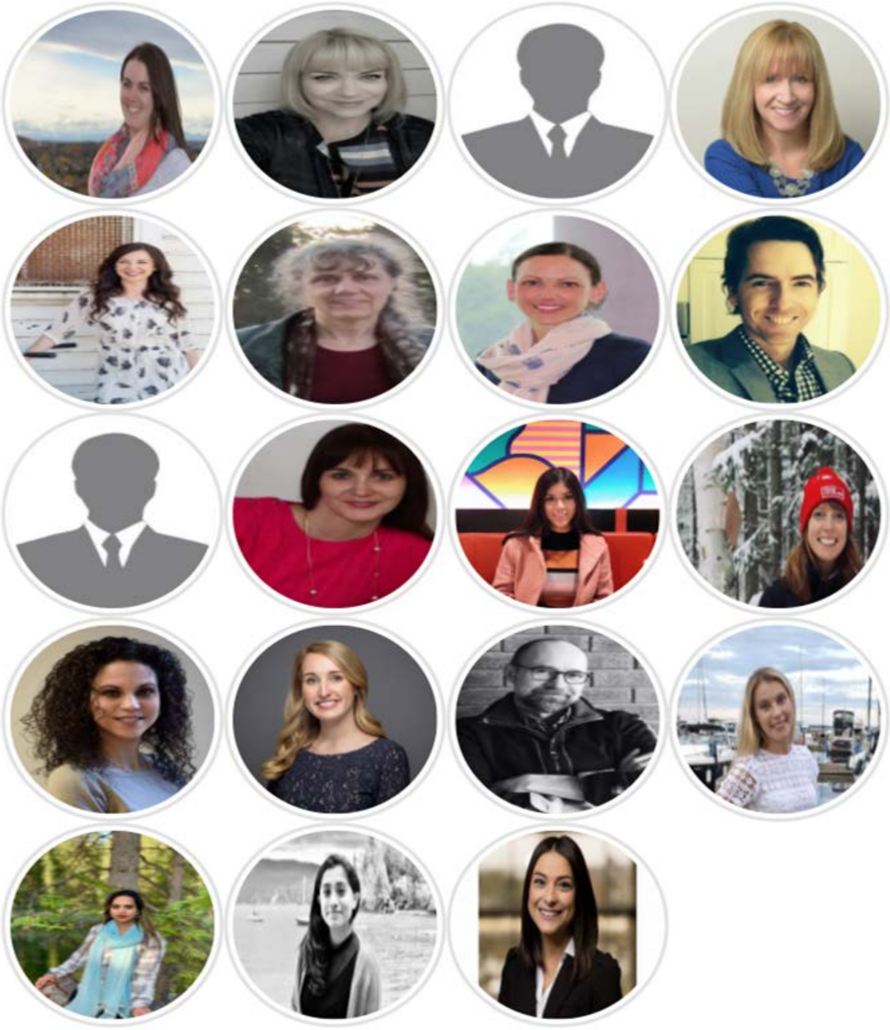


Patient Research Partners

- IBD and IBS patients and caregivers from across Canada who provide guidance and direction to the IMAGINE Network and our research
- Their involvement ensures the network addresses the unique needs of patients, ultimately improving the quality of life of those living with GI diseases

Who contribute as:

- Governance Committee members
- Working Group members
- Working as co-researchers and/or leading research projects

PRPs| IMAGINE Governance

IBD National Cohort Studies
Research Lead: Charles Bernstein
Clinical Lead: Remo Panaccione
Patient Lead: Anny Fernandez

IBS National Cohort Studies
Research Leads: Stephen Vanner, Premsyl Bercik
Patient Lead: Megan Marsiglio

Psychiatry Studies
Research Lead: Valerie Taylor
Patient Lead: Amy van Engelen

Diet and Environment
Research Leads: Elena Verdu, Leo Dieleman
Patient Lead: Shawn Reynolds

Sex and Gender Studies
Research Lead: Laura Targownik
Patient Lead: Kim Daley

Knowledge Translation, Education, and Policy
Research Leads: John Lavis, Gil Kaplan, Paul Beck
Patient Leads: Kate Lee, Glen Allison

Pediatrics
Research Lead: Anthony Otley
Patient Lead: TBD

Inflammation and Basic Science
Research Leads: Paul Kubes, Stephen Collins, John Bienenstock

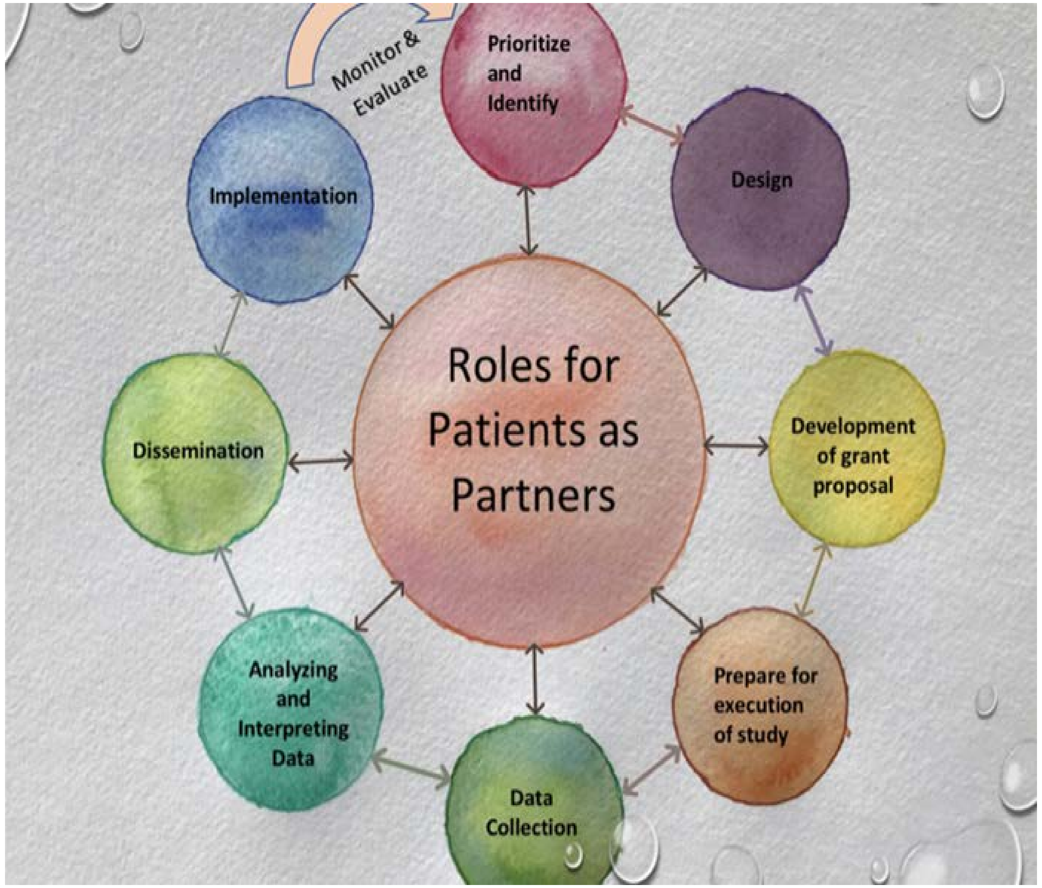
Patient Engagement
Research Lead: Deborah Marshall
Patient Lead: Sandra Zelinsky

Microbiome, Genetics, and Metabolomics
Research Lead: Mike Surette, Richard Fedorak, John Rioux

PRPs| Project Examples

IMAGINE Patient Engaged Projects

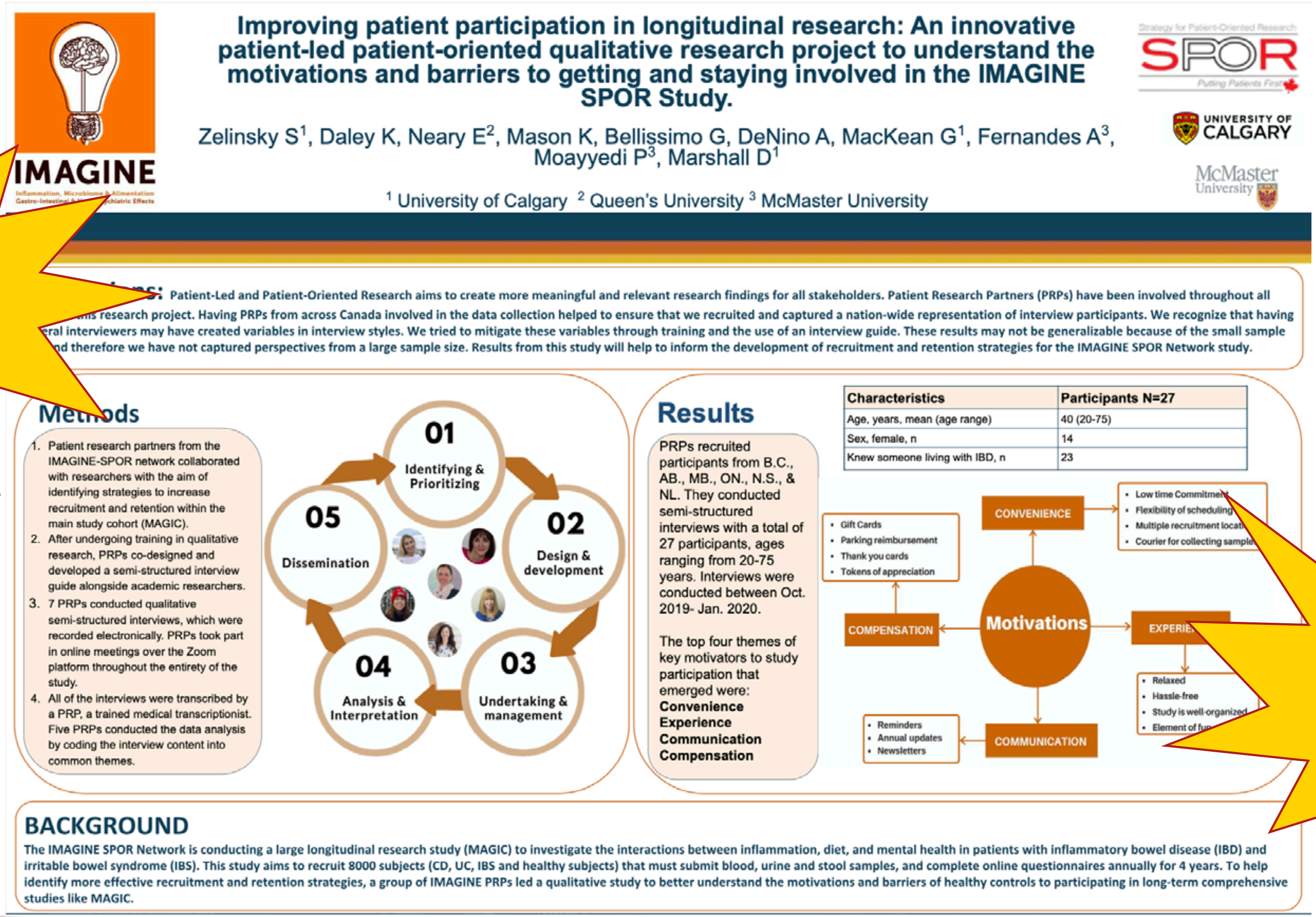
- Adult FMT Treatment Preferences Survey
- Child FMT Treatment Preferences Survey
- Priority Setting Study (paediatrics and adults)
- Recruitment and Retention Study
- PaCER Cohort Studies
- Health Economics/Health Resource Use Study
- IMAGINE SPOR AB/BC Co-Design Study
- Sex & Gender IBD/IBS Study
- IBD and Mental Health (anxiety and depression)



Graphic designed by Sandra Zelinsky

PRP | 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 S[1], Daley K, Neary E[2], Mason K, Bellissimo G, DeNino A, MacKean G[1], Fernandes A[3], Moayyedi P[3], Marshall D[1]

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

ns: 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 is 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 eral 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 nd 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) and irritable 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 annually for 4 years. To help 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 long-term comprehensive studies like MAGIC.

Accepted to the AbSPORU Virtual Institute 2020

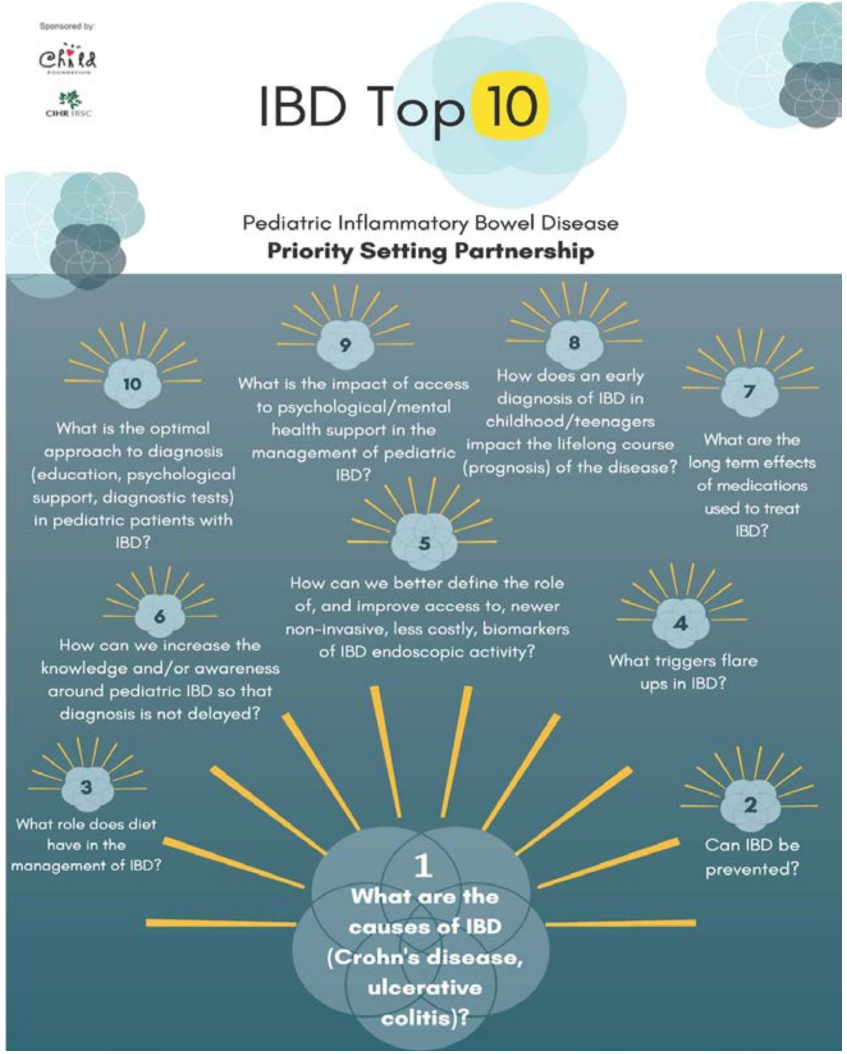
Submitted to the Crohn's & Colitis Congress 2021

PRPs | James Lind Alliance (JLA) Priority Setting

IBD in Pediatrics; CIDSCANN

Upcoming project:

- Develop research priorities for IBD/IBS with patients, caregivers, & clinicians
- The top ten previously unanswered research questions generated from this study will inform future quality improvement efforts & research within IMAGINE



Sponsored by:

Child

CIHR IRSC

IBD Top 10

Pediatric Inflammatory Bowel Disease
Priority Setting Partnership

10 What is the optimal approach to diagnosis (education, psychological support, diagnostic tests) in pediatric patients with IBD?

9 What is the impact of access to psychological/mental health support in the management of pediatric IBD?

8 How does an early diagnosis of IBD in childhood/teenagers impact the lifelong course (prognosis) of the disease?

7 What are the long term effects of medications used to treat IBD?

5 How can we better define the role of, and improve access to, newer non-invasive, less costly, biomarkers of IBD endoscopic activity?

6 How can we increase the knowledge and/or awareness around pediatric IBD so that diagnosis is not delayed?

4 What triggers flare ups in IBD?

3 What role does diet have in the management of IBD?

2 Can IBD be prevented?

1 **What are the causes of IBD (Crohn's disease, ulcerative colitis)?**

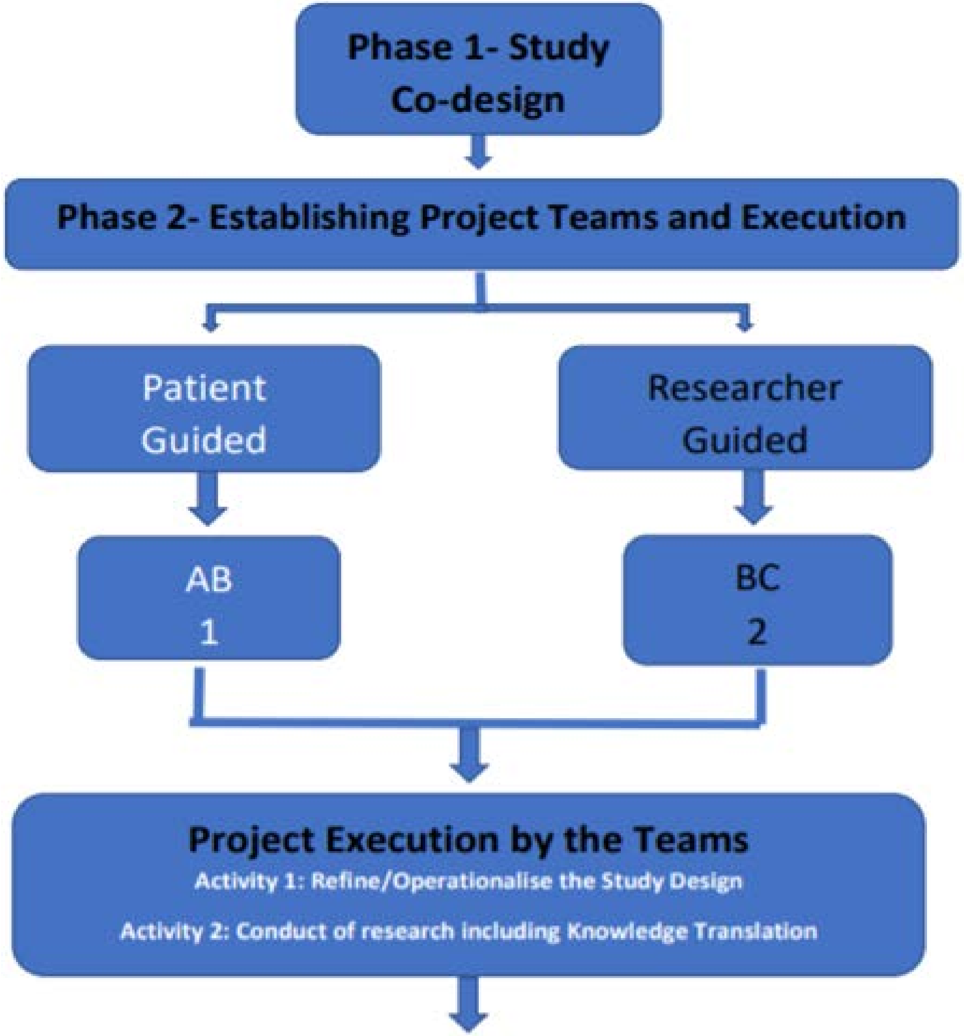
-CIDSCANN Network

PRPs | AB & BC SPOR SUPPORT Partnership Patient Engagement Study

Inflammation, Microbiome & Alimentation Gastro-Intestinal & Neuropsychiatric Effects

Does level of patient engagement make a difference?

Assess relationship between level of patient engagement and key research outputs



Phase 1- Study Co-design

Phase 2- Establishing Project Teams and Execution

Patient Guided

Researcher Guided

AB
1

BC
2

Project Execution by the Teams

Activity 1: Refine/Operationalise the Study Design

Activity 2: Conduct of research including Knowledge Translation

PRPs | Knowledge Translation Activities

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PLOS | ONE

RESEARCH ARTICLE

Patient preferences for maintenance therapy in Crohn's disease: A discrete-choice experiment

Glen S. Hazlewood[1]*, Gyanendra Pokharel[2], Robert Deardon[2,3], Deborah A. Marshall[1], Claire Bombardier[4,5], George Tomlinson[4], Christopher Ma[6], Cynthia H. Seow[1], Remo Panaccione[6], Gilaad G. Kaplan[1,6]*

1 Department of Medicine and Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada, 2 Department of Mathematics and Statistics, University of Calgary, Calgary, Alberta, Canada, 3 Department of Production of Animal Health, Faculty of Veterinary Medicine, University of Calgary, Calgary, Alberta, Canada, 4 Department of Medicine and Institute of Health Policy, Management, and Evaluation, University of Toronto, Toronto, Ontario, Canada, 5 Toronto General Research Institute, University Health Network, Toronto, Ontario, Canada, 6 Inflammatory Bowel Disease Unit, Division of Gastroenterology and Hepatology, Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

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Check for updates

OPEN ACCESS

Citation: Hazlewood GS, Pokharel G, Deardon R, Marshall DA, Bombardier C, Tomlinson G, et al. (2020) Patient preferences for maintenance therapy in Crohn's disease: A discrete-choice experiment. PLoS ONE 15(1): e0227635. https://doi.org/10.1371/journal.pone.0227635

Editor: Matthew Quaife, London School of Hygiene and Tropical Medicine, UNITED KINGDOM

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Copyright: © 2020 Hazlewood et al. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Data Availability Statement: Data cannot be shared publicly because of restrictions regarding sharing of data and informed consent of the participants. Data are available from the University of Calgary Conjoint Health Research Ethics Board (contact via chreb@ucalgary.ca) for researchers who meet the criteria for access to confidential data.

Funding: Funding for this study was received by the Canadian Institutes for Health Research (CIHR), funding reference number MP3-139793 (GH, GK,

Abstract

Objective

To quantify patient preferences for maintenance therapy of Crohn's disease and understand the impact on treatment selection.

Methods

We conducted a discrete-choice experiment in patients with Crohn's disease (n = 155) to measure the importance of attributes relevant to choosing between different medical therapies for maintenance of Crohn's disease. The attributes included efficacy and withdrawals due to adverse events, as well as dosing and other rare risks of treatment. From the discrete-choice experiment we estimated the part-worth (importance) of each attribute level, and explored preference heterogeneity through latent class analysis. We then used the part-worths to apply weights across each outcome from a prior network meta-analysis to estimate patients' preferred treatment in pairwise comparisons and for the overall group of treatments.

Results

The discrete-choice experiment revealed that maintaining remission was the most important attribute. Patients would accept a rare risk of infection or ca increased chance of remission. Latent class analysis demo was risk averse, either to adverse events or requiring a co preferences were used in modelling studies to compare pa 78% probability that all biologic treatments were preferred

PLOS ONE | https://doi.org/10.1371/journal.pone.0227635 January 16, 2020

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Inflammation, Microbiome & Alimentation Gastro-Intestinal & Neuropsychiatric Effects

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

Jenna Rines[1], Kim Daley[1], Sunny Loo[1], Kwestan Safari[1], Deirdre Walsh[2], Paul Moayyedi[3,4], Aida Fernandes[3], Deborah Marshall[3,5], Nancy Marlett[5]

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

METHODOLOGY

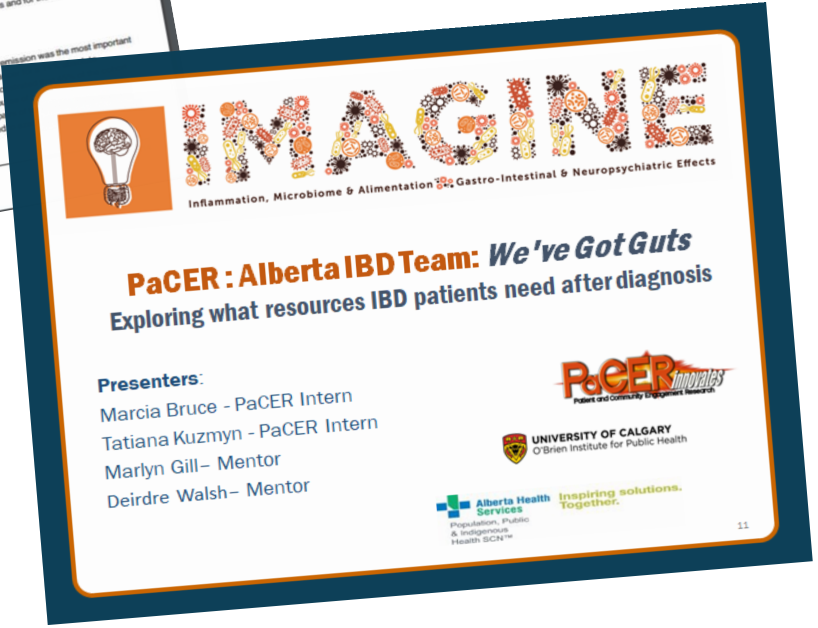
RESULTS

DISCUSSION

RECOMMENDATIONS

CONCLUSION

REFERENCES



IMAGINE

Inflammation, Microbiome & Alimentation Gastro-Intestinal & Neuropsychiatric Effects

PaCER : Alberta IBD Team: *We've Got Guts*

Exploring what resources IBD patients need after diagnosis

Presenters:

Marcia Bruce - PaCER Intern

Tatiana Kuzmyn - PaCER Intern

Marlyn Gill – Mentor

Deirdre Walsh – Mentor

PaCER innovates

Patient and Community Engagement Research

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O'Brien Institute for Public Health

Alberta Health Services
Population, Public & Indigenous Health SCN™

Inspiring solutions. Together.

11

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Inflammation, Microbiome & Alimentation Gastro-Intestinal & Neuropsychiatric Effects

The latest news and updates from the IMAGINE Network

WELCOME MESSAGE

As might be expected, the past few months have proven to be a challenge for the IMAGINE Network due to the COVID-19 pandemic. Many of our research studies have had to halt recruitment and cancel in-person meetings. However, we have made progress in a number of other fronts to overcome these barriers:

- All of our MAGIC Study recruitment centres have secured ethics amendments to enable virtual follow-up visits for our current study participants and a few sites are also in the process of applying for ethics approval to recruit new participants virtually and collect bio samples from their homes.
- We have updated our website with a new COVID-19 section to improve access to evidence-informed resources to help those living with IBD & IBS.
- Some of our IMAGINE patient representatives and investigators have been collaborating with our partners to host COVID-19 education webinars for patients and their families.
- Dr. Michael Surette, our Microbiome Lead, has been involved in creating a screening test that will identify coronavirus in stool. While this has enormous public health benefits, our Network also plans to use this test to help screen potential stool donors for our Fecal Transplantation studies and, once serum antibody tests are developed, to identify associations with COVID and health outcomes in IBD/IBS and healthy controls in our MAGIC Study.
- Dr. John Lavis, our KT Lead, has been working with the Ontario government to deliver on several COVID evidence summaries to inform relevant public policy.
- Dr. Paul Moayyedi, our Lead PI, has been serving on the provincial government's Ontario Innovation Fund Provincial Oversight Committee (IFPOC) to evaluate COVID research proposals from teaching hospitals across the province that are selected for funding.

I encourage you to read on to learn more about the Network's activities over the past few months including the appointment of our new Co-Principal Investigator, Dr. Deborah Marsh our PaCER-sponsored teams, and new monthly training webinar series. Also, visit ou regularly to stay updated on our Network's research progress.

Best wishes and stay healthy!

Aida Fernandes

Aida Fernandes,
Executive Director
IMAGINE N

2019/20 Patient and Community Engagement Researchers (PaCERs)

IBD National Team: The Mob

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

IBD Alberta Team: We've Got Guts

Exploring what resources IBD patients need after diagnosis

PaCER Training Program

Practicum in research and consultation skills in patient and community engagement research

CPE
219|40 Hours|Online

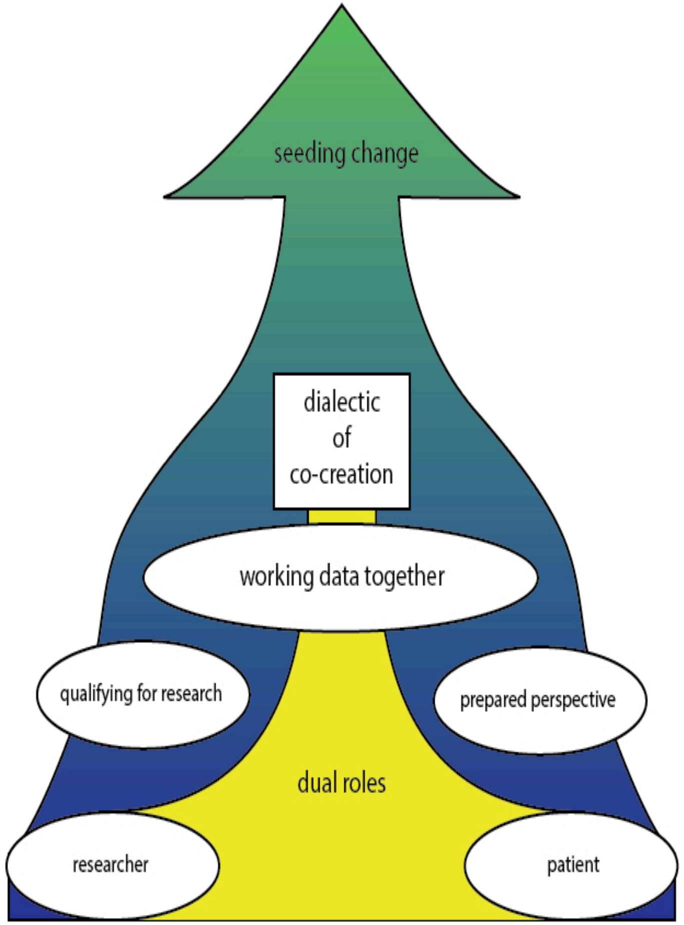
Theoretical foundations in patient and community engagement research

CPE
221|40 Hours|Online

Internship in conducting patient and community engagement research

CPE 220|80 Hours|
Online and field work

"Part of the Team": Building New Patient Roles and Relationships in Health Research and Planning



Model: Co-creation of PaCER role as a 'Twin Innovation'

Results: 3 major areas of impact:

1) increased capacity of patients to engage in healthcare research and planning

2) New roles for patients in health care planning **–** impacting attitudes and practices

3) New, collaborative roles for patients in research.

Interpretation: Fundamental cultural change, and a way to embed and measure patient value.

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We have come a long way …and we look forward to the journey ahead together!

IMAGINE a future without digestive disease

Share this page

The revolutionary SPOR IMAGINE Network could herald the end of digestive conditions like IBD and IBS

August 31, 2016

Megan Henry's digestive health journey began when she was 16 years old. Her life became dominated by severe abdominal pain and frequent trips to the bathroom, leading to feelings of isolation and embarrassment. Megan didn't understand what was happening in her body, until she was finally diagnosed with Crohn's disease and irritable bowel syndrome (IBS).

Inflammatory bowel disease (IBD) is comprised of two similar but

The Honorable Jane Philpott, Megan Henry, Filomena Tassi and Dr. Paul Moayyedi at the SPOR IMAGINE Network announcement.

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

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- Marlett N, Shklarov S, Marshall DA, Santana MJ, Wasylak T. Building New Relationships in Research: A Model of Patient Engagement Research. Qual Life Res 2015 May;24(5):1057-67

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Thank you!

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