# **Citizen Brief**

Reducing Emergency-department Usage in People with Inflammatory Bowel Disease in Provincial Health Systems in Canada 12 October 2018





### **EVIDENCE** >> **INSIGHT** >> **ACTION**

### The McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

### About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to reveal new understandings about an issue and spark insights about how it should be addressed.

### About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panels on reducing emergency-department use by people with inflammatory bowel disease in provincial health systems in Canada. This brief includes information on this topic, including what is known about:

- the underlying problem;
- three possible elements of an approach to addressing the problem; and
- potential barriers and facilitators to implement these elements.

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

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# Key messages

#### What's the problem?

- Canada has one of the highest rates of inflammatory bowel disease (IBD) in the world, affecting approximately one in every 150 Canadians.
- People with IBD do not always receive the care they need, particularly during flares.
- It is difficult to manage the symptoms of IBD, and patients don't always have timely access to specialty care. Therefore, many individuals with IBD go to emergency departments for care when other options are not available.
- Four factors contribute to the challenge of reducing emergency-department use by people with IBD:
  - 1) the number of Canadians living with IBD is increasing;
  - 2) a lack of awareness of IBD and its symptoms hinders timely diagnosis and access to appropriate care;
  - 3) access to timely and appropriate specialty care is uneven; and
  - 4) those needing urgent care often resort to emergency departments.

### What do we know about elements of an approach for addressing the problem?

- Element 1: Support patients to play a more active role in managing their condition
  - This element could include: 1) providing educational materials; 2) introducing in-person support; and 3) making available electronic tools to support self-management (such as mobile applications).
- Element 2: Help primary-care and emergency-department staff better support patients during IBD flares
  - This element could include: 1) introducing training and supports for primary-care and emergencydepartment professionals; 2) proactively identifying those patients at risk and connecting them to appropriate resources; and 3) integrating electronic tools into the care process.
- Element 3: Provide alternative ways for specialists to support patients during IBD flares
  - This element could include: 1) providing opportunities for remote consultations with an IBD care team; 2) establishing urgent-care clinics focused on supporting gastrointestinal care; and 3) creating clinics focused on patients who suffer from multiple chronic conditions.

#### What implementation considerations need to be kept in mind?

- Many barriers could make it difficult to implement these elements. Perhaps the biggest barrier is the difficulty in finding solutions that will be appropriate across each of the unique health systems in Canada.
- Many factors may be contributing to opening a window of opportunity for implementing these elements. For example, many health systems are actively considering ways to strengthen primary care to reduce the burden on emergency departments, with better chronic-disease management as a focus.

# Questions for the citizen panel

>> We want to hear your views about a problem, three elements of an approach to addressing it, and how to address barriers to moving forward.

### **Box 1: Questions for citizens**

### Questions related to the problem

- What has worked well and what has been a challenge to accessing support for inflammatory bowel disease (IBD) flares, for yourself, a family member or someone you provide care to?
- More specifically, what has worked well and what was a challenge with:
  - o getting a timely diagnosis?
  - o enabling you to manage your disease?
  - o accessing timely and appropriate specialty care?
  - o accessing urgent care?

### Questions related to the elements of an approach to address the problem

- Element 1 Support patients to play a more active role in managing their condition
  - What support would you like to see continued, or more of, to enable selfmanagement?
- Element 2 Help primary-care and emergency-department staff better support patients during IBD flares
  - What support would enable health professionals working within primary-care settings and emergency departments to provide better care during IBD flares?
- Element 3 Provide alternative ways for specialists to support patients during IBD flares
  - What alternative types of care could be organized to help with IBD flares?

### Question related to implementation considerations

• What are the biggest barriers to reducing emergency-department use by people with IBD?

### **Box 2: Glossary**

### Inflammatory bowel disease

Inflammatory bowel disease (IBD) refers to a group of inflammatory conditions, primarily of the colon and small intestine, with Crohn's disease and ulcerative colitis as the two main types.(1) Both are lifelong conditions that usually begin in early adulthood, but can occur at any age. The symptoms are unpredictable and include:

- cramps;
- stomach pain;
- vomiting;
- blood in stool;
- diarrhea;
- anemia (which is a low blood count that can make you tired and short of breath);
- feeling tired;
- fever; and
- reduced appetite .(3)

#### Flare

A flare is a period of time when symptoms of a disease are worse, or when a disease hurts more than normal.(4)

### Remission

Remission refers to a period of time when a disease is not active, or disease symptoms are not noticeable.(4)

#### Primary care

The first point of contact or entry into the health system. Individuals involved in providing primary care are: family physicians, nurse practitioners, registered nurses, social workers, dietitians and other health professionals.

### Specialty care

Specialized medical services, such as a specialized physician (gastroenterologist) for IBD.

### Urgent care

Care provided for illnesses or injuries that require prompt attention, but are typically not serious enough to require the services of an emergency department.

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Inflammatory bowel disease and the many complications associated with its appropriate diagnosis and care is a priority issue in Canada.

# **The context:** Why is reducing emergencydepartment use by people with IBD a high priority?

Canada has one of the highest rates of inflammatory bowel disease (IBD) in the world, affecting approximately one in every 150 Canadians.(6; 7) The symptoms experienced by people living with IBD can be severe and have serious consequences. They affect the ability to work and attend school, the capacity to plan for the future (for example, planning a career or travels), and the quality of life in general. People may also feel stigma (being perceived negatively by others) and have difficulty with intimate relationships because of the symptoms.(7-13)

After initial diagnosis, therapy focuses on two things:

- 1) managing symptoms, particularly during a flare (the period of time when symptoms are worse and when the disease hurts more than normal); and
- 2) maintaining remission (the period of time when the disease is not active).(8)

Most people living with IBD need ongoing medication and some may end up needing surgery.(7) Specialty care is generally led by a gastroenterologist (a physician specialized in the digestive system and its disorders). However, gastroenterologists are not always available to all Canadians with IBD. For example, there may be a lack of specialty care in many rural and remote areas.

People with IBD will usually use the most health services within the first year of their diagnosis.(14) However, there are often delays in diagnosis – and delay in accessing appropriate speciality care – due to a lack of awareness of IBD in primary care and emergency departments.(7) In addition, the symptoms of IBD are very unpredictable. Even when people have been diagnosed and referred to a gastroenterologist, they may be unable to access speciality care when they need it (for example, after hours and on weekends). In such cases, people with IBD may be forced to go to emergency departments to receive care.

Given the burden of IBD and the many complications associated with its appropriate diagnosis and care, reducing use of emergency departments by people with IBD is a priority issue in Canada.(15)

### Box 3: Key features of provincial health systems in Canada

### Key features of health systems

- The responsibility for health systems falls primarily to the provinces and territories, with broad rules set by the federal government.(2)
- Medically necessary care provided in hospitals or by a physician is fully paid for as part of each publicly funded provincial/territorial health system.(2)
- Other healthcare providers (for example, nurses, physiotherapists, occupational therapists) are typically not paid for by provincial/territorial health systems, unless their care is provided in a hospital or long-term care setting. Public coverage outside of these settings varies by province and territory.
- Other aspects of healthcare (for example, assistive technology and prescription drug coverage) and community services (for example, home care and long-term care homes) may be partly government funded, with the remaining portion of the costs paid through private insurance plans and/or out-of-pocket.(5)
- Healthcare is increasingly organized by region within provinces and territories. Planning and funding of healthcare is the responsibility of the regions.(2)

### Features most relevant to IBD specialty care

- Given the diversity and complexity of symptoms associated with IBD, many other health professionals working across a number of settings could be involved in an IBD care team, including:
  - o gastroenterologists;
  - o nurses with experience in IBD;
  - o nutritionists with experience in IBD;
  - o psychologists with a focus on helping patients to deal with the disease;
  - primary-care teams to help with the complications from IBD and those that can happen because of treatment; and
  - social workers who can connect patients with appropriate supports (for example, peer support groups, or guidance on employment and financial-related issues).

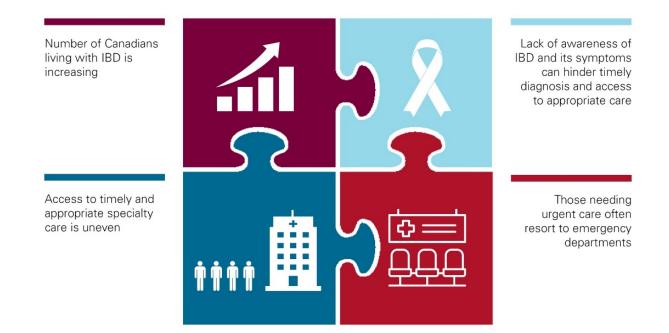


Due to the unpredictable nature of IBD and the lack of access to gastroenterologists, many seek care for IBD in emergency departments.

# **The problem:** Why is it challenging to reduce emergency-department use by people with IBD?

We identified four factors that contribute to the challenge of reducing emergencydepartment use by people with IBD. These challenges are presented in Figure 1 and described below.

# Figure 1. Factors contributing to the challenge of reducing emergency-department use by people with IBD



### The number of Canadians living with IBD is increasing

The number of Canadians living with IBD is growing and Canada has some of the highest rates in the world.(16) There are approximately 270,000 individuals with IBD in Canada (including 135,000 with Crohn's, 120,000 with ulcerative colitis, and 15,000 with IBD but no clear diagnosis).(16) By 2030, it is projected that 403,000 Canadians will have IBD.(16)

As the number of individuals living with IBD grows, it is likely that IBD will have a growing impact on health spending, and on society more generally (see Figure 2).(8) The costs associated with IBD in Canada have been estimated to be \$2.8 billion in 2012, which works out to an average cost of \$12,000 per patient.(8) This estimation includes direct and indirect costs. Direct costs of IBD - those related to the care provided to patients - are driven by:

- drugs;
- hospitalizations;
- physician visits;
- other health-system costs such as emergency department visits, diagnostics, home care and long-term care; and
- hospital outpatients such as same-day stays or procedures.(7; 8)
- 8

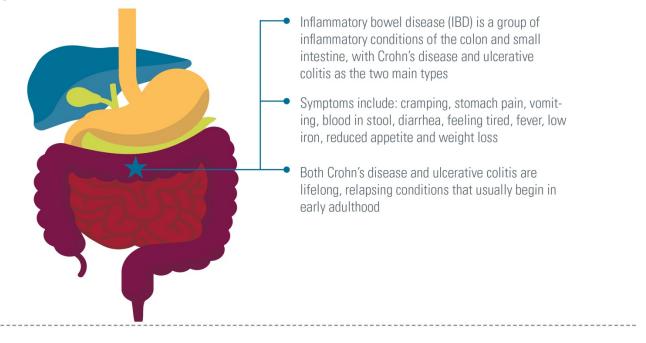
Indirect costs of IBD – those that fall on individuals or on society more broadly - are driven by:

- out-of-pocket expenses to buy ostomy supplies (for ostomy surgery which is an opening in the abdomen that allows for wastes to be passed), to make home modifications, to get home-care supports, or to get complementary and alternative therapies;
- short-term work losses due to taking time off of work; and
- long-term work losses due to withdrawing from the workforce and premature mortality.(8)

The many challenges faced by a growing number of Canadians living with IBD and its symptoms, combined with the high costs associated with the condition, highlight the need to find ways to provide more timely and appropriate care.

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### Figure 2. The burden of IBD in Canada





IBD and irritable bowel syndrome (IBS) are the same thing

False. They are often confused because of the similar name and they both affect the digestive tract, however, inflammation does not play a role in IBS whereas it is a key aspect of IBD.



Stress causes IBD

False. Although the cause of IBD is not well understood, we know that stress does not cause it. However, stress may make symptoms worse or contribute to a flare.



Canada has some of the highest rates of IBD in the world

**True.** Approximately 1 in every 150 Canadians has IBD, and approximately 270,000 people are living with IBD in Canada.

In 2012, the costs associated with IBD in Canada were estimated at

\$2.8 billion



... This is almost

equivalent to the budget for the city of Ottawa

# Ē

Prescription drugs







The top factors that make up that cost:

Hospital outpatient and inpatient care







Physician visits



Out-of-pocket expenses

ource: mcmasterforum.org/find-evidence/produc



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# A lack of awareness of IBD and its symptoms hinders timely diagnosis and access to appropriate care

Many Canadians are not aware of IBD and its symptoms. There is often a perception that IBD is not as common as other chronic diseases, despite being more common than multiple sclerosis or Parkinson's disease and just as common as epilepsy and Type 1 diabetes.(7; 17; 18) This lack of awareness creates a challenge in ensuring that people with IBD receive a timely diagnosis, and also the most appropriate care.(7)

Three factors could explain why there is a lack of public awareness:

- 1) IBD is not preventable;
- 2) there is a general confusion between irritable bowel syndrome (IBS) and IBD; and
- 3) there is stigma associated with IBD.

First, some other chronic conditions can be prevented with the right mix of approaches (for example, diet and exercise to reduce the likelihood of developing Type 2 diabetes). However, given the role of genetics and environmental factors, the prevention of IBD and its symptoms may not be possible regardless of how many proactive measures are taken by individuals.(19) As a result, IBD does not fall under publicly funded chronic-disease-prevention programs and services, and as such is not discussed as frequently as other conditions that are.(7)

Second, there is limited understanding in the general public of the differences between irritable bowel syndrome and IBD. IBS is a common gastrointestinal disorder, whereas inflammation is a key aspect of IBD. While not life-threatening, IBS does have a range of symptoms that can be distressing (for example, stomach pain, irregular bowel patterns and constipation).(20) The common confusion between the two conditions affect public awareness and understanding of IBD.(7)

Third, the lack of public awareness can reinforce the stigma associated with IBD. Research found that many people with IBD have the impression of being perceived negatively by others. This was particularly the case for those who experience IBD flares more often.(11) Perceptions of stigma were found to be a predictor of poorer health outcomes reported by people with IBD.(10) Another study found that many people with IBD reported some form of discrimination due to their condition.(9)

### Access to timely and appropriate specialty care is uneven

Access to appropriate specialty care for IBD is not always timely or consistent for all individuals who need care. This is due to at least three reasons:

- 1) there are challenges related to the delivery of care for IBD in primary-care settings and emergency departments;
- 2) treatments commonly used are not always optimal for each patient; and
- 3) access to specialty care is affected by the number and distribution of gastroenterologists.

First, there are challenges to the delivery of care for IBD in primary-care settings and in emergency departments. Health professionals in primary-care settings and in emergency departments may have limited training and tools specific to diagnosing and managing IBD. They may also lack the knowledge and skills to address the various needs of patients with IBD.

Second, treatments commonly used for IBD are not always optimal for each patient. Research increasingly shows that new biological therapies (a type of treatment that uses substances made from living organisms to treat a disease) can be an effective treatment to manage IBD. However, despite these advances, treatments using corticosteroids and opioids are still commonly used even when they may not be the best choice for the patient. Specifically, while corticosteroids can help symptoms associated with IBD go into remission, they are not effective in maintaining remission. In addition, there are numerous side effects and complications of using corticosteroids.(21)

Third, the number and distribution of gastroenterologists in Canada limits access to specialty care (especially in rural and remote areas). In 2016, it was estimated that there were between 782 and 848 gastroenterologists in Canada (2.14 gastroenterologists per 100,000 population).(22) Of the 10 provinces, six had fewer than two gastroenterologists per 100,000 population.(22) Furthermore, many gastrointestinal clinics run during standard office hours, which could make it difficult for individuals to see a specialist in the event a flare occurs during the evening or on a weekend. Therefore, patients may not feel they have access to their gastroenterologists when they need them most.

# Those needing urgent care often resort to emergency departments

As mentioned in the sections above, the symptoms of IBD are unpredictable and it is often challenging to access specialty care when it is most needed. Therefore, when people experience an IBD flare (for example, when the symptoms are getting worse, or when it hurts more than normal), many seek urgent care from emergency departments.(4)

This challenge was illustrated by a recent study conducted in Manitoba, which examined 1,143 individuals with IBD and found that:

- although 61% of patients had a gastroenterologist, when their IBD symptoms were active only 29% felt as though their specialist was available for an urgent appointment, and only 42% felt as though their specialist was available for a telephone call to discuss their issues;
- emergency departments remain the main choice among these patients;
- 9% visited the emergency department in the previous year;
- 48% said they would visit the emergency department if they had severe symptoms;
- higher bowel-symptom severity and higher health anxiety were associated with emergency-department visits; and
- showing up to an emergency department with a gastrointestinal complaint was a strong predictor of hospital admission later on.(23)

It is important to note that while alternative options (for example, urgent-care centres) are key to supporting individuals with IBD, some patients need emergency care during critical times. Emergency departments are the best fit for this type of care. For example, symptoms of an IBD flare may be the same as other conditions (for example, gastroenteritis, appendicitis or bowel obstruction) and need to be assessed in an emergency department.

### Questions to consider

- What has worked well and what has been a challenge to accessing support for inflammatory bowel disease (IBD) flares, for yourself, a family member or someone you provide care to?
- More specifically, what has worked well and what was a challenge with:
  - o getting a timely diagnosis?
  - o enabling you to manage your disease?
  - o accessing timely and appropriate specialty care?
  - o accessing urgent care?

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Reducing emergencydepartment use by people with IBD in Canada will require the consideration of a number of elements.

# Elements of an approach to address the problem

>> To promote discussion about the pros and cons of potential solutions, we have selected three elements of an approach to reduce emergency-department use by people with IBD

Many approaches could be selected as a starting point for discussion. We have selected the following three elements of an approach for which we are seeking input:

- 1. support patients to play a more active role in managing their condition;
- 2. help primary-care and emergency-department staff better support patients during IBD flares; and
- 3. provide alternative ways for specialists to support patients during IBD flares.

These elements should not be considered separately. Instead, each should be considered as contributing to a potentially comprehensive approach to addressing the problem. New elements could also emerge during the discussions. Box 4 below summarizes how research evidence has been identified, selected and synthesized for each element.

# Box 4: Identification, selection and synthesis of research evidence presented in this brief

- Whenever possible, we describe what is known about each element based on systematic reviews.
- A systematic review is a summary of all the studies looking at a specific topic.
- A systematic review uses very rigorous methods to identify, select and appraise the quality of all the studies, and to summarize the key findings from these studies.
- A systematic review gives a much more complete and reliable picture of the key research findings, as opposed to looking at just a few individual studies.
- We identified systematic reviews in Health Systems Evidence (<u>www.healthsystemsevidence.org</u>). Health Systems Evidence is the world's most comprehensive database of research evidence on health systems.
- A systematic review was included if it was relevant to one of the elements covered in the brief.
- We then summarized the key findings from all the relevant systematic reviews.

# Element 1 – Support patients to play a more active role in managing their condition

### Overview

This element is focused on supporting patients to play a more active role in managing their condition. Different types of 'self-management' interventions could help to achieve this. Self-management interventions support patients to develop their knowledge and skills necessary to manage their condition. Self-management interventions are often promoted to empower patients.

Self-management interventions could include the following:

- 1) providing educational materials for persons living with IBD;
- 2) introducing in-person support to enhance their capacity for self-management; and
- 3) providing electronic tools that can support self-management, such as the following applications:
  - Gi BodyGuard which allows individuals with IBD to track information about their health, symptoms, medications, food and exercise;
  - IBDoc which allows for a home test for calprotectin (a protein released by a type of white blood cell when there is inflammation in the gastrointestinal tract) that electronically communicates results to a health professional;
  - MyIBDcoach which allows for continuous home monitoring; and
  - healthPROMISE which allows for IBD symptom tracking that electronically communicates results to a health professional.

Evidence and questions to consider during your deliberations are provided below.

### Evidence to consider

We identified 10 systematic reviews that we deemed to be most relevant to element 1.

Overall, the evidence suggests that self-management interventions can benefit people with chronic diseases, including IBD. Self-management can also decrease healthcare utilization by patients with various chronic diseases.(24) There was limited evidence about the costs of electronic tools related to the management of patients with IBD.(25) Lastly, several factors can contribute to the success of self-management interventions, including:

• good collaboration between patients and health professionals;(26) and

• changes made by healthcare organizations to support self-management interventions (for example, having strong leadership, professional engagement, appropriate training and resources, as well as evaluating self-management interventions).(26)

We present a more detailed summary of the evidence in Table 1.

Area of focus	Key findings			
Providing educational materials for persons living with IBD	<ul> <li>Educational interventions (including providing information on the Web and printed materials) were found to have positive impacts, including:         <ul> <li>increasing knowledge about the disease;</li> <li>improving how patients take their medications as prescribed; and</li> <li>improving patient and professional engagement.(26-28)</li> </ul> </li> <li>There is mixed evidence about self-management programs focusing on educating patients and their effect on quality of life. One systematic review found that education interventions, particularly those done remotely, had a positive impact on health-related quality of life.(29) Two other systematic reviews found that education interventions resulted in decreased quality of life among patients with IBD.(27; 28) While this may have been attributable to study design, these findings highlight the importance of timely and appropriate information provision.(27; 28)</li> </ul>			
Introducing in- person support to enhance their capacity for self- management	<ul> <li>Providing personal support can improve self-management capacity among patients with IBD. Most notably it can help:         <ul> <li>improve quality of life;</li> <li>reduce disease activity; and</li> <li>reduce health service utilization.(24; 30)</li> </ul> </li> <li>Interventions led by nurses to help patients 'self-manage' their chronic diseases have positive effects (for example, improving blood pressure control for patients with hypertension).(31) However, it is unclear if interventions by nurses have a positive effect on quality of life and other health outcomes reported by patients.(31)</li> </ul>			
Providing electronic tools applications that can support self- management	<ul> <li>Research evidence shows that electronic tools can benefit people with IBD to manage their condition by:         <ul> <li>reduce disease activity;</li> <li>improving quality of life as reported by patients;</li> <li>reducing patient distress; and</li> <li>improving communication between patients and health professionals.(25; 32)</li> </ul> </li> <li>One systematic review highlighted that there is a paucity of online tools to help patients decide whether they should undergo surgery for ulcerative colitis. These findings highlight the need to develop tools to help patients engage in conversations with their health professionals and make decisions.(33)</li> </ul>			

### Questions to consider

Overarching questions to consider

• What support would you like to see continued, or more of, to enable self-management?

Additional questions to consider

- What kind of educational materials would you need?
- Who could provide the support to enhance your capacity for self-management?
- What kinds of electronic tools for self-management would you be open to?

# Element 2 – Help primary-care and emergency-department staff better support patients during IBD flares

### Overview

This element aims to help health professionals working in primary-care settings and emergency departments to better support patients during IBD flares. There could be many different ways to help these health professionals, including:

- 1) introducing training and support for health professionals in primary-care settings and emergency departments (for example, by creating a training certificate specifically for IBD, and creating resource centres and online networks where professionals can share best practices and the best available research evidence about how to manage IBD);
- 2) helping professionals to identify patients at risk (or higher IBD symptom severity) and connecting them to appropriate resources (for example, by improving mechanisms to classify IBD patients into varying levels of risk); and
- 3) integrating electronic tools (such as the apps listed in element 1) into the care process by linking patient data to service providers when needed (for example, linking symptom tracking and home-monitoring apps to an IBD care team).

Evidence and questions to consider during your deliberations are provided below.

### Evidence to consider

We identified six systematic reviews that we deemed to be most relevant to element 2.

Overall, the evidence suggests that telecommunication technologies (for example, telemedicine and mobile-health technologies) may have positive effects. However, health professionals see a number of challenges related to the use of these technologies in the delivery of care. Research evidence also highlights the use of patient-reported outcomes measures to better support the diagnosis of IBD. Lastly, proactively identifying patients at risk of a disease and connecting them to resources in primary-care settings has been shown to have positive effects.

We present a more detailed summary of the evidence in Table 2.

### **Table 2.** Summary of research evidence about element 2

Area of focus	Key findings
Introducing training and support for primary-care and emergency- department staff	<ul> <li>Telemedicine and mobile-health technologies used by patients and professionals generally have positive effects, including:         <ul> <li>improving quality of life;</li> <li>improving satisfaction among patients;</li> <li>improving symptom severity; and</li> <li>improving staff engagement in the delivery of care.(34-36)</li> </ul> </li> </ul>
Proactively identifying patients at risk and connecting them to appropriate resources	<ul> <li>One systematic review examined the value of patient-reported outcome measures (theses are measurement instruments that patients complete to provide information on aspects of their health) to better support the diagnosis of IBD.(37) These measures are increasingly used in health systems and have the potential to support disease monitoring. Research shows the importance of involving patients in developing patient-reported outcome measures.</li> <li>The following benefits were found for proactively identifying patients at risk of a disease and connecting them to resources in primary-care settings:         <ul> <li>improving how patients take their medications as prescribed;(38)</li> <li>improving health-related patient behaviours;(38)</li> <li>improving health professional behaviours;(38) and</li> <li>increasing the use of health services.(38; 39)</li> </ul> </li> </ul>
Integrating electronic tools into the care process by linking patient- monitoring data to service providers when needed	<ul> <li>Health professionals see a number of challenges related to the use of telecommunications technologies in the delivery of care. These barriers include: <ul> <li>perceived negative impact of these technologies on staff-patient relationships;</li> <li>perception that these technologies may not be needed, or that they will not have a lot of impact; and</li> <li>perceived negative impact of these technologies on professional autonomy and credibility.(36)</li> </ul> </li> <li>To improve the acceptance of these technologies by health professionals, it is important to: <ul> <li>pay attention to the quality of the technologies in terms of their ease of use, reliability and support available; and</li> <li>engage front-line staff in developing these new services.(36)</li> </ul> </li> </ul>

#### Questions to consider

Overarching questions to consider

• What support would enable health professionals working within primary-care settings and emergency departments to provide better care during IBD flares?

Additional questions to consider

- What kind of training do health professionals in primary-care settings and emergency departments need?
- What are the best ways to identify those who are at greater risk in order to connect them to appropriate resources?
- What kind of electronic tools would enable health professionals working within primary-care settings and emergency departments?
- How can primary-care settings and emergency departments better meet the needs of people with IBD?

# Element 3 – Provide alternative ways for specialists to support patients during IBD flares

### Overview

This element focuses on providing alternative ways for specialists to support patients during IBD flares, which will reduce unnecessary emergency-department use. This element could include:

- providing opportunities for remote consultations with an IBD care team and other electronic initiatives to support clinical decisions (for example, establishing IBD-specific programs to ensure patients have regular phone contact with an interprofessional care team);
- 2) establishing urgent-care clinics focused on supporting gastrointestinal care, including rapid access to diagnostics; and
- 3) creating clinics for patients with multiple chronic conditions who may need to be directed to the right specialist.

Evidence and questions to consider during your deliberations are provided below.

### Evidence to consider

We identified six systematic reviews that were most relevant to element 3.

Overall, the evidence on remote consultations with an IBD care team was positive and a range of benefits were found (for example, improved quality of life, better following of treatment plans, and improved symptoms).(25; 41-43) Some reviews found cost-savings with telemedicine (medicine at a distance),(41-43) while others found an increase in costs most likely due to initial start-up costs, technology costs, or travel costs for health professionals.(41; 42)

We were unable to find any systematic reviews about establishing urgent-care clinics focused on supporting gastrointestinal care.

For the third sub-element, creating clinics for patients with multiple chronic conditions, one review found that patient-initiated clinics (where patients schedule their appointments according to their need instead of traditional appointments set by physicians) had a range of benefits.(44) These benefits included improved mental health, general health and disease management.(44)

We present a more detailed summary of the evidence in Table 3. 22

### **Table 3.** Summary of research evidence about element 3

Area of focus	Types of activities			
Providing opportunities for remote consultations with an IBD care team	<ul> <li>Research evidence shows benefits of remote consultations, including:         <ul> <li>improving quality of life;(25; 41-43; 45)</li> <li>improving clinical outcomes and disease activity;(25; 41-43)</li> <li>decreasing clinic visits;(45)</li> <li>improving knowledge about the disease;(42)</li> <li>greater patient empowerment;(42) and</li> <li>patients being able to follow treatments as prescribed.(42; 43)</li> </ul> </li> <li>Patients found telemonitoring and other technologies easy to use, leading to improvements in satisfaction with care.(42; 43)</li> <li>A number of reviews reported a decrease in costs among patients receiving telemedicine care,(41-43) and one review found reduced costs in follow-up care and hospital admission charges.(41)</li> </ul>			
Establishing urgent-care clinics focused on supporting gastrointestinal care, including rapid access to diagnostics	We found no systematic reviews about this particular sub-element.			
Creating clinics that are similar to urgent-care clinics with a focus on patients with multiple chronic conditions	<ul> <li>One review focused on the creation of patient-initiated clinics to address multiple chronic conditions, including breast cancer, IBD and rheumatoid arthritis.(44)</li> <li>The review found that patient-initiated clinics had a range of benefits when compared to traditional consultant-led clinics in secondary care, including improved mental health, general health perceptions, and improved disease management.(44)</li> <li>Among all disease groups in the review, the best outcomes were observed when patients had positive relationships with their health professional.(44)</li> </ul>			

### Questions to consider

Overarching questions to consider

• What alternative types of care could be organized to help with IBD flares?

Additional questions to consider

- What types of remote consultations with an IBD care team would you be open to?
- Do you think that urgent-care clinics focused on supporting gastrointestinal care would help to reduce emergency-department use among people with IBD?
- Do you think that clinics for people with multiple chronic conditions would help to reduce emergency-department use among people with IBD?
- How can IBD care teams better meet the needs of people with IBD?

# Implementation considerations

We may face some barriers if we try to implement the three elements (and their subelements) discussed above. These barriers may be related to different groups (for example, people with IBD, the general public, health professionals), organizations, or to specific aspects of a health system (for example, how care is financed). Some of these barriers could be overcome. However, other barriers could be so important that we would need to reconsider whether we should pursue some elements.



Perhaps the biggest barrier is the difficulty in finding solutions that will be appropriate across each of the unique health systems in Canada. Other potential barriers are summarized in Table 4.

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Table 4: Potential	barriers to	Implementing	the elements

Element	Description of potential barriers
Element 1 - Supporting patients to play a more active role in managing their condition	<ul> <li>Some people living with IBD may not be comfortable playing a more active role in managing their condition, particularly if they were recently diagnosed.</li> <li>Some people living with IBD may not be comfortable using technologies such as mobile phone apps.</li> <li>Some health professionals may lack the knowledge and skills required to support people living with IBD.</li> <li>How physicians are paid (the 'fee-for-service' model) may not be appropriate to support patient self-management (for example, by providing incentives for physicians to provide in-person support, or enable them to support patients remotely).</li> </ul>
Element 2 - Helping primary-care and emergency- department staff better support patients during IBD flares	<ul> <li>Some people living with IBD may not be comfortable using technologies such as mobile phone apps, which could be used to link their health data with appropriate care options.</li> <li>Health professionals working in primary-care settings and emergency departments may not have the time or resources to get training about IBD.</li> <li>Health professionals may lack access to appropriate diagnostic tools in primary-care settings and emergency departments.</li> <li>Health professionals in primary-care settings and emergency departments may not have the necessary skills or infrastructure to enable them to integrate patient data from electronic applications.</li> <li>Information privacy and legal challenges may emerge when integrating patient self-monitoring data across professionals and settings.</li> </ul>
Element 3 - Providing alternative ways for specialists to support patients during IBD flares	<ul> <li>People with IBD who have established routines and are comfortable in managing their condition may have challenges adapting to new ways to access specialty care.</li> <li>There may be a shortage of professionals (particularly gastroenterologists and those trained to support people with IBD) with the ability to provide care in alternative service models.</li> <li>Organizations may lack the appropriate staff, technical capacity or infrastructure to shift towards new service models.</li> </ul>

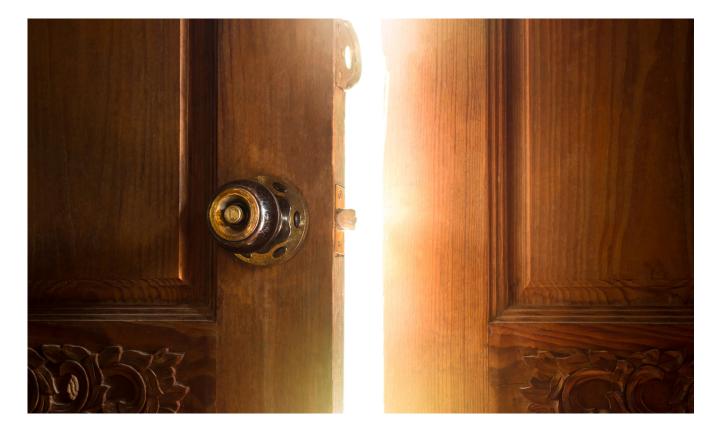
Some factors could also facilitate the implementation of the three elements discussed previously. Sometimes, there may be a window of opportunity, a period of time during which there is a chance to do something. A window of opportunity could take many forms: a recent event that was highly publicized in the media, a crisis, a new technology emerging, a change in public opinion, or an upcoming election.

Factors that may be contributing to opening a window of opportunity for implementing these elements include:

- many health systems are actively considering ways to strengthen primary care to reduce the burden on emergency departments, with better chronic-disease management as a focus;
- many health systems are actively considering new models of care for certain chronic diseases (for example, diabetes) and populations (for example, rural and remote patients);
- most health systems are now supporting patients to play a more active role in their care; and
- there are many chronic diseases (for example, arthritis and diabetes) for which selfmanagement supports have already been introduced, serving as an opportunity to learn from what works.

### Questions to consider

- What are the biggest barriers to reducing emergency-department use by people with IBD?
- What changes are you seeing that can help open a 'window of opportunity' for doing better?



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### Merit review

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