



# Canada Future Directions in IBD

## **SOCIAL MEDIA AND APPS IN IBD**

Waqqas Afif

Eric Benchimol





# CASE

**You are an astute health care provider and armchair epidemiologist who is anticipating the next global pandemic. You are planning to develop a communication pipeline for your patients with IBD to provide them with news, public health recommendations, vaccine education, and instructions on how and when to contact your clinic support staff.**





# SOCIAL MEDIA (DEFINITION)

- Any technology that facilitates communication or collaboration between humans.



Image: Vincent AF



# CRITICISMS OF SOCIAL MEDIA

- 1 Growth of technology
  - Information overload
- 2 Privacy
- 3 Banality
- 4 Loss of authoritative perspective
  - Unpublished, non-peer review
  - Accuracy
- 5 Work/life balance
- 6 Vitriol

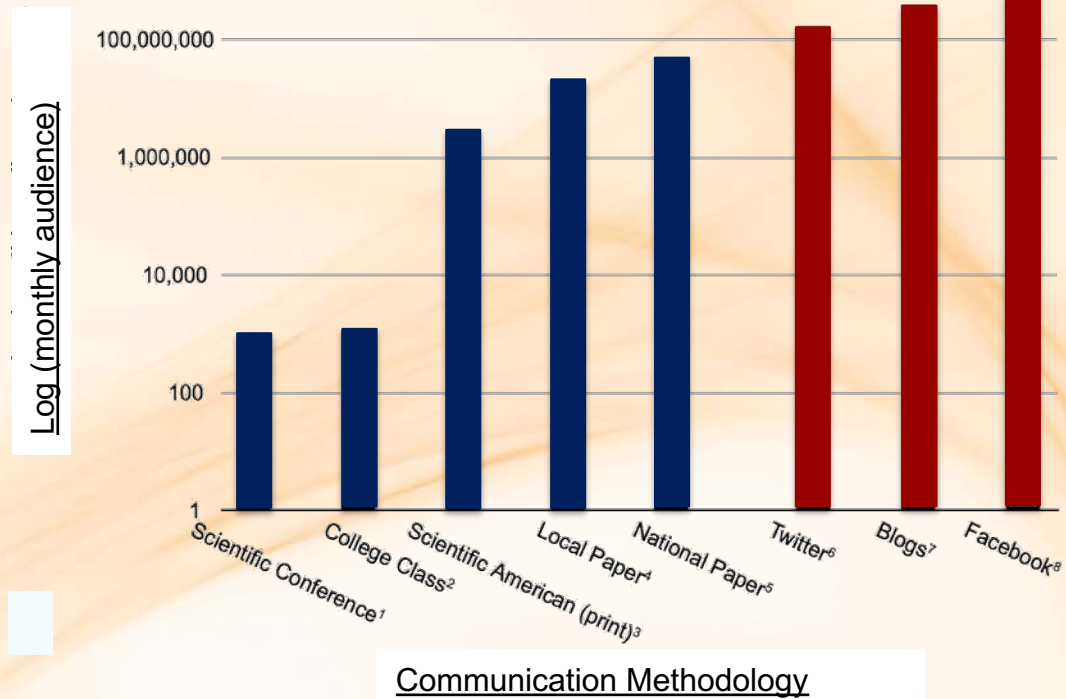
Cann, Social Media: A Guide for Researchers, 2011  
Nature Methods 2011;8(4):273  
Winstead, NCI Cancer Bulletin, 2011  
Social Media Guidelines for AACR Conferences





# BENEFITS OF SOCIAL MEDIA

- Reach



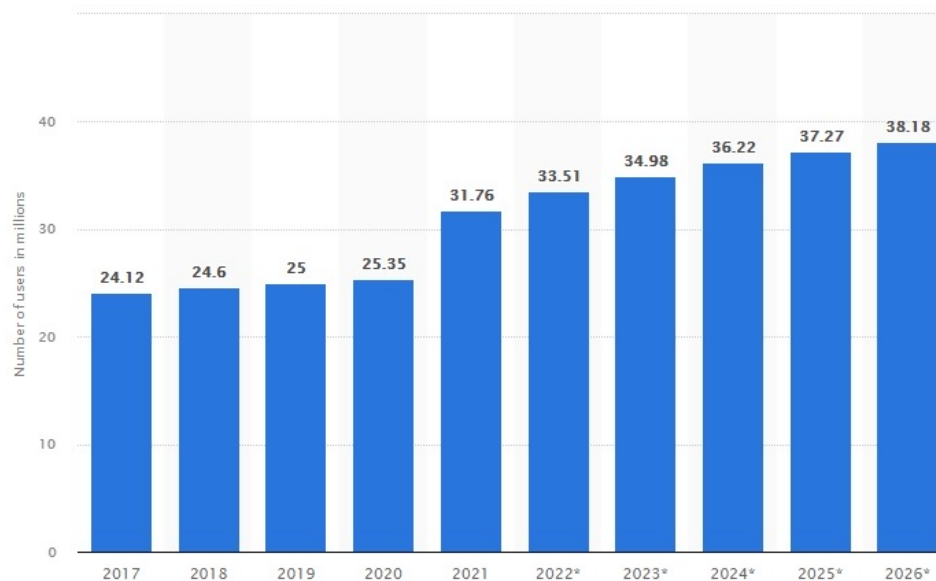
Bik and Goldstein, PLoS Biology, 2013



# REACH

Internet > Social Media & User-Generated Content

## Number of social network users in Canada from 2017 to 2026 (in millions)



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[Additional Information](#)

[Show source](#)

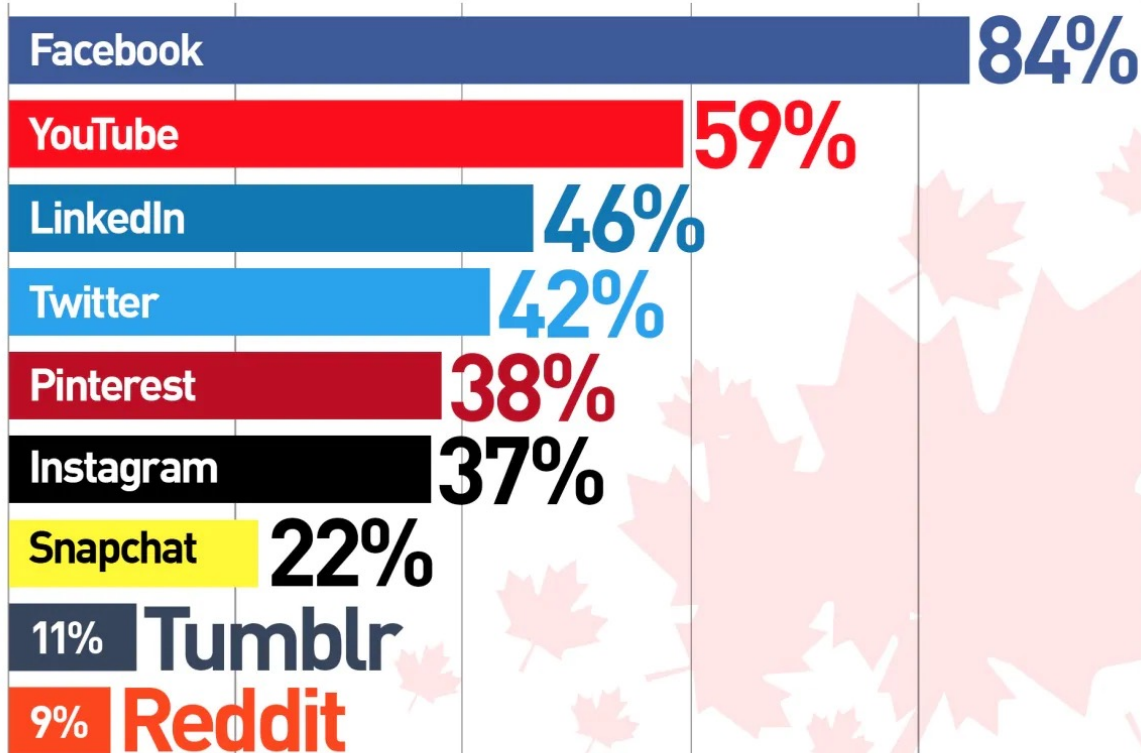
Published by [Statista Research Department](#), Aug 25, 2021  
<https://www.statista.com/topics/2729/social-networking-in-canada/>





# CANADIAN SOCIAL MEDIA USE:

PERCENTAGE OF ONLINE ADULTS WITH AN ACCOUNT ON THE FOLLOWING PLATFORMS:



SOURCE: RYERSON UNIVERSITY SOCIAL MEDIA LAB

[cbc.ca/spark](http://cbc.ca/spark)

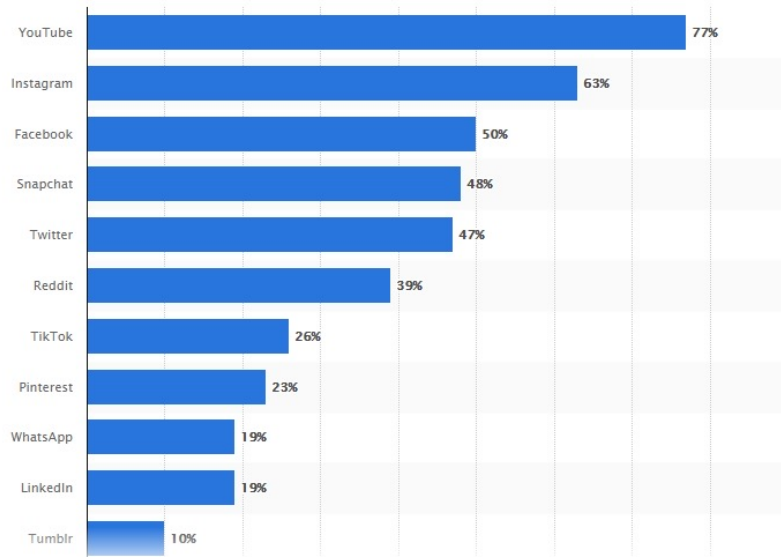


# REACH

Internet > Social Media & User-Generated Content

PREMIUM +

## Reach of leading social networking sites used by teenage and young adult online users in the United States as of 3rd quarter 2020



Expand statistic

Additional Information

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Show source

DOWNLOAD



Source

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IN COOPERATION WITH

AudienceProject

Release date

September 2020

Region

United States

Survey time period

Q3 2020

Age group

15 to 25 years

Method of interview

Online panel

Supplementary notes

total survey n=2,000+

Published by [Statista Research Department](#), Oct 19, 2021





Call for 'liberation': a November 2010 rally in Edmonton, Canada, for a multiple-sclerosis treatment.

# The rise of people power

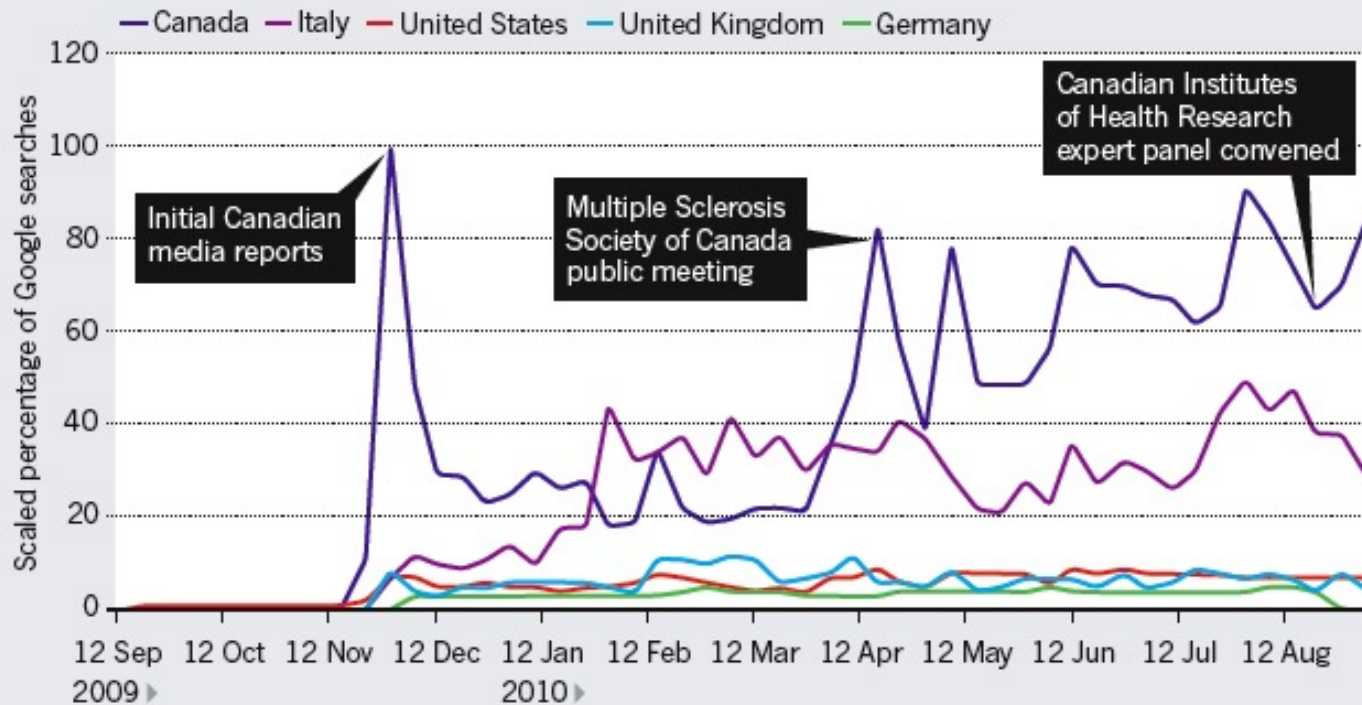
Calls in Canada for trials of a contentious treatment for multiple sclerosis illustrate how social media can affect research priorities, say **Roger Chafe** and his colleagues.

Chafe *et al.*, *Nature*, 2011



## HOT TOPIC

A measure of the number of Google searches for the term CCSVI (chronic cerebrospinal venous insufficiency) reveals that public interest in Canada soared in just one year.



Chafe *et al.*, Nature, 2011




- Clinicians use:
  - Scientific publications
  - Conferences
  - Briefing notes
  - Press releases, news conferences
- Patient groups:
  - Social media

**‘Clinical Equipoise’ vs. ‘Facebook Equipoise’ !**

Chafe *et al.*, Nature, 2011



# 'FACEBOOK EQUIPOISE'

[About](#) [Resources](#) [For Researchers](#) [For Kids & Teens](#) [Help](#) [Sign in](#)

[Home](#) [Research Ideas](#) [My Health Data](#) [My Contributions](#) [Members](#) [Blog](#) [COVID-19](#) [Project PREVENT](#)

## Research Ideas 1

All Categories

All Stages

Type a search term...

Search

Hottest

Newest

Most Voted

Most Discussed

Reviewed by Researchers

Collapsed

Expanded

Study Underway

Great Fit for Partners

What is the side effects of Covid-19 vaccines on Crohn's/Colitis patients? Since their immune systems do not work properly, is the vaccine even effective?

Medications

last activity 16 days ago

34

4

Proposed Idea

Do prior authorizations required by insurance companies cause delays in patient therapies, and can these delays be correlated in an increased risk of treatment failures or increased disease activity?

Other

last activity 16 days ago

68

11

Proposed Idea

Does medicinal marijuana have an anti-inflammatory response on IBD patients?

Alternative Therapies

last activity 16 days ago

187

30

Study Underway

Great Fit for Partners

What diet (i.e. plant based, whole food/vegan) is most likely to help IBD patients achieve and retain remission?

Diet

last activity 16 days ago

104

18

Proposed Idea

For those patients who have failed anti-TNF alpha therapy, what is the next best step? Is Entyvio, Stelara, or Xeljanz more effective?

Medications

last activity 7 days ago

49

11

Propose Research Idea

Published Studies [VIEW ALL](#)

Project PREVENT: A Randomized Controlled Trial of Preventive Interventions in Patients With Inflammatory Bowel Disease


Read Study

Delayed Diagnosis of Crohn's Disease is Common and Associated with An Increased Risk of Disease Complications

Read Study

A Patient-Prioritized Agenda for Information Needs During the COVID-19 Pandemic: A Qualitative Study of Patients With Inflammatory Bowel Disease

Read Study

da Future Directions in IBD 





# HOW TO CHOOSE

- **WHAT'S YOUR MESSAGE?**
- How much time to do you have?
- What's your audience?
  - Age
  - Disease
  - Education
  - Engagement
- How creative are you?





# HOW TO CHOOSE

- Follow people with a similar message to you
  - Follow lists on Twitter
  - Don't follow too many people
  - Don't engage until you understand 'the rules'
  - **NEVER SAY ONLINE WHAT YOU WOULDN'T WANT ON THE FRONT PAGE OF THE NEWSPAPER!!**





# PROFESSIONALISM

## TORONTO STAR

WEATHER HIGH 8 C | SUNNY | MAP S8

MONDAY, FEBRUARY 27, 2017

> STAR EXCLUSIVE

### Ontario doctors rocked by vicious infighting

Bullying, threats and intimidation have escalated since failed ratification vote, resignations at OMA

**THERESA BOYLE**  
HEALTH REPORTER

A damaging wave of cyberbullying and intimidation is sweeping through the ranks of Ontario doctors, complete with obscene emails, threats against each other's medical careers and refusals to take patient referrals from adversaries.

Although experts say bullying has always been a problem in medicine, in Ontario it has escalated since last summer's failed ratification vote over a proposed deal between the government and Onta-

rio Medical Association, which represents the province's 34,000 doctors and medical students.

The problem has grown even harsher since the sudden decision by the OMA executive to resign en masse following a vote of non-confidence by the group's 260-member elected council last month.

"I have not heard anything like this before to this degree," said Dr. Sharon Straus, vice-chair of the department of medicine at the University of Toronto and a researcher in the area of bullying

within the profession. "It makes me sad, ashamed and distressed."

She said the perpetrators of unprofessional behaviour are a minority among physicians.

The targets are mainly doctors who opposed the move last month to oust the OMA executive team and who voiced support for last summer's tentative deal between the province and OMA. They range from the youngest in the profession — students seeking training positions in hospitals and universities — to those at the top, including past OMA president Dr. Virginia Walley.

Walley served at the helm of the organization during one of the most tumultuous periods in its 136-year history until

her resignation this month. She and the rest of the six-member executive resigned a week after the OMA's council passed a non-confidence motion against them. (Votes on motions to force each member of the executive to step down failed.)

The Star has learned that dozens of disturbing emails were sent to Walley via the OMA. They include this misogynistic one from a southwestern Ontario anesthesiologist sent shortly before last August's ratification vote: "You are a c---. Crash and burn as you deserve to do!! This will be a NO vote and the end of the OMA. Sincerely, F--- YOU and the OMA!!!"

DOCTORS continued on A9



"It makes me sad, ashamed and distressed."

**DR. SHARON STRAUS**  
U OF T  
DEPARTMENT  
OF MEDICINE





# CPSO POLICY

- Conduct yourself in respectful, professional manner
- Consider potential impact on reputation (yours, the profession, and the public trust)
- Advocacy is important, but must still be professional and respectful





# CPSO POLICY

- Physicians **must not** engage in disruptive behaviour
  - Profane, disrespectful, insulting, demeaning, intimidating, abusive language
  - Bullying, attacking or harassing
  - Discriminatory
- Physicians **must** disclose COI and manage



# CPSO POLICY – HEALTH INFO

- Must disseminate information that is
  - Verifiable and supported by evidence and science
  - **Not** misleading or deceptive
- Be aware of and transparent about the limits of knowledge and expertise
- **Do not** misrepresent qualifications
- Be mindful of risks of creating a physician-patient relationship or creating the perception of one
- **Do not** provide specific clinical advice to others



# CPSO POLICY – CONFIDENTIALITY

- Adhere to CPSO privacy policies and PHIPA
- Original content must be de-identified, or get consent if anonymity of patient cannot be ensured
- Do not seek patient's health information online without patient consent
  - Document searches in the patient record







# READY?







# IBD Applications

Is there any benefit for IBD patients  
& healthcare providers ?





# IBD Applications (> 60)

**ColitisWatch - IBD Tra...**  
Health & Fitness **GET**

**IBD Healthline**  
Colitis and Crohn's Support **GET**  
★★★★★ 38

Join the Crohn's and Colitis community that gets it.

Match with members based on treatment, interests, and experience.

What are you here for?

**My IBD Care: Crohn's...**  
Manage Sleep, Stress an... **GET**  
★★★★★ 2

**MyGut**  
Health & Fitness **OPEN**  
★★★★☆ 11

**Gali Health**  
A friend for your IBD jour... **GET**  
★★★★★ 54

**MyGut**  
Crohn's and Colitis Canada **OPEN**

AGE: 12+ Years Old  
CATEGORY: Health & Fitness  
DEVELOPER: Crohn's and Colitis Canada  
LANGUAGE: English

**What's New** [Version History](#)

Version 1.1.2 4mo ago

Customizable and enhanced features are now available on the app, allowing users to now customize alerts and notifications.

**Preview**

5:46 5:46 5:46



# IBD Applications

## CLINICAL REVIEW ARTICLE

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### Can Smartphones Help Deliver Smarter Care for Patients With Inflammatory Bowel Disease?

*Michael Kelso, MD, and Linda A. Feagins, MD*

The addition of smartphone applications to the armamentarium of tools to help manage patients with inflammatory bowel disease (IBD) has the potential to improve care in multiple ways, including enhanced disease understanding, improved adherence to medications, accessible support networks, and earlier interventions by medical professionals when problems arise. However, at present, for patients with IBD, the development of such mobile applications is still in its infancy. We conducted a review of the literature and online resources including phone application stores (Apple and Android app stores) to assess the current availability of mobile health applications for IBD patients and opportunities to increase patient engagement. We also addressed the limitations and challenges of patient and provider adoption of mobile-based technologies for IBD self-management and remote monitoring.

**Key Words:** inflammatory bowel disease, smartphones, mobile apps





# Potential Benefits

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**TABLE 1: Potential Benefits of Smartphone Use in Caring for Patients With Inflammatory Bowel Disease**

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Patient education on disease and management

Remote disease monitoring

- Symptom tracking
- Medication adherence tracking
- Dietary logs

Earlier interventions based on tracked data

- Alerts to medical team if symptoms not on track

Improved adherence (alarms/reminders)

Improved self-management/patient empowerment

Online support network

---

- Remote patient monitoring via web applications has been studied with improvement in patient-reported quality of life, medication adherence, and decreased health care costs.



# Limitations

- Concerns over privacy and confidentiality
- Most mHealth apps are not integrated into EMR's
- Lack of medical involvement in the design of mHealth apps (validity and accuracy of content)
  - NodeHealth
- Frequency of mobile app usage by IBD patients may not follow disease activity
- Concordance gap between the mobile apps and digital tools promoted by gastroenterologists and patient preference







# Improved Quality of Care and Quality of Life for IBD Patients Using Mobile Based Remote Monitoring Platform: A Randomized Control Trial

Ashish Atreja, MD, MPH  
Associate Professor and  
Chief Innovation Officer, Medicine  
Icahn School of Medicine at Mount Sinai



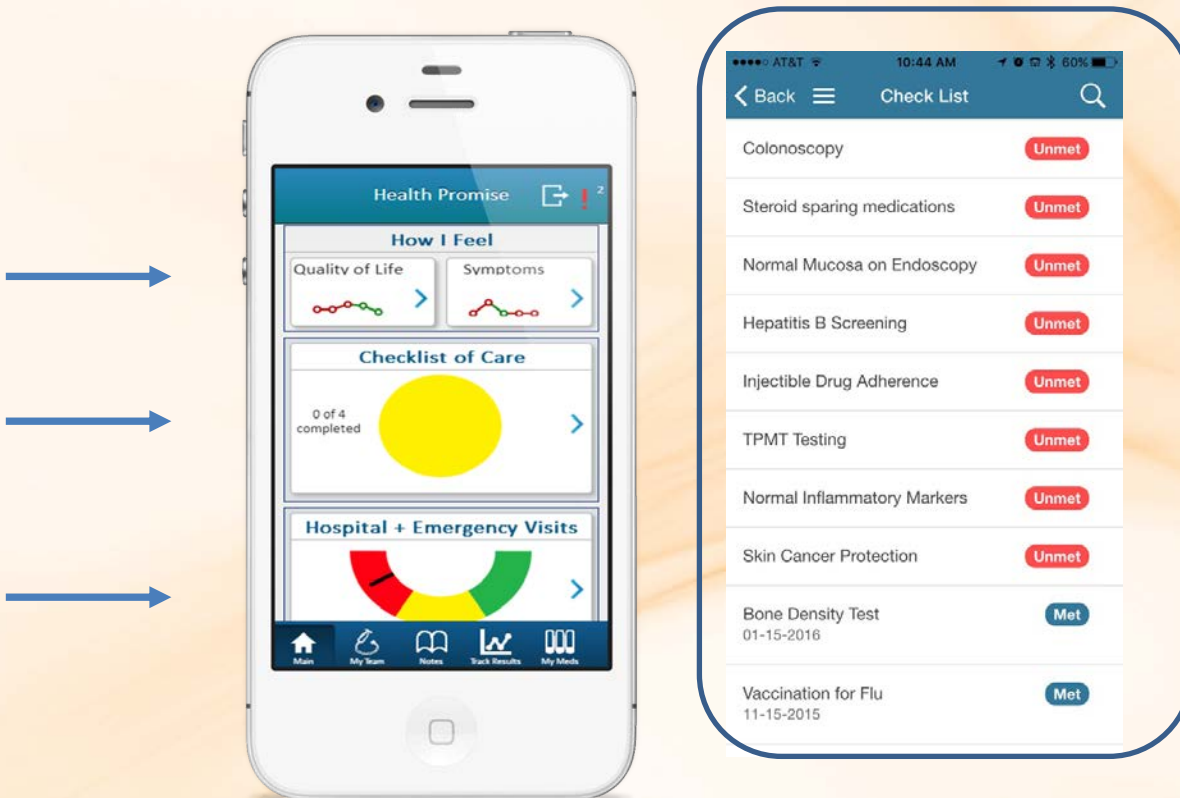


## Aims and Objectives

- **Aim:** The study aims to understand the impact of home based monitoring via a prescribed mobile application, HealthPROMISE, on improving patients' quality of care (QOC) and quality of life (QOL).
- **Primary outcome:** Change in percentage of met quality of care items between Control and HealthPROMISE groups
- **Secondary outcomes:** Change in quality of life ("QOL") score from baseline. Explore impact on ER visits and Hospitalization days



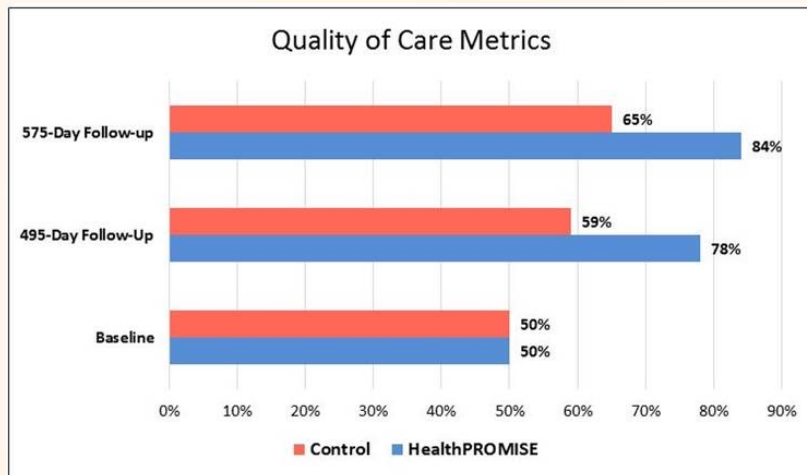
## Intervention: HealthPROMISE App



Atreja A, JMIR Res Protocol, 2015



## Results: Improvement in Quality of Care (Primary Outcome)



- After an average follow-up of  $575 \pm 135$  days, QOC continued improving (84% vs. 65% control) with a more significant change from baseline observed among HealthPROMISE users (+34 ppt vs. +15 ppt,  $p < 0.01$ )

- Those randomized to the mobile health app arm having significantly higher quality of life (quality of life score, 30.0 vs 25.2;  $P < 0.001$ )



## Interim Survey (n=37)

### High Engagement with HealthPROMISE vs Control (Education App)

	Education App	HealthPROMISE
Actively using app	0.24	0.88
Ability to Manage IBD	0.20	0.60
Met some of my needs	0.68	0.96
Refer to a friend	0.53	0.75

Atreja A, DDW, San Diego. 2016



# MyGut Application (CCC)



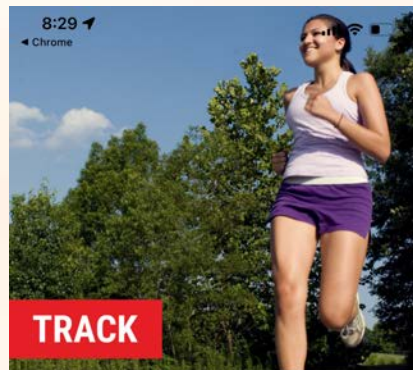
DASHBOARD



Browse your dashboard for everything you need to see at a glance!

Skip

Next



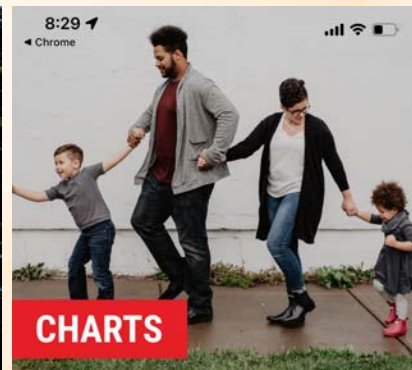
TRACK



Track your exercise, washroom visits, symptoms, sleep and more. Just tap the plus button at the bottom of your dashboard!

Skip

Next



CHARTS



Visualize trends for your quality of life!

Skip

Next



LEARN



Discover Crohn's and Colitis Canada approved content about managing life with IBD

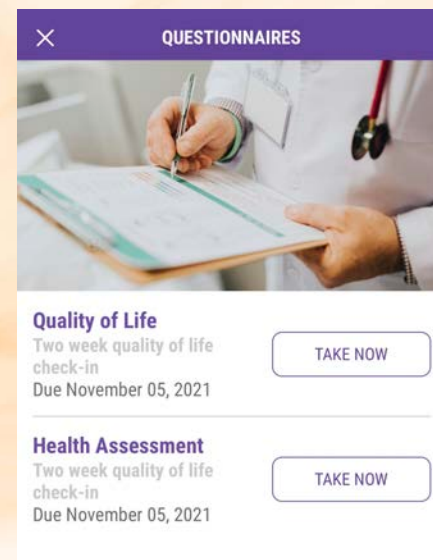
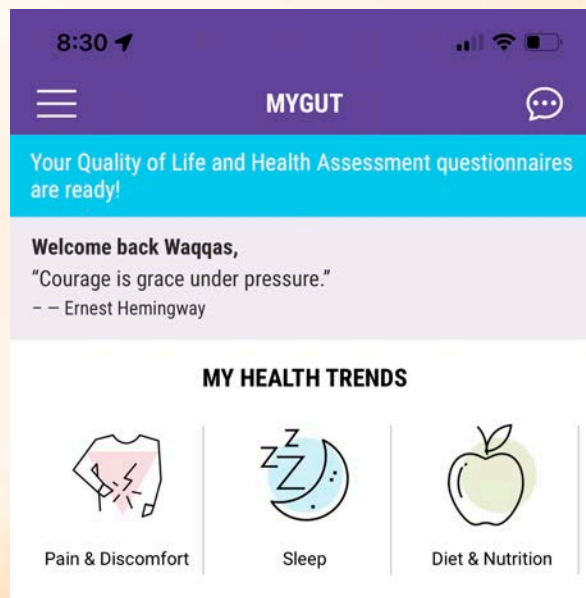
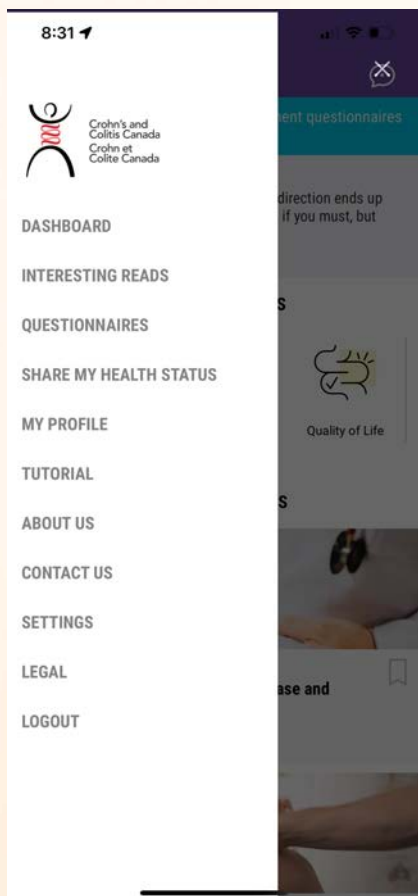
Skip

Finish





# MyGut Application







# MyGut Provider Portal

MyGut Provider Portal

Waqqas Afif

Broadcast Message 1 - 20 of 72 Search

<input type="checkbox"/>	LAST NAME	FIRST NAME	AGE	SEX	DIAGNOSIS	LAST CLINIC VISIT	CLINIC NAME	STATUS	ACTION
			36	Male	Ulcerative Colitis	—	Dr Waqqas Afif	Requires Attention	
			33	Male	Crohn's Disease	—	Dr Waqqas Afif	Requires Attention	
			27	Male	Crohn's Disease	—	Dr Waqqas Afif	—	
			26	Female	Crohn's Disease	—	Dr Waqqas Afif	—	
			N/A	N/A	N/A	—	Dr Waqqas Afif	—	
			33	Female	Crohn's Disease	—	Dr Waqqas Afif	—	
			27	Male	Crohn's Disease	—	Dr Waqqas Afif	—	
			30	Male	Crohn's Disease	—	Dr Waqqas Afif	—	
			32	Male	Crohn's Disease	—	Dr Waqqas Afif	—	
			44	Female	Crohn's Disease	—	Dr Waqqas Afif	—	
			39	Male	Crohn's Disease	—	Dr Waqqas Afif	—	
			39	Female	Ulcerative Colitis	—	Dr Waqqas Afif	—	
			44	Male	Crohn's Disease	—	Dr Waqqas Afif	—	

Screenshot



# MyGut Provider Portal



Canadian Society of  
Gastroenterology and  
Endoscopy

**MyGut**  
Provider Portal



Waqas Afif



## NOTIFICATION SETTINGS

HBI Score



SIBDQ Score



pMayo Score



Hospital Admission



ER Visit



Auto Reply



Allow Chat



Email Notification





# MyGut Provider Portal



MyGut  
Provider Portal



Waqas Afif



## NOTIFICATIONS

Patients that require your attention are shown below.

1 - 4 of 4

Search

DATE	ALERT DESCRIPTION	LAST NAME	FIRST NAME	DIAGNOSIS	ACTION
10/20/2021 8:31 AM	pMayo Score > 2.5	Cunningham	Daniel	Ulcerative Colitis	
10/06/2021 12:07 PM	HBI Score > 7	Bouvier	Julien	Crohn's Disease	
09/30/2021 10:08 PM	pMayo Score > 2.5	Cunningham	Daniel	Ulcerative Colitis	
09/30/2021 10:06 PM	Poor QoL Score < 30	Cunningham	Daniel	Ulcerative Colitis	





# MyGut Provider Portal

## PATIENT PROFILE

[Patient List](#) » [Patient Profile](#)



Last Clinic Visit: —

SIBDQ Baseline: 42

pMayo Baseline: 4

**STATUS : REQUIRES ATTENTION**

10/20/2021 08:31 am pMayo Score > 2.5

09/30/2021 10:08 pm pMayo Score > 2.5

## PATIENT OVERVIEW

[Print Report](#)

### PROFILE

Age  
36 (YOB 1985)

Sex  
Male

Height  
5' 11"

Weight  
201 lb

Pregnant  
N/A

Smoking Habits  
Never smoked

Region  
Quebec

Education  
Secondary

### MEDICAL HISTORY

IBD Diagnosis  
Ulcerative Colitis

Time to Diagnosis  
2-5 years

Diagnosis Year  
2019

IBD Surgery Performed  
No

Medication(s)  
5ASA (Pentasa, Mezavant, Salofalk, Asacol)  
Prednisone  
Other

Healthcare Team  
Gastroenterologist  
IBD Nurse

Patient Support Program  
No

Compassionate Use Program  
No

[Screenshot](#)



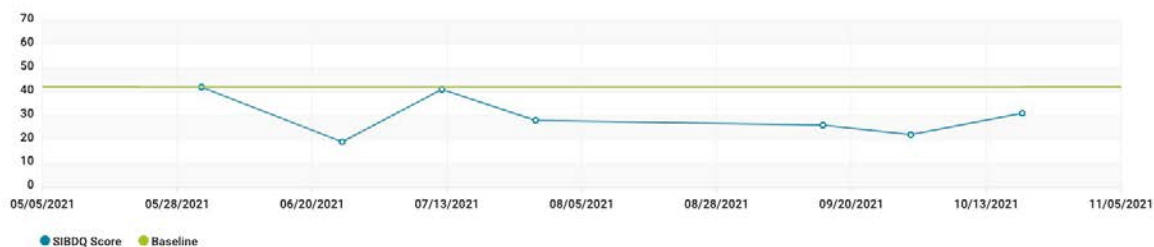
# Health Trends

## HEALTH TRENDS

Time Horizon: Last 6 Months

### SIBDQ SCORE

[View Details](#)



### HBI SCORE



### PMAYO SCORE

[View Details](#)



Screenshot





# MyGUT: Multicenter Study (McGill/McMaster/U of T)

- To determine the acceptability and feasibility of implementing the MyGut application into IBD- specific clinical practice
- To investigate whether use of the MyGut application improves the quality of care and quality of life of the patient as measured by various quality indicators after one year of use compared to the year prior to use.





# Conclusions

- Remote monitoring is the future of IBD care
  - Symptom monitoring, home fecal calprotectin
- Will improve patient care: education, access to healthcare team, improve quality of care metrics (increased patient involvement)
- Needs integration into EMR for widespread use for healthcare providers and patients
  - For patients: access to medical chart/providers
  - For providers: ability to track patients remotely, avoid increased workload, decrease “well-patient” visits
  - For researchers: PROs, mobility tracking, other outcomes





# Thank-you !

## Questions/Comments ?