

Pediatric Inflammatory Bowel Disease **Priority Setting Partnership**

Identifying the top 10
research priorities
for Pediatric Inflammatory
Bowel Disease in Canada

#IBDTop10



Why patient engagement is important

Improve research design

- Identify right research question
- Clearly defined outcomes more likely to directly benefit patients
- Research methods that are more accessible & make it easier for people to take part

Improve patient participation in research

- Explore and overcome barriers to recruitment
- Better recruitment strategies & information for potential participants
 - Studies with robust patient engagement, 4x more likely to recruit to time and target



Improve results of research

- Making research relevant and credible
- Improved dissemination of results & implementation of change
 - Create commitment, energy & enthusiasm amongst potential participants

- Robinson A. Patient and public involvement: in theory and in practice. *Journal of Laryngology & Otology* 2014;128:318-325.
- Ennis L and Wykes T. Impact of patient involvement in mental health research: longitudinal study. *BJPsych.* 2013;203:381-386.
- Robinson A. Patient and public involvement: in theory and in practice. *Journal of Laryngology & Otology* 2014;128:318-325.

The process

Our journey to the top 10

1

366 participants filled out National Survey #1, resulting in **1209** raw questions.

2

We identified **626** unique questions from this group.

3

A literature review was completed to eliminate all questions that were already answered, or out of scope, **388** questions remained.

4

Next, our steering group created indicative questions from the list of **388**. They came up with **73** indicative questions.

5

An additional **32** questions from clinical practice guidelines were included.

6

Respondents completed a second national survey ranking their top **20** questions from the list of **105**.

8

From the **19**, we prioritized the **top 10** most important questions at our patient engagement meeting in Toronto.

7

The national survey results were tabulated, and a list of the top **19** prioritized questions remained.



Survey demographics

First National Survey

Participant Category

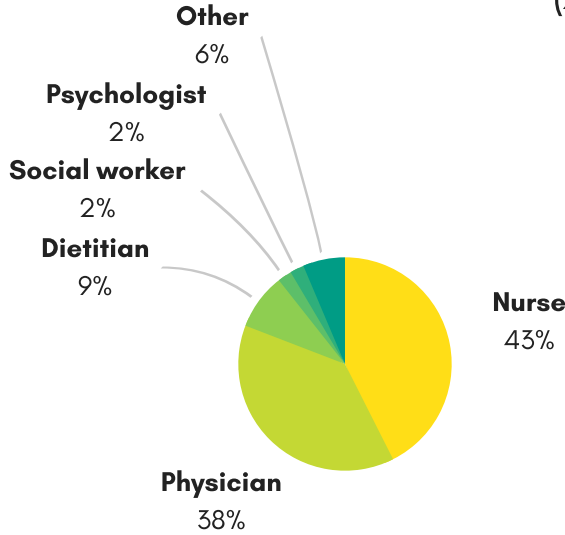
Patient who developed IBD before 18 years
 Caregiver of current /former pediatric IBD patient
 Healthcare professional
 Other

Age (years)
21 (10-85)
44 (29-59)
48 (24-56)

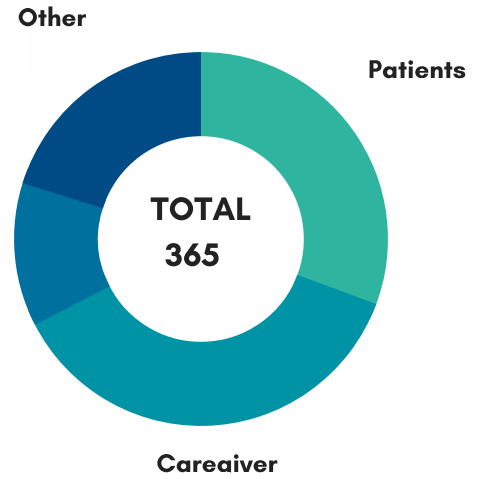
Gender (Males) (Females)
49 60
19 112
11 30

Provinces

AB, BC, MB, NB, NS, ON, QC
AB, BC, MB, NB, NFLD, NS, ON, QC, SK
AB, BC, MB, NB, NFLD, NS, ON, QC



Respondents



Second National Survey

Participant Category

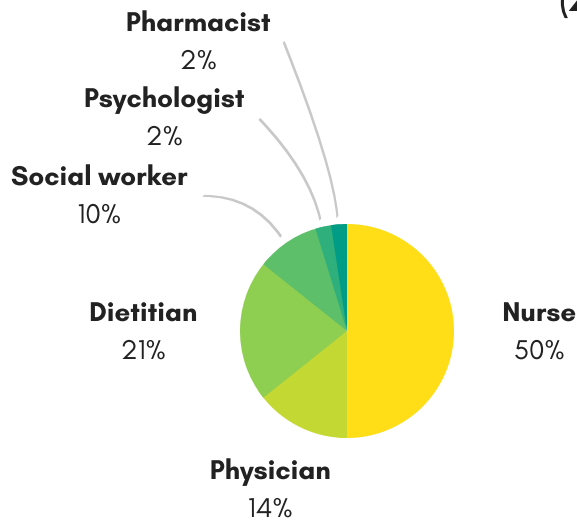
Patient who developed IBD before 18 years
 Caregiver of current /former pediatric IBD patient
 Healthcare professional
 Pharmacist
 Psychologist
 Social worker
 Dietitian
 Physician

Age (years)
20 (11- 35)
46 32-63
44 (28-61)

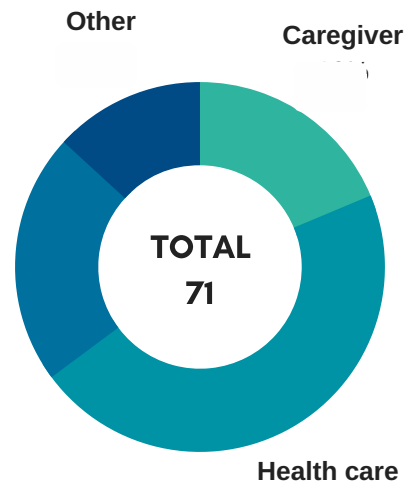
Gender (Males) (Females)
9 10
2 15
5 14

Provinces

BC, ON, NB, NS
BC, AB, ON, NS
BC, AB, ON, QC, NS, NFLD



Respondents



Themes

After all out-of-scope questions were eliminated, the remaining research questions were separated into themes using qualitative methodologies. This thematic analysis resulted in the following 17 themes:

| | Survey #1 | Top 27 |
|------------------------------|------------|-----------|
| General Research | 9 | 0 |
| Diet | 34 | 6 |
| Cause | 54 | 3 |
| Treatment | 51 | 2 |
| Medical Tests | 23 | 2 |
| Emotions | 42 | 2 |
| Future | 22 | 1 |
| Diagnosis | 28 | 5 |
| Symptoms | 22 | 1 |
| System | 27 | 0 |
| Prevention | 24 | 2 |
| Cure | 9 | 1 |
| Prevalence | 11 | 1 |
| Information Sources | 4 | 0 |
| Case differences | 13 | 0 |
| Affect on other health | 10 | 0 |
| Transitions in care | 5 | 1 |
| Total | 388 | 27 |

2017 Pediatric Inflammatory Bowel Disease Priority Setting Partnership



Patients / Former Patients / Caregivers / Siblings / Physicians / Nurses /
Social Workers / Dietitians / Psychologists

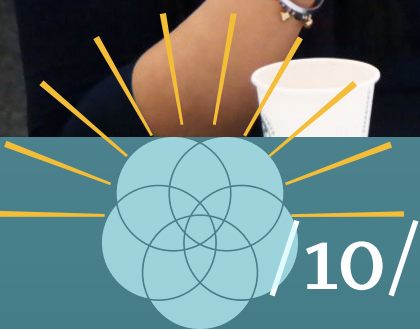


The team at the
priority setting
conference in
Toronto

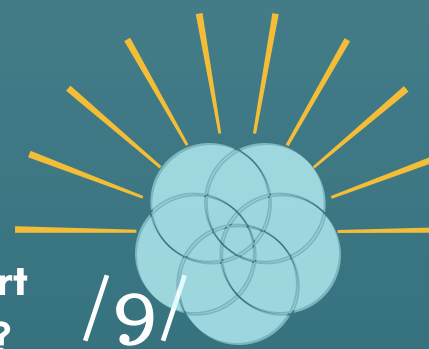
See the results



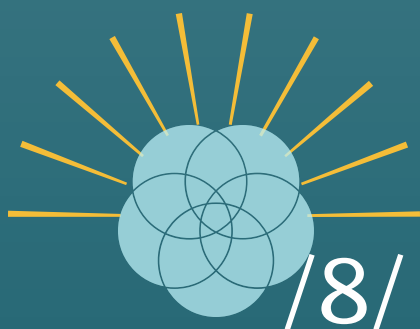
IBD Top 10



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

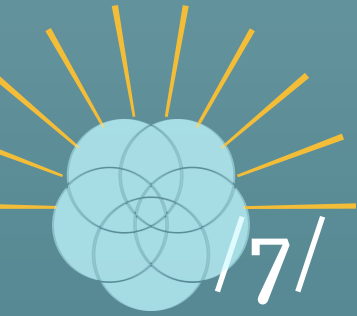


What is the impact of access to psychological/mental health support in the management of pediatric IBD?

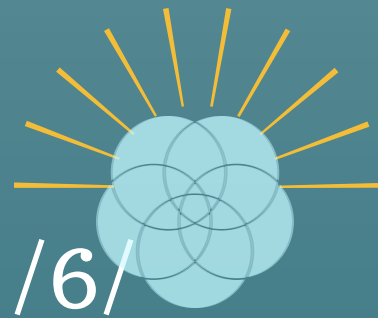


What is the optimal approach to diagnosis (education, psychological support, diagnostic tests) in pediatric patients with IBD?

IBD Top 10



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

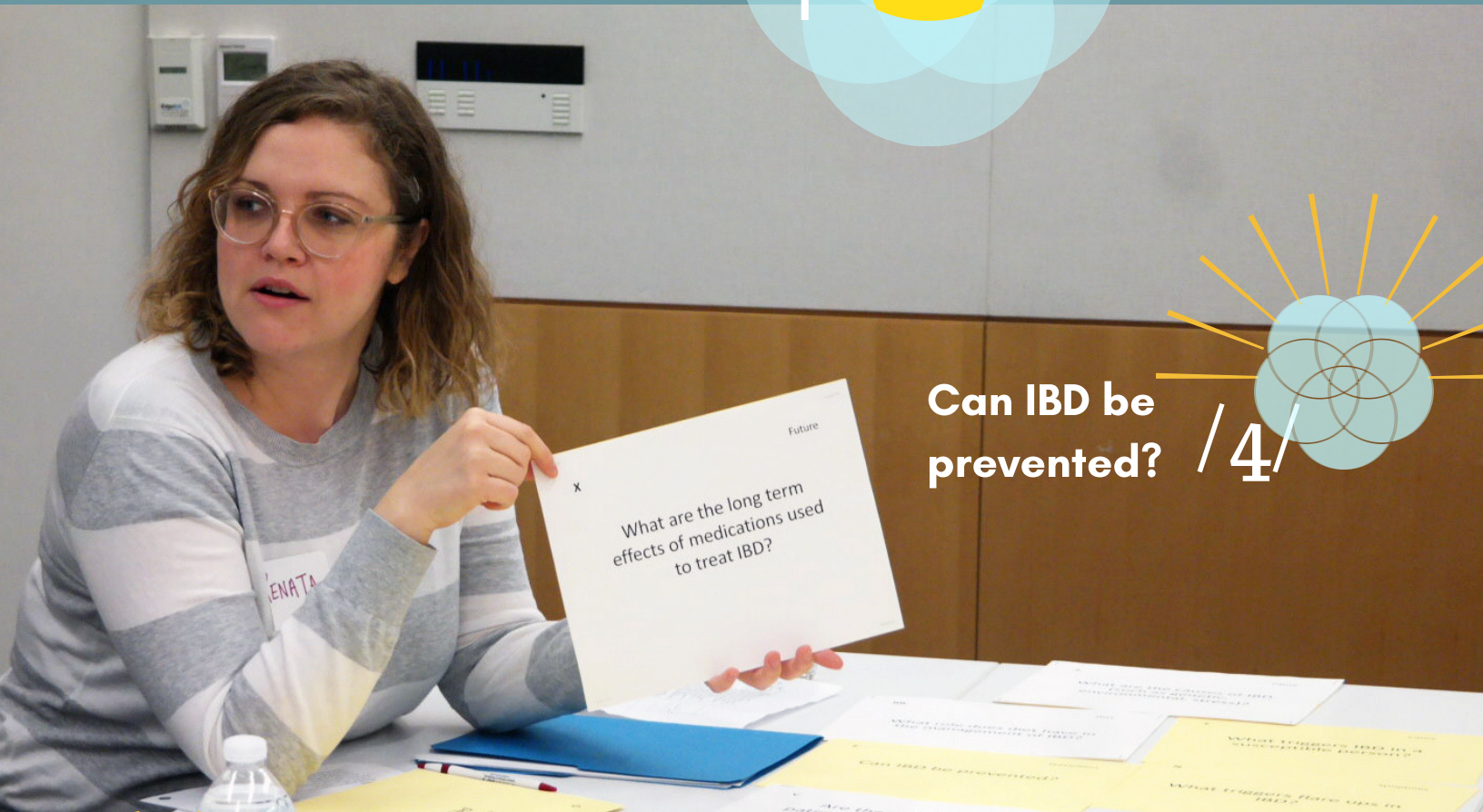


How can we increase the knowledge and/or awareness around pediatric IBD so that diagnosis is not delayed?

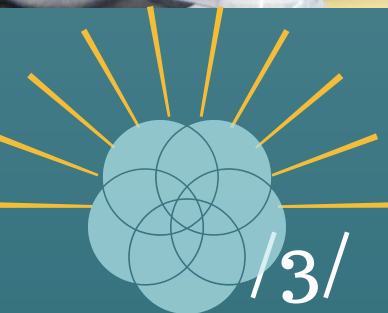
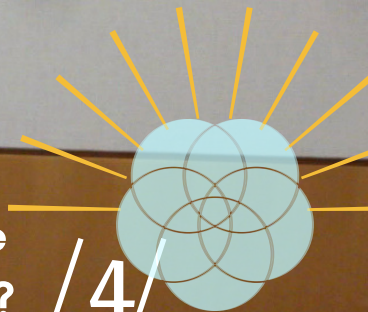


What are the long term effects of medications used to treat IBD?

IBD Top 10

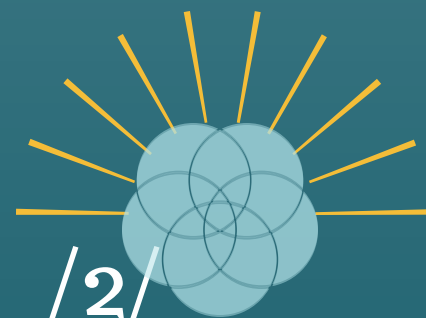


Can IBD be prevented? /4/



/3/

What role does diet have in the management of IBD?



/2/

What triggers flare ups in IBD?



/1/

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

A big thank you to all who participated

Principal Investigator

Dr. Anthony Otley (Halifax)

Facilitators

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Renata Axler

Anjana Aery

Observers

Philip Sherman - CIHR

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Steering committee & Workshop attendees

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Marie-Josée Trempe (Montreal).....Dietitian

Amanda Hood (Halifax)..... Former IBD patient

Muneet Maghera (Vancouver)..... Former IBD patient

Melissa Mansi (Edmonton).....Mother to IBD patient

Kate Murray (Toronto).....Mother to IBD patient

Malcolm Mann (Halifax).....IBD Patient

Cheryl Kluthe (Edmonton)..... Nurse



Workshop attendees

Dr. Mary Sherlock (Hamilton)..... Physician

Jackie Pidduck (Halifax)..... Social Worker

Inez Martincevic (Toronto)..... Dietitian

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Kristeen McGowan (Toronto)..... Mother to IBD patient

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Sophie LeBlanc (Halifax)..... IBD Patient