

# Evidence Brief

## Reducing Emergency-department Usage in People with Inflammatory Bowel Disease in Provincial Health Systems in Canada

22 November 2018



**McMaster**  
**HEALTH FORUM**



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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.

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The evidence brief was reviewed by a small number of policymakers, stakeholders and researchers in order to ensure its scientific rigour and system relevance.

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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, and people with this condition do not always receive the care they need, particularly during flares.
- Given the challenges associated with symptom management and ensuring timely access to specialty care, many individuals with IBD turn to emergency departments for care when other options aren't available.
- Four main themes underpin the challenges related to emergency department usage in people with IBD:
  - the number of Canadians living with IBD is increasing;
  - lack of awareness of IBD and its symptoms can hinder timely diagnosis and access to appropriate care;
  - access to timely and appropriate specialty care is uneven; and
  - those needing urgent care often resort to emergency departments.

### What do we know (from systematic reviews) about three elements of a potentially comprehensive approach to addressing the problem?

- Element 1 – enable self-management of IBD through better supports for patients
  - This element could include: 1) providing educational materials; 2) introducing in-person (personal) support; and 3) making electronic self-management initiatives available.
  - Reviews about this element showed positive impacts for: 1) provision of educational materials (e.g., improved disease-related knowledge, medication adherence, patient and professional engagement); 2) personal support among patients with IBD (e.g., improvements in quality of life and disease activity and reduced health-service utilization); and 3) electronic self-management (e.g., improvement in disease activity, patient-reported quality of life and communication between patients and providers).
- Element 2 – strengthen primary care and emergency-department care of IBD and improve connections to specialty care
  - This element could include: 1) introducing training and supports for primary care and emergency-department professionals; 2) proactively identifying those patients at risk and connecting them to appropriate resources; and 3) integrating electronic supports into the care process.
  - Reviews about this element found that health professionals perceived a number of challenges related to the acceptance of telehealth technologies (e.g., the impact of telehealth integration into services, perceived negative impact of telehealth on staff-patient relationships, low expectations of impact/lack of need and perceived negative impact on staff autonomy and credibility).
- Element 3 – introduce comprehensive alternative-service options for IBD specialty care
  - 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 with multiple chronic conditions.
  - Reviews about this element found that: 1) remote consultations with an IBD care team had a range of benefits (e.g., improved patient quality of life, clinical outcomes, disease activity, disease knowledge, patient empowerment, treatment adherence and decreased clinic visits); and 2) patient-initiated clinics to address multiple chronic conditions improved mental health and disease management, and general health perceptions.

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

- While potential barriers exist at the levels of patients/citizens, providers, organizations and health systems, perhaps the biggest barrier lies in trying to find solutions that will be appropriate across each of the unique health systems in Canada.
- Despite these barriers, many health systems across Canada are at critical junctures, and increasingly looking for ways to achieve the 'triple aim' of improving the patient experience and population health while keeping per capita costs manageable. Addressing emergency-department use among individuals with a chronic condition such as IBD provides a unique opportunity to develop focused solutions that can serve as an exemplar for how health systems can be strengthened to achieve the 'triple aim' more broadly.





## REPORT

Canada has one of the highest rates of inflammatory bowel disease (IBD) in the world, affecting approximately one in every 150 Canadians.(1-3) There is the perception that IBD is not as prevalent as other chronic conditions, however, IBD is more common than multiple sclerosis or Parkinson’s disease, and just as common as epilepsy and Type I diabetes.(2; 4; 5)

IBD is made up of a group of inflammatory conditions of the colon and small intestine, with Crohn’s disease and ulcerative colitis as the two main types.(6) Both Crohn’s and ulcerative colitis are lifelong, relapsing, conditions that usually begin in early adulthood, with the former typically affecting the lower part of the small bowel and the colon,(7) and the latter affecting the colon only, including the rectum and anus.(8) The symptoms of both conditions are similar, and can include the following (which usually present in an unpredictable and episodic manner): abdominal pain, cramping, rectal bleeding, diarrhea, vomiting, reduced appetite, weight loss, fever, anemia and fatigue.(9) The severity of these symptoms, which is linked with disability (e.g., work-related productivity losses) and stigma associated with the disease, present challenges that can negatively influence an individual’s quality of life in general, while limiting their ability to work and engage in intimate relationships more specifically.(2; 10-15)

After initial diagnosis, therapy focuses on symptom management, particularly during a flare, and maintaining remission.(10) Most people living with IBD require ongoing medication and some may end up needing surgery (e.g., repair fistulas, remove obstruction and rectum/colon removal).(2) Individual specialty care is generally led by a gastroenterologist, although given the lack of specialty care in many rural areas gastroenterologists are not always available or accessed by all Canadians with IBD.

In view of the diversity and complexity of symptoms associated with IBD, a number of additional providers may be involved in an IBD care team, including:

- nurses with experience in IBD;
- dietitians with experience in IBD;
- psychologists with a focus on behavioural coping strategies;

### Box 1: Background to the evidence brief

This evidence brief mobilizes both global and local research evidence about a problem, three elements of a potentially comprehensive approach for addressing the problem, and key implementation considerations. Whenever possible, the evidence brief summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The evidence brief does not contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of the evidence brief involved five steps:

- 1) convening a Steering Committee comprised of representatives from the Canadian Society of Intestinal Research, Crohn’s and Colitis Canada, Mount Sinai Hospital, University of British Columbia, University of Manitoba, Winnipeg Regional Health Authority and the McMaster Health Forum;
- 2) developing and refining the terms of reference for an evidence brief, particularly the framing of the problem and three viable elements for addressing it, in consultation with the Steering Committee and a number of key informants, and with the aid of several conceptual frameworks that organize thinking about ways to approach the issue;
- 3) identifying, selecting, appraising and synthesizing relevant research evidence about the problem, options and implementation considerations;
- 4) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence; and
- 5) finalizing the evidence brief based on the input of several merit reviewers.

The three elements could be pursued simultaneously or in a sequenced way, and each element could be given greater or lesser attention relative to the others.

The evidence brief was prepared to inform a stakeholder dialogue at which research evidence is one of many considerations. Participants’ views and experiences and the tacit knowledge they bring to the issues at hand are also important inputs to the dialogue. One goal of the stakeholder dialogue is to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. A second goal of the stakeholder dialogue is to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants.

- primary-care physicians addressing the systemic complications of both the IBD, as well as those that can arise as a result of treatment; and
- social workers who can connect patients with appropriate supports (e.g., community peer support groups and guidance on employment and financial-related issues).

Health-services utilization is highest within the first year of an IBD diagnosis,(16) although there are often delays in diagnosis – and appropriate speciality care – due to lack of awareness of IBD in primary care and emergency departments.(2) Furthermore, the unpredictable nature of symptoms means that even when individuals have been diagnosed and referred to a gastroenterologist, they may be unable to access speciality care when they need it (e.g., after hours and weekends) forcing them to emergency departments for care.

Given the burden of IBD and the many complications associated with its appropriate diagnosis and care, it has been deemed a priority issue in Canada.(17) In tandem with the growing awareness of the need to improve care for those with IBD, the IMAGINE (Inflammation, Microbiome, and Alimentation: Gastro-Intestinal and Neuropsychiatric Effects) Chronic Disease Network was formed in 2017 to study “the interactions between the inflammation, microbiome, diet and mental health in patients with IBD and irritable bowel syndrome.”(17) The network, which is an initiative of the Canadian Institutes of Health Research and one of the five chronic disease networks in the Strategy for Patient Oriented Research, involves 17 hospitals/universities and 75 researchers from across Canada. The network also engaged the McMaster Health Forum as a partner to consider the best ways to strengthen health systems in Canada.

This evidence brief, and the stakeholder dialogue it was designed to inform, have been developed within this context, and focuses on approaches to reducing emergency department usage in people with IBD in provincial health systems in Canada. The evidence brief reviews the research evidence about: 1) features of the problem; 2) three elements (of a potentially comprehensive approach) for addressing the problem; and 3) key implementation considerations for moving any of the elements or their sub-elements forward.

This specific topic was prioritized by members of the IMAGINE Network and the McMaster Health Forum, presenting an issue that can act as a powerful exemplar for government policymakers (e.g., those working in ministries of health) to consider how to systematically deal with issues pertaining to complex single conditions, instead of a one-size-fits-all approach to chronic-disease management. Specifically, in determining how to ensure appropriate, cost-effective services for IBD are available to those who need them, policymakers will have the tools to think through how they can establish nimble health systems that are positioned to develop a range of condition-specific responses when necessary.

### **Box 2: Equity considerations**

A problem may disproportionately affect some groups in society. The benefits, harms and costs of the elements to address the problem may vary across groups. Implementation considerations may also vary across groups.

One way to identify groups warranting particular attention is to use “PROGRESS,” which is an acronym formed by the first letters of the following eight ways that can be used to describe groups†:

- place of residence (e.g., rural and remote populations);
- race/ethnicity/culture (e.g., First Nations and Inuit populations, immigrant populations and linguistic minority populations);
- occupation or labour-market experiences more generally (e.g., those in “precarious work” arrangements);
- gender;
- religion;
- educational level (e.g., health literacy);
- socio-economic status (e.g., economically disadvantaged populations); and
- social capital/social exclusion.

The evidence brief strives to address all Canadians, but (where possible) it also gives particular attention to two groups:

- people living in rural and remote communities; and
- immigrant populations.

Many other groups warrant serious consideration as well, and a similar approach could be adopted for any of them.

† The PROGRESS framework was developed by Tim Evans and Hilary Brown (Evans T, Brown H. Road traffic crashes: operationalizing equity in the context of health sector reform. *Injury Control and Safety Promotion* 2003;10(1-2): 11–12). It is being tested by the Cochrane Collaboration Health Equity Field as a means of evaluating the impact of interventions on health equity.

**THE PROBLEM**

Increases in the incidence and prevalence of IBD coupled with the poor management of its symptoms mean that many people across Canada are not currently receiving the supports they need.(10) In addition, the costs to the health system and those borne by the individual living with IBD and by society more generally are also increasing.(2)

The factors underpinning the problem can be broken down into the following four interrelated themes (Figure 1):

- 1) the number of Canadians living with IBD is increasing;
- 2) lack of awareness of IBD and its symptoms can hinder 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.

**Box 3: Mobilizing research evidence about the problem**

The available research evidence about the problem was sought from a range of published and 'grey' research literature sources. Published literature that provided a comparative dimension to an understanding of the problem was sought using three health services research 'hedges' in MedLine, namely those for appropriateness, processes and outcomes of care (which increase the chances of us identifying administrative database studies and community surveys). Published literature that provided insights into alternative ways of framing the problem was sought using a fourth hedge in MedLine, namely the one for qualitative research. Grey literature was sought by reviewing the websites of a number of domestic organizations, such as the Crohn's and Colitis Foundation of Canada, Crohn's and Colitis Canada and the Institute for Clinical and Evaluative Sciences.

Priority was given to research evidence that was published more recently, that was locally applicable (in the sense of having been conducted in Canada), and that took equity considerations into account.

**Figure 1. Factors contributing to the challenges related to emergency-department use among people with IBD in provincial health systems in Canada**



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

The number of Canadians living with IBD is increasing, with the incidence and prevalence of IBD in Canada amongst the highest in the world.(3; 18) Currently, there are approximately 270,000 individuals living with IBD (including 135,000 with Crohn's, 120,000 with ulcerative colitis and 15,000 with IBD but no clear diagnosis).(18) By 2030, it is estimated that 403,000 Canadians will have IBD.(18) As mentioned above, the symptomatic burden placed on individuals with IBD is high, and the unpredictability of these symptoms creates challenges for individuals in terms of planning for their future (e.g., career, travel and relationships), and can reduce their quality of life.(19)

As the number of individuals living with IBD grows, it is likely that there will be corresponding increases in the costs to the health systems providing them with care, and to society more generally.(10) Specifically, the costs associated with IBD in Canada – both direct medical and indirect – were estimated to be \$2.8 billion in 2012 (\$12,000 per patient).(10)

The direct costs – those related to the care provided to patients – include hospital-related costs (e.g., inpatient and emergency-department visits), surgeries, physician services, medication and diagnostics, and were estimated to be \$1.2 billion in Canada in 2012.(2; 10) These were driven by:

- drugs costs (\$521 million);
- hospitalizations (\$395 million);
- physician visits (\$132 million);
- other health-system costs such as emergency-department visits, diagnostics, home care and long-term care (\$101 million); and
- hospital outpatients (\$61 million).(10)

The high direct costs related to pharmaceuticals are attributed to the increased use of biological drugs (e.g., infliximab and adalimumab), making up approximately 84% of total drug expenditures.(10)

The indirect costs – those that fall to the individual or to society more broadly – were estimated at \$1.6 billion in Canada in 2012.(10) These indirect costs were driven by:

- long-term work losses due to withdrawing from the workforce (\$979 million);
- short-term work losses due to taking time off of work (\$181 million);
- out-of-pocket expenditures such as ostomy supplies, home modifications, home-care supports and complementary and alternative therapies (\$300 million); and
- premature mortality (\$9.4 million).(10)

The many challenges faced by a growing number of Canadians living with IBD and its symptoms, combined with the high direct and indirect costs associated with the condition, suggests there is a need to consider how to provide the most appropriate care for patients in the most efficient manner.

## **Lack of awareness of IBD and its symptoms can hinder timely diagnosis and access to appropriate care**

Unlike many other chronic conditions such as diabetes, Canadians lack awareness of IBD and its symptoms, which creates a challenge in ensuring individuals with IBD are receiving appropriate supports. The lack of awareness is also linked to challenges ensuring those with IBD receive a timely diagnosis and the most appropriate care at the right time.(2)

Although IBD falls under the umbrella of chronic diseases, there are three factors that create barriers to awareness among Canadians: 1) IBD is not preventable; 2) there is general confusion about the differences between irritable bowel syndrome (IBS) and IBD; and 3) there is stigma associated with IBD. First, compared

to some other chronic diseases that can be managed and in some cases prevented with the right mix of approaches (e.g., diet and exercise to reduce the likelihood of developing Type 2 diabetes), the prevention of IBD and its symptoms may not be possible regardless of how many proactive measures are taken by individuals (e.g., given the role of genetics and environmental factors).(20) As a result, IBD does not fall under publicly funded chronic-disease prevention programs and services.(2)

Second, there is limited understanding in the general public of the differences between irritable bowel syndrome and IBD. Irritable bowel syndrome is a common gastrointestinal disorder and while not life-threatening does have a range of symptoms (e.g., abdominal pain, irregular bowel patterns and constipation) that can be distressing to the individual.(21) The common misunderstanding and often confusion between IBD and irritable bowel syndrome create further impacts and decreases public awareness of the disease.(2)

Third, there is stigma associated with IBD, which also affects awareness of the disease. People living with IBD face unpredictability and fluctuation of symptoms, often disrupting every day and normal activities.(10; 22) The unpredictability of flares and the variability in symptoms, including severity, may cause challenges for individuals to seek appropriate supports. Symptoms may signal a dangerous progression in the disease, a need for acute medical therapy, surgical intervention or symptom control. In addition, low levels of public awareness can reinforce the stigma associated with the disease. Research on stigma in IBD found that many people with IBD experience perceived stigmatization, and people that have greater frequency of flares also have higher levels of perceived stigma.(13) Perceptions of stigma were found to be a predictor of poorer patient-reported outcomes in IBD patients.(12) Another study found that most participants experienced mild levels of internalized stigma and a quarter reported some form of discrimination due to the disease.(11)

The timeliness of diagnosis or lack thereof is closely tied to the general lack of awareness of IBD. Delayed diagnosis of IBD is a significant challenge.(23) A study conducted in the United States found that diagnostic delays for Crohn's disease was associated with increased complications.(24) The same study found that patients with Crohn's disease experienced longer delays in diagnosis (approximately 10 months) compared to patients with ulcerative colitis (three months).(24) Time to specialist was key and although patients presented to their primary-care provider within a month of the onset of symptoms, it took an additional six months for patients with Crohn's disease to see a specialist, compared with two months for patients with ulcerative colitis.(24) Research on wait times for gastroenterology services in Canada is similar and surpass wait-time benchmarks.(25-27) The most recent survey of gastroenterologists in Canada was completed in 2012 and found that:

- the median wait time to consultation was 92 days (72 days for clinical features indicative of active IBD);
- the wait time to procedure was 55 days (44 days for clinical features indicative of active IBD);
- total wait time was 155 days (126 days for clinical features indicative of active IBD);
- overall the wait times for procedure and consultation, and total wait times were significantly longer than those reported in 2005, but did not differ from the 2008 survey; and
- the wait times for procedure and consultation for clinical features indicative of active IBD were significantly longer than those reported in both the 2005 and 2008 surveys, but not for the total wait times.(27)

Compounding both the awareness challenges and those linked to delayed diagnosis of IBD is a public perception that IBD is not as prevalent as other chronic conditions, despite being more common than multiple sclerosis or Parkinson's disease, and just as common as epilepsy and Type 1 diabetes.(2; 4; 5)

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

For individuals with IBD, access to appropriate supports for IBD is not always timely or consistent. This is due to at least three interrelated reasons: 1) challenges related to the treatment for IBD; 2) related to the delivery of specialty care for IBD in both primary and emergency settings; and 3) access to care is affected by the supply, density and distribution of gastroenterologists.

First, there are a number of challenges associated with the treatment of IBD. Before the introduction of biological therapies, corticosteroids and opioids were used to manage the long-term effects of IBD.(28) While corticosteroids have been found to be effective in the induction of remission in both Crohn's disease and ulcerative colitis, they are not effective in maintaining remission.(29) In fact, long-term and/or high-dose users of corticosteroids are at a higher risk for numerous side effects and complications including: impaired glucose tolerance, bone mineral loss and fracture, cataracts and atherosclerosis.(29) Furthermore, opioid analgesics are used for pain management in IBD (e.g., abdominal pain and diarrhea), however, there are significant concerns with side effects and addiction.(30) Heavy opioid use in IBD are associated with a significant risk of mortality.(30) An additional challenge is physician reluctance to prescribe opioids as a result of increased scrutiny by regulatory colleges, which places poorly controlled IBD patients in a difficult position (e.g., poor pain management and no access to effective therapies).(31; 32)

Although biological therapies have emerged as a more effective treatment for IBD, less effective therapies of corticosteroids and opioids are still commonly used. Data from the U.S. suggests that there is still a reliance on corticosteroids and opioids when patients visit outpatient settings to address symptoms related to IBD.(28) In addition, there has been no reduction in their use as biologicals become more available.(28) Data from Canada also show that chronic use of corticosteroids is also high among Crohn's disease and ulcerative colitis patients:

- one study from Manitoba found that within 10 years of being diagnosed, the majority (63%) of patients with IBD will have been prescribed corticosteroids;(29) and
- another study from Manitoba found that higher opioid or corticosteroid use was associated with emergency-department attendance among prevalent IBD cases.(33)

It is important to note that despite challenges associated with the overuse and reliance on corticosteroids, it should be acknowledged that corticosteroids are not the only driver of poor outcomes in IBD patients. One of the Promoting Access and Care through Centres of Excellence (PACE) network centres (University of Alberta and the University of Calgary) are currently addressing the issue through the development and implementation of clinical care pathways for health professionals to reduce the chronic use of corticosteroids.(34)

Second, there are challenges related to the delivery of specialty care for IBD in both primary and emergency settings. While there are a number of factors that may contribute to high corticosteroid use among Crohn's and ulcerative colitis patients in Canada, primary-care teams may have limited training specific to IBD management. Primary-care and emergency physicians are rarely equipped with the range of knowledge and skills they require to address the full scope of IBD patients' needs, which may result in sub-optimal treatment decisions outside of specialty-care settings. In primary-care settings, this may be the result of a lack of emphasis on IBD in family medicine residency programs, or a lack of opportunity for residents to interact with enough IBD patients during their training. Given this gap in knowledge and skills, primary-care physicians may continue to prescribe corticosteroids because this is 'what they know' even though they may not be the best option. This may be one factor (among many) underpinning the prolonged use of corticosteroids for IBD patients in Canada. In emergency departments, this same lack of knowledge and skills related to the management of IBD may also result in investigations and/or treatment decisions that are not always appropriate. An example of this in emergency departments provided by one of the 18 key informants we interviewed in preparing this brief is that given the constellation of symptoms associated with an acute flare, there is a high likelihood that an emergency-department physician will order a CT scan, whereas a provider more familiar with the patient and disease might have deemed it unnecessary. A number of studies

have shown that IBD patients undergo frequent diagnostic imaging, and those with Crohn's disease in particular are exposed to high doses of cumulative radiation.(35-37)

Within specialty-care settings, a primary challenge is the availability of gastroenterologists. Most gastrointestinal clinics run during office hours, and patients may not feel they have access to their gastroenterologist when they need them most. The majority of care for IBD is done by specialists in dedicated clinics, despite many patients being open to a range of other options for managing their illness. A study conducted in Manitoba showed that most of the cases presenting with IBD in the emergency department did not get admitted, suggesting that these patients could be managed in an alternate setting.(38) The study also found that if alternate services were available, a majority of patients with IBD who were surveyed would use phone contact with IBD nurses or gastroenterologists, or attend a walk-in gastroenterology clinic if available when acutely unwell.(38)

Third, an additional access challenge relates to the supply, density and distribution of gastroenterologists. In 2016, it was estimated that there were between 782 and 848 gastroenterologists in Canada (2.14 gastroenterologists per 100,000 population).(39) Of the 10 provinces, six had less than two gastroenterologists per 100,000 population.(39) Data on the distribution, rural versus urban, of gastroenterologists is not available, but based on the primary work settings of the profession (private office/clinic 39% and academic centre 30%) it can be assumed that the majority of gastroenterologists practise in urban centres.(40) The maldistribution of gastroenterologists, IBD nurses and clinics across the country, many of which are located in urban centres, make it difficult for those living in remote and rural areas to see their specialist when needed.

It is important to note that many factors other than the number of gastroenterologists affect patients' wait times for IBD-related services, including the number of endoscopists, availability of tests (e.g., sophistication of laboratory testing in the community) and patient-related factors (e.g., following the necessary preparations for endoscopies and bloodwork). For example, a patient may have access to a gastroenterologist but encounter challenges in accessing an urgent scan, endoscopy or fecal calprotectin test, and may choose to visit an emergency department in order to get faster access to the necessary diagnostic procedures. This challenge has been captured in a vignette in the Government of Manitoba's report of the wait times reduction task force.(41)

### **Those needing urgent care often resort to emergency departments**

As mentioned in the preceding section, the availability of gastroenterologists poses a significant challenge, and due to the unpredictable nature of IBD the limited alternative options leave many seeking care in emergency departments. A population-based study of IBD patients in Ontario in 2014-2015 found that there was significant geographic variation of gastroenterologists by Local Health Integration Network (LHIN), ranging from 1.33 gastroenterologists per 1,000 in the North East LHIN to 10.65 gastroenterologists per 1,000 in the Toronto Central LHIN.(42) The same study found that along with poor access to a gastroenterologist, a diagnosis of Crohn's disease, low neighbourhood income and comorbidity were associated with IBD-related emergency-department visits.(42)

A study conducted in Manitoba of 1,143 individuals in an IBD research registry found that:

- while 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 prominent choice among these patients;
- 9% (or 102 individuals) in the study visited the emergency department in the previous year, while 48% said they would visit if they had severe symptoms;



- higher bowel-symptom severity and higher health anxiety was associated with those who did visit the emergency department; and
- presenting to the emergency department with a primary gastrointestinal complaint is a strong predictor of subsequent hospital admission.(38)

Another study also conducted in Manitoba found that those newly diagnosed with Crohn's disease or those with a history of opioid use were more likely to attend the emergency department.(33) Emergency-department attendance by both incident and prevalent cases of IBD was high. Of the 300 incident cases included in the study, 76% attended the emergency department, and of the 3,394 prevalent cases included, 49% attended the emergency department during the study period.(33) The study also found that visiting a gastroenterologist within the previous year was associated with a lower likelihood of visiting the emergency department.(33)

It is important to recognize that while alternative options are key to appropriately addressing IBD, some patients need emergency care during critical moments in their disease, and emergency departments are the most appropriate setting for this type of care. For example, symptoms of an IBD flare may be indistinguishable from other conditions (e.g., gastroenteritis or ischemia, appendicitis or bowel obstruction) and warrant assessment and care in an emergency department.

There are initiatives that seek to support those with complex chronic conditions. In Ontario, Health Links provides team-based care, across sectors (e.g., home and community care, primary care, specialty care, rehabilitation care, long-term care) in a geographic area working together to provide coordinated healthcare for patients with multiple complex conditions.

Three of the five PACE network centres are focused on how to best serve underserved and remote communities, with specialized IBD care (Toronto), to advance the use of an electronic interface for patients and physicians (Hamilton), and to develop and track quality indicators of care (Montreal).(34)

### **Additional equity-related observations about the problem**

As noted in box 2, an important element of the problem that requires further discussion is how the problem may disproportionately affect certain groups or communities. With respect to reducing emergency-department usage in people with IBD in provincial health systems in Canada, many groups warrant attention. Based on feedback from the 18 key informants we interviewed in preparing this brief, we focus on those living in rural or remote communities and immigrant populations.

People living in rural or remote communities often experience difficulties accessing necessary healthcare services, which affects a large number of people living in Canada given that:

- approximately one in five (19%) Canadians live in rural areas (defined by Statistics Canada as those with a population less than 1,000 and with less than 400 persons per square kilometre);(43) and
- there are 292 remote communities in Canada with a total population of approximately 194,281 (remote communities do not have year-round access to roads or they rely on a third party for transportation such as ferry or airplane).(44-46)

Given that health professionals, programs and services are not distributed equitably across geographic areas in Canada, individuals living in rural and remote communities often face barriers to accessing needed healthcare services.(46) Studies have also examined the association between incidence and prevalence of IBD and geographic areas (urban versus rural) and the results have been mixed.(47) Some studies have found that the rates of IBD are higher in urban areas, however, the issue is difficult to address due to data limitations.(48)



Health-services utilization for IBD (including emergency department visits) varies across different groups in the population. A study in Ontario showed that immigrants to Canada are more likely to utilize health services including the emergency department as a result of IBD, although they had a lower risk of surgery.(49) Another study focused more broadly on racial disparities and utilization of specialist care in IBD between black and white populations. The study found that black people were less likely to be under the care of a gastroenterologist and were more likely to visit the emergency department.(50) With regards to treatment, black people were less likely to have been on infliximab, however, no differences were found in the use of immunomodulators.(50)

**Citizens’ views about key challenges related to emergency-department use among people with IBD in provincial health systems in Canada**

Two citizen panels – which engaged a total of 23 ethnoculturally and socio-economically diverse citizens who were either diagnosed with IBD or had a family member living with IBD – were convened in Saskatoon (Saskatchewan) on 14 September 2018, and Hamilton (Ontario) on 12 October 2018. The Saskatoon panel consisted of panellists from western provinces (British Columbia, Alberta, Saskatchewan and Manitoba) and the Hamilton panel consisted of panellists from eastern provinces (Ontario, Quebec, Nova Scotia and Prince Edward Island). Panellists were provided with an abridged version of the evidence brief prior to the citizen panel, which was written in plain language, and served as an input into citizens’ deliberations.

During the deliberation about the problem, citizens were asked to share what they perceived to be the main challenges related to reducing emergency-department use among people with IBD. They were also asked to identify any challenges that either they encountered personally, or that a member of their family had encountered with respect to: getting a timely diagnosis, managing their IBD, accessing timely and appropriate specialty care, and accessing urgent care. Panellists identified eight important challenges, which are summarized in detail in Table 1: 1) limited understanding about the causes of IBD; 2) inconsistent and multiple diagnoses; 3) limited access to primary care and care provided by specialists (including an IBD care team); 4) limited understanding about and experience with IBD among health professionals; 5) inadequate facilities and supports available for IBD patients in emergency departments; 6) pervasive stigma associated with IBD at both the individual and societal level; 7) significant costs associated with the sub-optimal management of IBD; and 8) limited access to reliable and trustworthy information sources about IBD.

**Table 1. Summary of citizens’ views about challenges**

Challenge	Description
Limited understanding about the causes of IBD	<ul style="list-style-type: none"> <li>• Most panellists shared concerns about the high prevalence of IBD in Canada and our limited understanding of the factors that cause the condition (ranging from genetics, environmental factors, geographic location).</li> <li>• Panellists were concerned that the limited understanding of the factors underpinning the development of IBD reduces the likelihood that it can be managed well.</li> </ul>
Inconsistent and multiple diagnoses	<ul style="list-style-type: none"> <li>• The majority of panellists expressed deep frustration with the process of getting an IBD diagnosis, as well as challenges with multiple misdiagnoses.</li> <li>• Some panellists described being dismissed by their primary-care provider when signalling concerning symptoms experienced by themselves during their youth or experienced by their children. Loss of weight and energy should not be dismissed as a normal process of growing up and should be thoroughly investigated.</li> <li>• The experiences shared by panellists ranged from misdiagnoses (e.g., gastroenteritis, appendicitis and inconsistent diagnoses between Crohn’s disease and ulcerative colitis) to lack of diagnostic certainty (e.g., limitations in endoscopy), all of which led to delays in receiving appropriate care for their condition.</li> </ul>

Challenge	Description
<p>Limited access to primary care and care provided by specialists (including an IBD care team)</p>	<ul style="list-style-type: none"> <li>• Many panellists expressed frustrations with the lack of access to both primary care and care provided by specialists.</li> <li>• Within primary care, many panellists discussed challenges in their region in terms of primary-care physician shortages. This lack of access to primary-care physicians was troublesome since these are the gatekeepers to specialists.</li> <li>• Long wait times for referrals to gastroenterologists was cited as a significant barrier, and among those panellists with a gastroenterologist, many cited that they did not have timely access to their gastroenterologist when they needed it the most. Some panellists indicated that appointments with their gastroenterologist were booked every six months in order to stay on the patient list. However, panellists felt this was an inefficient use of resources and not an effective approach given the unpredictable nature of IBD symptoms.</li> <li>• Many panellists also expressed concerns with the general shortage of gastroenterologists in Canada, but also with the wide regional variations in access to specialist care (including gastroenterologist, IBD nurses, as well as surgeons with experience with IBD). For example, some panellists from P.E.I. discussed having only one gastroenterologist in their province.</li> <li>• Within specialty care, the majority of panellists indicated that they have never had access to an IBD care team that was similar to the kind described in the pre-circulated citizen brief (which included gastroenterologists, IBD nurses, social workers, psychologists and others). Some panellists referred to this type of care team as a “dream team.”</li> <li>• When discussing what other professionals should be part of the IBD care team, panellists indicated that pharmacists and surgeons should be included.</li> </ul>
<p>Limited understanding about and experience with IBD among health professionals</p>	<ul style="list-style-type: none"> <li>• All panellists expressed concerns that health professionals had limited understanding and experience with IBD (in both primary-care settings and emergency departments). This was a significant obstacle to timely diagnosis and optimal management of IBD.</li> <li>• In elaborating on these concerns, panellists shared experiences with physicians not prescribing treatment options that were best suited to their condition and that aligned with the best-available research evidence, and others voiced concerns about the types of dietary advice received by dietitians who are unfamiliar with how to manage flares.</li> <li>• Panellists described challenges with triage systems within emergency departments, particularly when staff were not recognizing the severity of their symptoms, which led to long wait times.</li> <li>• Panellists also favoured emergency departments over urgent-care centres because many had experiences with being referred from urgent-care centres to emergency departments.</li> <li>• Stemming from the lack of trust in health professionals and the system more broadly, many panellists felt that they need to be their own advocates and have learned by experience to tell emergency-department staff the care they need.</li> </ul>
<p>Inadequate facilities and supports available for IBD patients in emergency departments</p>	<ul style="list-style-type: none"> <li>• Panellists shared their negative experiences with emergency departments and categorized them in two distinct phases: pre-diagnosis and post-diagnosis.</li> <li>• The pre-diagnosis phase was described as a very scary period in which they had repeated visits to the emergency department as a result of the severity of the symptoms (e.g., significant weight loss, intense abdominal pain and rectal bleeding). These repeated visits to the emergency department are attributable to the severity of the symptoms, the lack of diagnosis so far to explain those symptoms, the inability of primary-care professionals in providing adequate support, and the pain, anxiety and fear experienced by patients.</li> <li>• In the post-diagnosis phase, although they are becoming more knowledgeable about their condition, panellists shared their frustrations with the inadequate supports provided to them by health professionals and many avoided going to the emergency department unless they felt critical.</li> </ul>

Challenge	Description
	<ul style="list-style-type: none"> <li>• Panellists gave a number of reasons why they avoid emergency departments and consider them the last resort, including: inappropriate facilities in the waiting room (only one bathroom), long wait times to be admitted and receive the needed interventions (e.g., fluids and pain management), inappropriate interventions (e.g., treatment approaches), and lack of control over diet once admitted.</li> <li>• Many panellists indicated that they preferred the comfort and privacy of their own home (or bathroom) when experiencing a flare, and that they were often unable to move (and thus unable to go on their own to the emergency department to wait for hours in the hope of receiving care).</li> </ul>
<p>Pervasive stigma associated with IBD at both the individual and societal level</p>	<ul style="list-style-type: none"> <li>• Most panellists experienced stigma associated with IBD. The stigma was perceived at both the individual and societal levels.</li> <li>• At the individual level, panellists indicated that the stigma associated with IBD had an impact on their personal, social and professional lives.               <ul style="list-style-type: none"> <li>○ They were often unable to attend social events and if they did, they often needed special accommodations.</li> <li>○ Panellists also described challenges with stigma in the workplace and difficulties with maintaining employment. A few panellists had experiences with coworkers questioning their frequent use of the washroom and assumptions that the repeated trips were due to an eating disorder or addiction.</li> <li>○ Given the nature of IBD symptoms, most people were not comfortable discussing their condition, which often led to social isolation and solitude. Many panellists indicated that they felt on their own. This situation could contribute to depression, anxiety and stress among people living with IBD.</li> </ul> </li> <li>• At the societal level, panellists felt there was a general lack of public awareness about IBD, which exacerbated the stigma associated with IBD. And given the nature of IBD symptoms, panellists indicated that it would be difficult to find a corporation or spokesperson willing to be associated with a large-scale public awareness campaign about IBD.</li> </ul>
<p>Significant costs associated with the sub-optimal management of IBD</p>	<ul style="list-style-type: none"> <li>• Many panellists were aware that the delivery of care is not optimal for IBD, which leads to high costs for patients and health systems.</li> <li>• At the level of the patient, the cost of biological therapies was listed as a significant barrier to managing IBD. Panellists also raised challenges with out-of-pocket costs for food in order to meet dietary restrictions.</li> <li>• A few panellists mentioned the need for (and difficulty accessing) financial assistance to help them cope with the costs associated with this lifelong condition. Two panellists mentioned that their health professionals refused to complete the forms allowing them to apply for disability tax credits.</li> </ul>
<p>Limited access to reliable and trustworthy information sources about IBD</p>	<ul style="list-style-type: none"> <li>• The majority of panellists described the lack of trusted information sources about IBD and difficulties in knowing where to look for reliable information.</li> <li>• Most were not familiar with existing sources (e.g., Crohn’s and Colitis Canada and Gastrointestinal Society’s websites, webinars, brochures, etc.), despite their relevance to them.</li> <li>• Panellists also described having limited connections with their peers and/or support networks, with the exception of one participant with extensive experience with a local chapter.</li> </ul>

### **THREE ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH FOR ADDRESSING THE PROBLEM**

Many approaches could be selected as a starting point for deliberations about an approach for reducing emergency-department usage in people with IBD in provincial health systems in Canada. To promote discussion about the pros and cons of potentially viable approaches, we have selected three elements of a larger, more comprehensive approach to reducing emergency-department usage among people with IBD. The three elements were developed and refined through consultation with the Steering Committee and key informants who we interviewed during the development of this evidence brief. The elements are:

- 1) enable self-management of IBD through better supports for patients;
- 2) strengthen the role of primary and emergency-department care and improve connections to specialty care; and
- 3) introduce comprehensive alternative-service options for IBD specialty care.

The elements could be pursued separately or simultaneously, or components could be drawn from each element to create a new (fourth) element. They are presented separately to foster deliberations about their respective components, the relative importance or priority of each, their interconnectedness and potential of or need for sequencing, and their feasibility.

The principal focus in this section is on what is known about these elements based on findings from systematic reviews. We present the findings from systematic reviews along with an appraisal of whether their methodological quality (using the AMSTAR tool) (9) is high (scores of 8 or higher out of a possible 11), medium (scores of 4-7) or low (scores less than 4) (see the appendix for more details about the quality-appraisal process). We also highlight whether they were conducted recently, which we define as the search being conducted within the last five years. In the next section, the focus turns to the barriers to adopting and implementing these elements, and to possible implementation strategies to address the barriers.

#### **Box 4: Mobilizing research evidence about the elements of a potentially comprehensive approach for addressing the problem**

The available research evidence about elements of a potentially comprehensive approach for addressing the problem was sought primarily from Health Systems Evidence ([www.healthsystemsevidence.org](http://www.healthsystemsevidence.org)), which is a continuously updated database containing more than 5,000 systematic reviews and more than 1,500 economic evaluations of delivery, financial and governance arrangements within health systems. The reviews and economic evaluations were identified by searching the database for reviews addressing features of each of the elements of a potentially comprehensive approach.

The authors' conclusions were extracted from the reviews whenever possible. Some reviews contained no studies despite an exhaustive search (i.e., they were 'empty' reviews), while others concluded that there was substantial uncertainty about the elements of a potentially comprehensive approach based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the reviews' quality, the local applicability of the reviews' findings, equity considerations, and relevance to the issue. (See the appendices for a complete description of these assessments.)

Being aware of what is not known can be as important as being aware of what is known. When faced with an empty review, substantial uncertainty, or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a review that was published many years ago, an updating of the review could be commissioned if time allows.

No additional research evidence was sought beyond what was included in the systematic review. Those interested in pursuing a particular element of a potentially comprehensive approach may want to search for a more detailed description of the approach element or for additional research evidence about the element.

**Citizens’ values and preferences related to the three elements**

To inform the citizen panels, we included in the citizen brief the same three elements of a potentially comprehensive approach to address the problem as are included in this evidence brief. These elements were used as a jumping-off point for the panel deliberations. During the deliberations we identified several values and preferences from citizens in relation to these elements, which we summarize in Table 2.

**Table 2. Summary of citizens’ values and preferences related to the three elements**

Element	Values expressed	Preferences for how to implement the element
Enable self-management of IBD through better supports for patients	<ul style="list-style-type: none"> <li>• Empowerment of patients to better manage their IBD</li> <li>• Competence of patients to manage their IBD</li> <li>• Appropriateness/convenience of tools that enable self-management</li> <li>• Trusting relationships between patients, health professionals and organizations within the system</li> <li>• Visibility of IBD</li> </ul>	<ul style="list-style-type: none"> <li>• Enhance access to reliable and trusted sources of information and tools (e.g., pamphlets in primary-care clinics and emergency departments, website or 1-800 number)</li> <li>• Create and provide patients with access to a digital or physical binder, which would include information on IBD (including the latest evidence on treatment options) and provide a central place to file diagnostic results</li> <li>• Establish peer supports and create opportunities for one-on-one consults with health professionals trained to provide IBD care</li> <li>• Reframe the issue from a focus on bowels to the gastrointestinal tract or as an autoimmune disease more broadly, to help increase the visibility of IBD</li> </ul>
Strengthen primary care and emergency-department care of IBD and improve connections to specialty care	<ul style="list-style-type: none"> <li>• Trusting relationships between patients, health professionals and organizations within the system</li> <li>• Competence of primary-care and emergency-department professionals</li> </ul>	<ul style="list-style-type: none"> <li>• Introduce educational programs for new health professionals that integrate material focused on IBD, and create opportunities for continuing education among existing health professionals (particularly to improve diagnosis and symptom management, as well as communication skills when communicating sensitive and private information)</li> <li>• Connect patients with an IBD nurse or a patient navigator (e.g., someone living with IBD available either in-person or by telephone) following diagnosis</li> </ul>
Introduce comprehensive alternative-service options for IBD specialty care	<ul style="list-style-type: none"> <li>• Fairness/equity</li> <li>• Collaboration among patients, health professionals and organizations within the health system</li> <li>• Trusting relationships between patients and health professionals</li> </ul>	<ul style="list-style-type: none"> <li>• Introduce remote consultations (e.g., e-mail, telephone or web-based) with an IBD care team as an option for those living in rural and remote communities, or those experiencing an IBD flare who may not be physically able to attend an in-person consultation</li> <li>• Introduce mobile diagnostic clinics (similar to breast cancer screening trailers) to ensure access to IBD diagnostic services in underserved areas</li> <li>• Create a role for pharmacists on teams involved in the management of IBD to support access to up-to-date information on treatments and medication counselling</li> <li>• Expand paramedics’ scope of practice to include providing home-based care for pain management during a flare</li> <li>• Introduce clinics focused on supporting those with multiple chronic conditions (including IBD), given many patients with IBD have more than one chronic condition</li> </ul>

## **Element 1 – Enable self-management of IBD through better supports for patients**

As discussed in the problem section, people with IBD experience difficulty accessing appropriate specialty care, and symptom management is a significant challenge. While the number of Canadians living with IBD is increasing, a general lack of awareness and understanding hinders access to appropriate supports and care. This element aims to highlight a number of efforts to support persons living with IBD improving patients' knowledge and awareness of their condition and improving their self-management skills. Sub-elements could include:

- 1) providing educational materials for persons living with IBD to support self-management;
- 2) introducing in-person (personal) support to enhance their capacity for self-management; and
- 3) making electronic self-management initiatives available, such as the following apps:
  - Gi BodyGuard - allows individuals with IBD to track information about their health, symptoms, medications, food and exercise,
  - IBDoc - allows for a home test for calprotectin that electronically communicates results to the health professional,
  - MyIBDcoach - allows for continuous home monitoring, and
  - healthPROMISE - allows for IBD symptom tracking that is linked to a health professional for monitoring.

### *Key findings from the citizen panels*

There were five main values-related themes that emerged during the discussion about element 1 across both panels:

- 1) empowerment (of patients to better manage their IBD);
- 2) competence (of patients to manage their IBD);
- 3) appropriateness/convenience (of tools that enable self-management);
- 4) trusting relationships between patients, health professionals and organizations within the system; and
- 5) visibility of IBD.

The two key values-related themes that emerged with consistency were empowerment and competence. Panellists emphasized the need to be more empowered to manage their IBD. Poor care experiences in primary-care settings and emergency departments made them realize that they better understand than anyone their IBD symptoms, and that they generally have the competence to manage their symptoms. Both empowerment and competence appear to be fundamental in supporting self-management and IBD. To do so, they need access to reliable and trusted sources of information and tools. Preferences for educational materials included pamphlets in primary-care clinics and emergency departments to be used after diagnosis, which cover the basic details of Crohn's disease and ulcerative colitis, as well as information (e.g., website or 1-800 number) for where to access further supports. Many panellists were not familiar with some resources already available.

The third values-related theme focused on the appropriateness and convenience of self-management tools. Panellists had mixed reactions to the use of electronic tools. While some were open to the use of IBD symptom tracking apps, others were concerned that they were onerous and may lack compliance, and had concerns with privacy. Panellists preferred a digital or physical binder, which would include information on IBD (including the latest evidence on treatment options) and provide a central place to file diagnostic results.

In discussing in-person supports, the fourth values-related theme to emerge related to building trusting relationships between patients, health professionals and organizations within the system. Preferences for in-person supports included peer supports and one-on-one consults with health professionals trained to provide IBD care (e.g., consult with an IBD nurse, dietitian or pharmacist), particularly around time of diagnosis, when patients have questions about symptom management (e.g., treatment options and nutrition).

The final values-related theme to emerge was the need for increasing the visibility of IBD and reducing stigma. Panellists discussed that despite the prevalence of IBD, there is a general lack of visibility compared to other less prevalent conditions. Preferences for generating greater public awareness included a reframing of the issue from a focus on bowels to the gastrointestinal tract or autoimmune disease more broadly, and having a high-profile spokesperson living with IBD. Raising the profile of Crohn's and Colitis Canada was also identified as key to building visibility in the general public.

It should be noted that across both panels, the overall emphasis by panellists was on the discussion of element 1. While panellists deliberated on elements 2 and 3, they prioritized element 1 as being key to improving the management of IBD (and hence reducing emergency-department usage). In deliberating about the problem, panellists shared a number of negative experiences with the health system related to IBD, which may explain why panellists generally lacked confidence in primary and emergency-department professionals (element 2) and urgent-care centres (element 3).

#### *Key findings from systematic reviews*

We identified 10 systematic reviews that we deemed to be most relevant to these sub-elements.

For the first sub-element, providing educational materials for persons living with IBD to support self-management, we identified three systematic reviews, one recent high quality, one older high quality and one older medium quality, focusing on the effect of education interventions and information provision on self-management among patients with IBD.(51-53) The educational interventions that were assessed in the identified reviews (e.g., web-based information provision and printed patient-education interventions) were generally found to have positive impacts, including increased disease-related knowledge, improved medication adherence, and improved patient and professional engagement.(51-53) One recent high-quality review found that self-management programs centering on education, particularly distance interventions, had a positive impact on health-related quality of life.(54) In contrast to this result, two of the reviews, one older high quality and one older medium quality, found that education interventions resulted in decreased quality of life among patients with IBD.(51; 52) While this may have been attributable to study design, these findings highlight the importance of timely and appropriate information provision.(51; 52)

With regards to the second sub-element, introducing in-person (personal) support to enhance a persons' capacity for self-management, we identified two relevant reviews. Both reviews, one recent high quality and one recent medium quality, found positive evidence for the effect of personal support on self-management capacity among patients with IBD.(55; 56) These benefits included improvements in quality of life, improvements in disease activity and reduced health-service utilization.(55; 56) In addition, one recent high-quality review found that nurse-led self-management interventions for patients with chronic or multimorbid conditions resulted in improved disease outcomes, such as blood pressure control and reductions in HBA1c levels among patients with cardiovascular disease and diabetes.(57) However, the review found mixed results for patient-reported measures and quality of life.(57)

Finally, we found three reviews that addressed the third sub-element, making electronic self-management initiatives available. One recent medium-quality review and one older high-quality review found a range of benefits stemming from the use of electronic self-management tools for patients with IBD, including:

- improvement in disease activity;
- improvement in patient-reported quality of life;
- reduced patient distress; and
- improved communication between patients and providers.(58; 59)

The two reviews focused on web-based interventions and electronic symptom reporting initiatives.(58; 59) Despite evidence from these reviews indicating positive outcomes, another medium-quality review found that there is a paucity of online decision-making resources for patients considering surgery for ulcerative colitis.

These findings highlight a gap in the shared decision-making process, and points to a need for the development of new decision aids.(60)

We also identified one recent high-quality review and one recent medium-quality review that examined the cost-effectiveness of self-management approaches.(56; 58) Self-management interventions for a range of chronic conditions were found to decrease healthcare utilization by patients.(56) While the effect of interventions on total cost was variable, the authors found that costs typically increased with interventions that reported better health outcomes.(56) Increased costs occasionally resulted from electronic interventions, suggesting that future research on both the direct and indirect costs of technologies on the management of patients with IBD is needed.(58)

Finally, in addition to reviews focusing on costs, we identified one recent, high-quality review that focused on factors that can contribute to the success of self-management interventions. Specifically, collaboration between patients and professionals can contribute to the success of self-management, an important component of IBD care.(53) One recent high-quality review found that organizational change was central to the success of self-management programs, which was supported by strong leadership, professional engagement, appropriate training, resource support and evaluation.(53)

A summary of the key findings from the synthesized research evidence is provided in Table 3. For those who want to know more about the systematic reviews contained in Table 3 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 1.

**Table 3: Summary of key findings from systematic reviews relevant to Element 1 – Enable self-management of IBD through better supports for patients**

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> <li>• <b>Providing educational materials for persons living with IBD to support self-management</b> <ul style="list-style-type: none"> <li>○ One recent high-quality review found that self-management programs had a positive effect on health-related quality of life, with distance interventions having a stronger effects size, and the review noted that education was central to the success of IBD self-management programs.(54)</li> <li>○ Three reviews, two older high and medium quality, and one recent and of high-quality, found the following benefits of educational materials:                             <ul style="list-style-type: none"> <li>▪ increased disease-related knowledge;(51; 52)</li> <li>▪ improved medication adherence;(52) and</li> <li>▪ improved patient and professional engagement.(53)</li> </ul> </li> </ul> </li> <li>• <b>Introducing in-person (personal) support to enhance their capacity for self-management</b> <ul style="list-style-type: none"> <li>○ Two recent reviews, one medium-quality and one high-quality, found the following benefits of personal support for self-management of IBD:                             <ul style="list-style-type: none"> <li>▪ improvement in quality of life;(55)</li> <li>▪ improvement in disease activity;(55) and</li> <li>▪ reduced health-service utilization;(56).</li> </ul> </li> <li>○ One recent high-quality review found that nurse-led self-management interventions for patients with chronic or multimorbid conditions improved disease management, including blood pressure and HBA1c levels.(57)</li> </ul> </li> <li>• <b>Making electronic self-management initiatives available</b> <ul style="list-style-type: none"> <li>○ Two reviews, including one recent medium-quality review and one older high-quality review, found the following benefits of electronic self-management for IBD:                             <ul style="list-style-type: none"> <li>▪ improvement in disease activity;(58)</li> <li>▪ patient-reported quality of life;(58)</li> <li>▪ reduced patient distress;(59) and</li> <li>▪ improved communication between patients and provider.(59)</li> </ul> </li> </ul> </li> </ul>



Category of finding	Summary of key findings
Potential harms	<ul style="list-style-type: none"> <li>● <b>Providing educational materials for persons living with IBD to support self-management</b> <ul style="list-style-type: none"> <li>○ One older and high-quality review found that education intervention resulted in decreased quality of life among patients with IBD, highlighting the need for appropriate and timely provision of information.(51)</li> <li>○ One older and medium-quality review found that quality of life declined among patients with IBD who were provided print education, however, the authors note that this may have been due to chance randomization.(52)</li> </ul> </li> </ul>
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> <li>● <b>Introducing in-person (personal) support to enhance their capacity for self-management</b> <ul style="list-style-type: none"> <li>○ One recent high-quality review examined the effects of self-management interventions on healthcare utilization for patients with a variety of chronic conditions, finding reduced utilization across the majority of studies.(56) <ul style="list-style-type: none"> <li>▪ The review found the strongest evidence for reduced hospital use was present for cardiovascular and respiratory diseases.(56)</li> <li>▪ While the effect of interventions on cost was variable, costs typically increased with the interventions that reported better health outcomes.(56)</li> </ul> </li> </ul> </li> <li>● <b>Making electronic self-management initiatives available</b> <ul style="list-style-type: none"> <li>○ One recent medium-quality review found that electronic interventions occasionally increased costs, however, the authors noted that future research must aim to encapsulate both the direct and indirect costs of this form of care.(58)</li> </ul> </li> </ul>
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	<ul style="list-style-type: none"> <li>● Uncertainty because no systematic reviews were identified <ul style="list-style-type: none"> <li>○ Not applicable</li> </ul> </li> <li>● Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review <ul style="list-style-type: none"> <li>○ Not applicable – no ‘empty reviews’ were identified</li> </ul> </li> <li>● No clear message from studies included in a systematic review</li> <li>● <b>Introducing in-person (personal) support to enhance their capacity for self-management</b> <ul style="list-style-type: none"> <li>○ One recent and medium-quality review examined the impact of self-management interventions on IBD symptoms, but a lack of consistency among measures limited the authors’ ability to draw conclusions.(55)</li> </ul> </li> <li>● <b>Making electronic self-management initiatives available</b> <ul style="list-style-type: none"> <li>○ One medium-quality review found a paucity of online decision-making resources for patients considering surgery for ulcerative colitis, despite an examination of 25 sources, and the lack of resources suggests a gap in shared decision-making, and the need for new decision aids to be developed.(60)</li> </ul> </li> </ul>
Key elements of the policy option if it was tried elsewhere	<ul style="list-style-type: none"> <li>● <b>Introducing in-person (personal) support to enhance their capacity for self-management</b> <ul style="list-style-type: none"> <li>○ One recent high-quality review found that a shift in organizational culture is necessary for a consistent and ongoing self-management program, and patients and professionals must embrace similar principles of care.(53) <ul style="list-style-type: none"> <li>• In addition, the review found that organizational change was supported by strong leadership, engagement of professionals, appropriate training, support of resources and ongoing evaluation. (53)</li> </ul> </li> </ul> </li> </ul>
Stakeholders’ views and experiences	<ul style="list-style-type: none"> <li>● <b>Making electronic self-management initiatives available</b> <ul style="list-style-type: none"> <li>○ One recent medium-quality review found that patient-reported quality of life improved after the use of web-based interventions and the extent of impact depended on a range of factors, potentially including culture, disease sub-type, and baseline quality of life.(58)</li> </ul> </li> </ul>

## **Element 2 – Strengthen primary care and emergency-department care of IBD and improve connections to specialty care**

This element aims to strengthen the role of primary care and emergency-department care in the management of IBD, and to enable those with IBD to seek timely appropriate supports from specialty care when necessary. The element may include a number of sub-elements such as:

- 1) introducing training and supports for primary and emergency-department professionals (e.g., by creating an IBD educator certificate, and establishing resource centres, online virtual networks or communities of practice to facilitate the exchange of the best-available research evidence and tacit knowledge about how to support the management of IBD);
- 2) proactively identifying those patients at risk and connecting them to appropriate resources by;
  - improving mechanisms to stratify IBD patients into varying levels of risk for an emergency-department visit,
  - ensuring those at greatest risk receive the necessary primary and specialty care when they need it, and
  - enhancing urgent- and emergency-care triage systems to ensure those who present with IBD symptoms are identified and provided the most appropriate care (e.g., or immediate referral to alternate-care facility); and
- 3) integrating electronic tools (such as the apps listed in element 1) into the care process by linking patient monitoring data to service providers when needed (e.g., linking symptom tracking and home monitoring apps to an IBD care team).

### *Key findings from the citizen panels*

Two main values-related themes emerged during the discussion about element 2 across both panels:

- 1) trusting relationships between patients, health professionals and organizations within the system; and
- 2) competence (of primary-care and emergency-department professionals).

The values-related themes of building trusting relationships and competence of health professionals were intertwined in element 2. In particular, a number of panellists expressed that their lack of trust in the quality of IBD care was directly related to what they flagged as limited competence/expertise to manage IBD patients among primary-care and emergency-department professionals. While some panellists were keen on the idea of introducing educational programs about IBD for new health professionals and continuing education opportunities for existing health professionals (particularly to improve diagnosis and symptom management, as well as communication skills when communicating sensitive and private information), others were skeptical about whether this could improve the competence of primary-care and emergency-department professionals in managing IBD. A number of panellists stated that there was a perception that primary-care and emergency-department professionals were overloaded with work, and building new competencies through education wouldn't address this. However, panellists generally agreed that efforts should be invested to help primary-care and emergency-department professionals in proactively identifying those patients at risk and connecting them to appropriate resources (particularly following a diagnosis). An IBD nurse or a patient navigator (e.g., someone living with IBD available either in-person or by telephone) could be promising to address this need. With regards to integrating electronic tools (such as the apps listed in element 1), while they were supportive of the sub-element, panellists felt they were most likely unsustainable, given the resources required for symptom monitoring by a health professional.

### *Key findings from systematic reviews*

We identified seven systematic reviews that we deemed to be most relevant to these sub-elements.

For the first sub-element, introducing training and supports for primary and emergency-department professionals, we identified three relevant reviews, including two recent medium-quality reviews and one older high-quality review.(61-63) The reviews focused on interventions provided by specialist nurses and the

acceptance of telemedicine and mobile health technologies by patients and professionals, finding that interventions improved quality of life and satisfaction among patients, improved symptom severity and physiological markers, and improved staff engagement.(61-63)

In terms of the second sub-element, proactively identifying patients at risk and connecting them to appropriate resources, one recent medium-quality review examined the value of patient-reported outcome measures for diagnostic support in IBD.(64) These measures are becoming increasingly prevalent in clinical environments and demonstrate strong potential to support disease monitoring.(64) However, the review noted that greater patient involvement is necessary to facilitate content validity and uptake.(64)

We identified two reviews that focused on the importance of proactively identifying patients at risk of disease and connecting them to resources in the primary-care setting. One older high-quality review and one older medium-quality review found that enhancing access to primary care had the following benefits:

- improved medication adherence;(65)
- improved health-related patient behaviours;(65)
- improved health-provider behaviours;(65) and
- increases in use of services and those receiving care.(65; 66)

We identified one recent medium-quality review that evaluated the effectiveness of patient-initiated follow-up care in the secondary outpatient setting, which found that patients who initiated care reported higher satisfaction and quality of life, in addition to fewer hospital visits and an improved ability to manage care.(67)

The utility and effectiveness of a strategy for identifying patients at risk and increasing access to care depends on the type of care and a given country's health system.(66) One older medium-quality review found that for chronic-disease management, financial incentives and practice re-organization were effective tools for increasing access to care. These factors should be taken into consideration when implementing policy.(66)

With regards to the third sub-element, integrating electronic supports into the care process by linking patient monitoring data to service providers when needed, we identified one recent medium-quality review.(63) The review found that health professionals perceived a number of challenges related to the acceptance of telehealth technologies. These barriers included:

- the impact of telehealth integration into services;
- perceived negative impact of telehealth on staff-patient relationships;
- low expectations of impact/lack of need; and
- perceived negative impact on staff autonomy and credibility.(63)

While many challenges related to the acceptance were cited in the review, the quality of technology in terms of its ease of use, reliability and support available were identified as key components contributing to acceptance.(63) The review suggests that including front-line staff in the service design and development involving telehealth technologies may facilitate the change process.(63)

A summary of the key findings from the synthesized research evidence is provided in Table 4. For those who want to know more about the systematic reviews contained in Table 4 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 2.

**Table 4: Summary of key findings from systematic reviews relevant to Element 2 – Strengthen primary care and emergency-department care of IBD and improve connections to specialty care**

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> <li>● <b>Training and supports for primary and emergency-department care professionals</b> <ul style="list-style-type: none"> <li>○ Three reviews, including two recent medium-quality reviews and one older high-quality review, found that training and supports for professionals have the following benefits:                             <ul style="list-style-type: none"> <li>▪ improved generic and disease-specific quality of life among patients;(61; 62)</li> <li>▪ high patient satisfaction;(62)</li> <li>▪ improved symptom severity and physiological markers;(62) and</li> <li>▪ staff engagement.(63)</li> </ul> </li> </ul> </li> <li>● <b>Proactively identifying patients at risk</b> <ul style="list-style-type: none"> <li>○ One recent medium-quality review examined the value of patient-reported outcome measures for diagnostic support in IBD, and found that many measures demonstrate good validity, accuracy, reliability and responsiveness to change.(64)                             <ul style="list-style-type: none"> <li>▪ Patient-reported outcome measures have potential to support disease monitoring, but the review notes that greater patient involvement is needed to facilitate content validity and uptake.(64)</li> </ul> </li> <li>○ One older high-quality review and one older medium-quality review, found that proactively identifying patients at risk by furthering access to primary care had the following benefits:                             <ul style="list-style-type: none"> <li>▪ improved medication adherence;(65)</li> <li>▪ improved health-related patient behaviours;(65)</li> <li>▪ improved health-provider behaviours;(65) and</li> <li>▪ increases in use of services and those receiving care.(65; 66)</li> </ul> </li> <li>○ One recent medium-quality review evaluated the effectiveness of patient-initiated follow-up care in the secondary outpatient setting and found that patients who initiated care reported higher satisfaction and quality of life.(67)</li> </ul> </li> </ul>
Potential harms	<ul style="list-style-type: none"> <li>● <b>Training and supports for primary and emergency-department professionals</b> <ul style="list-style-type: none"> <li>○ One study included in a recent medium-quality review reported a decrease in quality of life following patient engagement with telemedicine and mobile health technology, however, most studies in this review reported improvements in this measure. (62)</li> <li>○ One recent medium-quality review found that stakeholders perceive a number of challenges to acceptance of telehealth technologies, such as perceived loss of autonomy and concerns about the staff-patient relationship.(63)</li> </ul> </li> </ul>
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> <li>● No economic evaluations or costing studies were identified that provided information about costs or cost-effectiveness</li> </ul>
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	<ul style="list-style-type: none"> <li>● Uncertainty because no systematic reviews were identified             <ul style="list-style-type: none"> <li>○ Not applicable</li> </ul> </li> <li>● Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review             <ul style="list-style-type: none"> <li>○ Not applicable – no ‘empty reviews’ were identified</li> </ul> </li> <li>● No clear message from studies included in a systematic review</li> <li>● <b>Training and supports for primary and emergency-department professionals</b> <ul style="list-style-type: none"> <li>○ One older high-quality review examining the impact of specialist-nursing interventions on patients with IBD found positive outcomes among quality of life measures, however, the risk of bias limited the ability to draw conclusions.(61)</li> </ul> </li> </ul>
Key elements of the policy option if it was tried elsewhere	<ul style="list-style-type: none"> <li>● <b>Proactively identifying patients at risk</b> <ul style="list-style-type: none"> <li>○ One older medium-quality review examining interventions for furthering access to primary care found that the utility and effectiveness of a strategy for increasing access to primary care depended on the domain of care and the country’s health system.(66)                             <ul style="list-style-type: none"> <li>▪ For instance, for chronic-disease management, financial incentives and practice re-organization were found to be effective.(66)</li> <li>▪ Countries which already have public primary healthcare such as the United Kingdom</li> </ul> </li> </ul> </li> </ul>

Category of finding	Summary of key findings
Stakeholders' views and experiences	<p data-bbox="574 205 1446 264">focused on decreasing wait times to episodic care, while policies in the United States focused on issues such as access to procedures in general.(66)</p> <ul style="list-style-type: none"> <li data-bbox="467 268 1357 300">• <b>Training and supports for primary and emergency-department professionals</b> <ul style="list-style-type: none"> <li data-bbox="500 302 1438 390">○ One recent medium-quality review found that stakeholders perceived a number of challenges to acceptance of telehealth technologies, such as perceived loss of autonomy and concerns about the staff-patient relationship.(63)                             <ul style="list-style-type: none"> <li data-bbox="537 392 1455 449">▪ The review examined the factors affecting staff acceptance of telehealth technologies, and identified the following barriers:                                     <ul style="list-style-type: none"> <li data-bbox="581 451 1114 480">• the impact of telehealth integration into services;</li> <li data-bbox="581 483 1321 512">• perceived negative impact of telehealth on staff-patient relationships;</li> <li data-bbox="581 514 1078 543">• low expectations of impact/lack of need; and</li> <li data-bbox="581 546 1273 575">• perceived negative impact on staff autonomy and credibility.(63)</li> </ul> </li> <li data-bbox="537 577 1101 606">▪ The review also identified the following facilitators:                                     <ul style="list-style-type: none"> <li data-bbox="581 609 976 638">• easy-to-use and reliable equipment;</li> <li data-bbox="581 640 932 669">• collaboration in service design;</li> <li data-bbox="581 672 829 701">• training and support;</li> <li data-bbox="581 703 992 732">• flexible and responsible services; and</li> <li data-bbox="581 735 935 764">• risk and safety assessments.(63)</li> </ul> </li> </ul> </li> </ul> </li> <li data-bbox="467 766 927 798">• <b>Proactively identifying patients at risk</b> <ul style="list-style-type: none"> <li data-bbox="500 800 1468 869">○ Patient-reported outcome measures are becoming more prevalent in clinical environments to support monitoring of conditions such as IBD, and there is a need to further engage patients with the development of these measures.(64)</li> </ul> </li> </ul>

### **Element 3 – Introduce comprehensive alternative-service options for IBD specialty care**

This element would introduce comprehensive alternative-service options to better manage IBD and reduce unnecessary emergency-department usage. Sub-elements could include:

- 1) providing opportunities for remote consultations with an IBD care team and other electronic initiatives to support clinical decisions (e.g., establishing IBD-specific telehealth 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 ‘quick chronic care’ clinics or ‘multi-resource access centres’ that are similar to urgent-care clinics but are focused on patients with multiple chronic conditions who may need to be directed to the right specialist.

#### *Key findings from the citizen panels*

There were three main values-related themes that emerged during the discussion about element 3:

- 1) fairness/equity;
- 2) collaboration (among patients, health professionals and organizations within the health system); and
- 3) trusting relationships (between patients and health professionals).

In deliberating on element 3, panellists identified fairness and equity considerations as the first values-related theme that underpinned preferences for comprehensive alternative-services options for IBD. Panellists recognized the challenges to accessing care that individuals living in rural and remote communities often face. As such, remote consultations (e-mail, telephone or web-based) with an IBD care team were preferred not only for those living in rural and remote communities, but also for those experiencing an IBD flare. Panellists discussed their experiences during an IBD flare and described being unable to leave their home to seek care because of their symptoms, which could delay treatment seeking until the condition becomes critical and in need of urgent medical attention (e.g., in need of fluids and pain relief). Panellists identified that remote consultations could provide an opportunity for IBD care and intervention before symptoms require attention in an emergency department. In addition to remote consultations, mobile diagnostic clinics (similar to breast cancer screening trailers) were proposed as a way to bring diagnostic capabilities to those living in underserved areas.

The second values-related theme to emerge during deliberations on element 3 was enhancing collaboration among patients, health professionals and organizations within the health system. Panellists discussed harnessing the full range of health professionals in caring for IBD, and also increasing collaboration across professions. Within the IBD care team, panellists focused on the role of nurse practitioners, pharmacists and paramedics. Given advances in biological therapies, pharmacists could play a significant role in the management of IBD in terms of having up-to-date information on treatments and providing medication counselling. Increasing the scope of paramedics was also viewed by panellists as an option to provide care in the home during a flare. Both pharmacists and paramedics were seen as being well-suited to administering medication during flares and as key to reducing emergency-department usage.

The final values-related theme to emerge during deliberations about the third element was trusting relationships between patients and health professionals. As mentioned in element 1, panellists shared a number of negative care experiences and expressed a general lack of confidence in primary-care and emergency-department professionals. A few panellists had experiences with visiting urgent-care centres during IBD flares, and all were referred to the emergency department. In deliberating on alternative-services options for IBD care, panellists did not think that urgent-care clinics focused on supporting gastrointestinal care was a feasible option. They preferred clinics focused on multiple chronic conditions, given the likelihood of IBD patients having other chronic conditions to deal with.

*Key findings from systematic reviews*

We identified six systematic reviews that we deemed to be most relevant to these sub-elements.

For the first sub-element, providing opportunities for remote consultations with an IBD care team, reviews found a range of benefits to these alternative-service options. We identified five recent reviews, two high quality, two medium quality and one low quality, that reported the following benefits:

- improved patient quality of life;(58; 68-71)
- improved clinical outcomes and disease activity;(58; 68; 70; 71)
- decreased clinic visits;(69)
- improved disease knowledge;(70)
- patient empowerment;(70) and
- treatment adherence.(70; 71)

One study within a recent high-quality review found that adults with IBD who engaged with distance management reported increased relapse rates, however, the review noted that this may have been attributable to variations in the definition of “relapse”.(69)

Patient views and experiences were identified as an important component in the success of remote consultations. Two recent high-quality reviews and two recent medium-quality reviews identified improvements in patient-reported quality of life following the use of telemedicine technologies.(58; 68; 69; 71) While these differences were not always statistically significant, the authors noted that any change in quality of life can have a significant impact on the patient.(69) Two recent reviews, one medium quality and one low quality, found that telemonitoring and other electronic technologies were feasible and acceptable to patients, leading to improvements in satisfaction with care.(70; 71)

In terms of cost-effectiveness, we identified one recent high-quality review, two recent medium-quality reviews and one recent low-quality review that reported on the cost-effectiveness of telemedicine interventions.(68; 70; 71) Three of the reviews reported a decrease in costs among patients receiving telemedicine care,(68; 70; 71) and one review observed reduced costs in follow-up care and hospital admission charges.(68) Increases in cost were identified in three reviews, and the increases may have been attributable to travel costs, intervention costs and initial installation costs.(58; 68; 70)

We were unable to find any systematic reviews that directly addressed the second sub-element, establishing urgent-care clinics focused on supporting gastrointestinal care, including rapid access to diagnostics.

With respect to the third sub-element, creating clinics that are similar to urgent-care clinics with a focus on patients with multiple chronic conditions, we identified one relevant recent high-quality review.(72) The review focused on the creation of patient-initiated clinics to address multiple chronic conditions, including breast cancer, IBD and rheumatoid arthritis.(72) 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.(72) However, while these improvements were observed at the 12-month mark, some studies demonstrated better outcomes for control groups at 24 months.(72) Among all disease groups examined, the best outcomes were observed when patients had positive relationships with their consultant.(72) Given that positive relationships yielded higher satisfaction among patients, the review suggests that this could be a key focus when implementing policy.(72)

A summary of the key findings from the synthesized research evidence is provided in Table 5. For those who want to know more about the systematic reviews contained in Table 5 (or obtain citations for the reviews), a fuller description of the systematic reviews is provided in Appendix 3.

**Table 5: Summary of key findings from systematic reviews relevant to Element 3 – Introduce comprehensive alternative-service options for IBD specialty care**

Category of finding	Summary of key findings
Benefits	<ul style="list-style-type: none"> <li>• <b>Providing opportunities for remote consultations with an IBD care team</b> <ul style="list-style-type: none"> <li>○ Five recent reviews, two high quality, two medium quality and one low quality, found that remote consultations and distance management using telemedicine have the following benefits:                             <ul style="list-style-type: none"> <li>▪ improved patient quality of life;(58; 68-71)</li> <li>▪ improved clinical outcomes and disease activity;(58; 68; 70; 71)</li> <li>▪ decreased clinic visits;(69)</li> <li>▪ improved disease knowledge;(70)</li> <li>▪ patient empowerment;(70) and</li> <li>▪ treatment adherence.(70; 71)</li> </ul> </li> </ul> </li> <li>• <b>Creating clinics to address multiple chronic conditions</b> <ul style="list-style-type: none"> <li>○ One recent high-quality 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.(72)</li> </ul> </li> </ul>
Potential harms	<ul style="list-style-type: none"> <li>• <b>Providing opportunities for remote consultations with an IBD care team</b> <ul style="list-style-type: none"> <li>○ One study within a recent high-quality review found adults with IBD engaged with distance management reported increased relapse rates; however, the authors noted that this may have been due to varying definitions of “relapse”.(69)</li> </ul> </li> <li>• <b>Creating clinics to address multiple chronic conditions</b> <ul style="list-style-type: none"> <li>○ One recent high-quality review reported improved mental health scores and general health perceptions among patients with IBD engaged with patient-initiated clinics at 12 months, however, some studies demonstrated better outcomes for control groups at 24 months.(72)</li> </ul> </li> </ul>
Costs and/or cost-effectiveness in relation to the status quo	<ul style="list-style-type: none"> <li>• <b>Providing opportunities for remote consultations with an IBD care team</b> <ul style="list-style-type: none"> <li>○ One recent high-quality review, two recent medium-quality reviews and one recent low-quality review reported on the cost-effectiveness of telemedicine interventions.(58; 68; 70; 71)                             <ul style="list-style-type: none"> <li>▪ A number of reviews reported a decrease in costs among patients receiving telemedicine care,(68; 70; 71) and one review observed reduced costs in follow-up care and hospital admission charges.(68)</li> </ul> </li> <li>○ Five studies within a recent high-quality review reported an increase in costs among patients using telemedicine, which may have been partially due to travel costs of healthcare professionals or intervention costs.(68)</li> <li>○ Electronic interventions were found to occasionally increase healthcare costs,(58) and the initial cost of telemedicine technology installation may be high.(70)</li> </ul> </li> </ul>
Uncertainty regarding benefits and potential harms (so monitoring and evaluation could be warranted if the option were pursued)	<ul style="list-style-type: none"> <li>• Uncertainty because no systematic reviews were identified             <ul style="list-style-type: none"> <li>○ <b>Establishing urgent-care clinics focused on supporting gastrointestinal care</b></li> </ul> </li> <li>• Uncertainty because no studies were identified despite an exhaustive search as part of a systematic review             <ul style="list-style-type: none"> <li>○ Not applicable – no ‘empty reviews’ were identified</li> </ul> </li> <li>• No clear message from studies included in a systematic review</li> <li>• <b>Providing opportunities for remote consultations with an IBD care team</b> <ul style="list-style-type: none"> <li>○ While differences in quality of life measures were not statistically significant in one recent high-quality review, authors noted that any improvement may be important to the patient.(69)</li> </ul> </li> </ul>
Key elements of the policy option if it was tried elsewhere	<ul style="list-style-type: none"> <li>• <b>Creating clinics to address multiple chronic conditions</b> <ul style="list-style-type: none"> <li>○ Among all disease groups examined by one recent high-quality review evaluating patient-initiated clinics, the best outcomes were observed when patients had positive relationships with their consultant, which yielded higher satisfaction.(72)</li> </ul> </li> </ul>
Stakeholders’ views and experiences	<ul style="list-style-type: none"> <li>• <b>Providing opportunities for remote consultations with an IBD care team</b> <ul style="list-style-type: none"> <li>○ Two recent high-quality reviews and two recent medium-quality reviews identified</li> </ul> </li> </ul>



Category of finding	Summary of key findings
	<p>improvements in patient-reported quality of life following the use of telemedicine technologies.(58; 68; 69; 71)</p> <ul style="list-style-type: none"> <li>▪ While differences in quality of life measures were not always statistically significant, the review noted that any improvement may be important to the patient.(69)</li> <li>▪ Differences in quality of life may depend on a range of factors, including culture, disease sub-type, and baseline quality of life.(58)</li> <li>○ One recent medium-quality review reported improvements in patient satisfaction, and acceptance of technology, knowledge and adherence were also observed following the use of electronic technologies in the field of gastroenterology.(71)</li> <li>○ One recent low-quality review found that patients using telemonitoring for IBD found the system to be highly feasible and acceptable; acceptance and satisfaction with this method of care was high among patients.(70)</li> <li>• <b>Creating clinics to address multiple chronic conditions</b> <ul style="list-style-type: none"> <li>○ One recent high-quality review found that individuals engaged with patient-initiated clinics experienced improved mental health and general health perception at 12 months, and reported higher satisfaction if a positive relationship was built with their consultant.(72)</li> </ul> </li> </ul>

**Additional equity-related observations about the three elements**

None of the systematic reviews identified in relation to the elements included insights about the populations prioritized for equity considerations.

**IMPLEMENTATION CONSIDERATIONS**

A number of barriers might hinder implementation of the three elements of a potentially comprehensive approach to reducing emergency-department usage in people with IBD in provincial health systems in Canada, which needs to be factored into any decision about whether and how to pursue any given element (Table 6). While potential barriers exist at the levels of patients/citizens, providers, organizations and systems, perhaps the biggest barrier lies in trying to find solutions that will be fit for purpose across each of the unique health systems in Canada. Despite the many common challenges that exist in trying to improve care for individuals with IBD across the country, it’s likely the case that all of the elements and sub-elements presented need to be considered in light of the specific health- and political-system contexts that exist within each province and territory.

**Table 6: Potential barriers to implementing the elements**

Levels	Element 1 – Enable self-management of IBD through better supports for patients	Element 2 – Strengthen primary care and emergency-department care of IBD and improve connections to specialty care	Element 3 – Introduce comprehensive alternative-service options for IBD specialty care
<b>Patient/citizen</b>	<ul style="list-style-type: none"> <li>• Patients/citizens may feel uneasy taking a more prominent role in the management of their condition, particularly if recently diagnosed</li> <li>• Patients/individuals may not be comfortable using technology such as mobile phone apps</li> </ul>	<ul style="list-style-type: none"> <li>• Patients/citizens may not be comfortable using technology such as mobile phone apps to help link their monitoring data with appropriate care options</li> </ul>	<ul style="list-style-type: none"> <li>• Patients/citizens who have established routines and developed a level of comfort in managing their condition may have challenges adapting to or making the best use of alternative options</li> </ul>
<b>Providers</b>	<ul style="list-style-type: none"> <li>• Providers may feel that they should play a more active leadership role in supporting their patients, particularly when they have recently been diagnosed</li> <li>• Providers may view an increasing reliance on electronic tools and self-management efforts as a reduction in their role in the care process</li> <li>• Providers with the appropriate knowledge and skills required to provide personal support may be lacking</li> </ul>	<ul style="list-style-type: none"> <li>• Providers in primary- and emergency-care settings may not have the time or resources to gain additional knowledge about and skills related to IBD</li> <li>• Providers may lack access to appropriate diagnostic tools in primary- and emergency-care settings</li> <li>• Providers in primary- and emergency-care settings may not have appropriate technical skills or infrastructure to enable them to integrate patient data from electronic supports</li> </ul>	<ul style="list-style-type: none"> <li>• There may be a shortage of available providers (particularly gastroenterologists and those trained to support individuals with IBD) with the ability to provide care in alternative-service models</li> </ul>
<b>Organization</b>	<ul style="list-style-type: none"> <li>• None identified</li> </ul>	<ul style="list-style-type: none"> <li>• Organizations may lack the technical capacity or infrastructure to ensure staff and patients have access to the latest diagnostic tools and mechanisms to support better care coordination</li> </ul>	<ul style="list-style-type: none"> <li>• Organizations may lack the appropriate staff, technical capacity or infrastructure to shift towards new service models</li> </ul>
<b>System</b>	<ul style="list-style-type: none"> <li>• Remuneration mechanisms for providers may not be appropriately suited to support their role in patient self-management (e.g., by providing incentives for them to provide in-person support, or enable them to self-manage remotely)</li> </ul>	<ul style="list-style-type: none"> <li>• Information privacy and legal challenges may emerge when integrating patient self-monitoring data across providers and settings</li> <li>• It isn’t clear what appropriate funding and remuneration mechanisms would be required to support organizations and providers to provide coordinated integrated care with data inputs from patients</li> </ul>	<ul style="list-style-type: none"> <li>• Introducing new types of settings for care delivery (e.g., chronic-care clinics) may require changes to regulatory frameworks that govern how organizations and providers operate, as well as the funding and remuneration mechanisms needed to pay for these new options</li> </ul>

Despite these challenges, many health systems across Canada are at critical junctures, where demographic shifts, rising costs and technological advances combined with changing patient needs and preferences are forcing rapid changes to the status quo. As such, there are a number of windows of opportunity that should be acknowledged (Table 7), since they provide a promising jumping-off point for actively working towards addressing the problems described in this brief.

**Table 7: Potential windows of opportunity for implementing the elements**

Type	Element 1 – Enable self-management of IBD through better supports for patients	Element 2 – Strengthen primary care and emergency-department care of IBD and improve connections to specialty care	Element 3 – Introduce comprehensive alternative-service options for IBD specialty care
<b>General</b>	<ul style="list-style-type: none"> <li>Health systems across Canada are increasingly looking for ways to achieve the ‘triple aim’ of improving the patient experience and population health while keeping per capita costs manageable, and addressing emergency-department use among individuals with a chronic condition such as IBD provides an opportunity to develop focused solutions that can serve as an exemplar for how the system can be strengthened to achieve the ‘triple aim’ more broadly</li> </ul>		
<b>Element-specific</b>	<ul style="list-style-type: none"> <li>There are many chronic conditions (e.g., arthritis and diabetes) for which self-management supports have been introduced, serving as an opportunity to learn from what works</li> <li>There is an increasing emphasis in most health systems on engaging patients in their care</li> </ul>	<ul style="list-style-type: none"> <li>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</li> </ul>	<ul style="list-style-type: none"> <li>Many health systems are actively considering an array of alternative-service options for select conditions (e.g., diabetes), select treatments (e.g., high-volume low-risk procedures) and populations (e.g., rural and remote patients)</li> </ul>

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## APPENDICES

The following tables provide detailed information about the systematic reviews identified for each option. Each row in a table corresponds to a particular systematic review and the reviews are organized by element (first column). The focus of the review is described in the second column. Key findings from the review that relate to the option are listed in the third column, while the fourth column records the last year the literature was searched as part of the review.

The fifth column presents a rating of the overall quality of the review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered “high scores.” A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.

The last three columns convey information about the utility of the review in terms of local applicability, applicability concerning prioritized groups, and issue applicability. The third-from-last column notes the proportion of studies that were conducted in Canada, while the second-from-last column shows the proportion of studies included in the review that deal explicitly with one of the prioritized groups. The last column indicates the review’s issue applicability in terms of the proportion of studies focused on IBD. Similarly, for each economic evaluation and costing study, the last three columns note whether the country focus is Canada, if it deals explicitly with one of the prioritized groups and if it focuses on IBD.

All of the information provided in the appendix tables was taken into account by the evidence brief’s authors in compiling Tables 1-3 in the main text of the brief.

**Appendix 1: Systematic reviews relevant to Element 1 - Better support IBD through improved self-management**

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
Self-management supports	Examining the effectiveness of self-management and educational interventions among patients with IBD (51)	<p>The review examined 23 studies in order to examine the effectiveness of self-management and educational interventions among patients with IBD. Primary outcomes of interest were quality of life, disease activity and symptom reporting, psychological well-being, impact on healthcare resources and disease-related knowledge.</p> <p>Of the 16 studies examining quality of life among patients with IBD, three examined self-management interventions, three examined educational interventions, and 10 incorporated self-management approaches. While the majority of studies reported no significant changes in quality of life among patients, one study reported improvement in mental health among patients with Crohn’s disease at the six-month mark. Further, two studies found that stress management and exercise improved quality of life. While one study found that an educational intervention group experienced a decrease in quality of life, this may have been due to a disproportionate increase in disease activity.</p> <p>Thirteen studies examined disease activity and symptom reporting, with the majority finding no effect. However, three studies examining self-management and relaxation reported positive effects in the form of fewer symptom relapses, reductions in disease activity, less intense pain, and pain relief. One study found that controls experienced a greater reduction in symptoms among patients who were not engaged with an intervention.</p> <p>While measures of psychological well-being varied between studies, 10 reported improvements on at least one measure. Significant improvements in stress levels, anxiety, disease-related concern, coping, distress related to pain, and general psychological well-being were observed.</p> <p>Six studies examined the impact of interventions on the use of healthcare resources. While two studies found no differences, four studies found that after these interventions, there were significantly fewer hospital visits. Deduced sick leave and faster treatment of relapses were also reported.</p> <p>Five studies examined changes in disease-related knowledge following intervention, with all reporting significant increases.</p> <p>There is a limited evidence base on the effectiveness of self-management among patients with IBD, as the emphasis is largely on management of chronic disease rather than the control of symptoms. The interventions examined by the studies included in</p>	2007	10/11 (AMSTAR rating from McMaster Health Forum)	6/23	0/23	23/23

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		the review varied widely, with all targeting a component of the disease-management process. While the focus was general, the results indicate that outcomes may be improved if education is given in a timely and appropriate manner.					
	Evaluating the effectiveness of printed patient-education interventions (52)	<p>The review examined seven studies in order to evaluate the effectiveness of printed patient-education interventions among patients with chronic disease.</p> <p>Of the seven studies included in this review, three studies focused on IBD. This review found that evidence for the effectiveness of print interventions is limited, with positive outcomes emerging on few measures. Five interventions scored zero on the quality criteria used by the authors. Given the limitations, it was not possible to draw concrete conclusions from the review. However, there is evidence that current forms of printed patient education are not sufficient for improving health-related quality of life; future research should explore these outcomes in a rigorous manner.</p>	2005	5/9 (AMSTAR rating from McMaster Health Forum)	1/7	0/7	3/7
	Evaluating the evidence on self-management support for long-term conditions (53)	<p>The rapid synthesis examined 30 qualitative systematic reviews, 102 quantitative systematic reviews, and 61 studies in order to evaluate the evidence on self-management support for long-term conditions.</p> <p>This rapid synthesis focused on a range of chronic diseases, including asthma, diabetes, depression, hypertension, chronic obstructive pulmonary disease, chronic kidney disease, low back pain, stroke and irritable bowel syndrome. A range of self-management support interventions were evaluated, delivered by a range of allied health professionals and sometimes lay educators and mentors. This review found that a shift in organizational culture is necessary for a consistent and ongoing self-management program, so that professionals and patients embrace similar principles of care. The most successful self-management programs included a range of components, including education, psychological training, practical support and social support. A whole-systems approach to implementation is crucial to the success of these interventions, with effective programs being multidisciplinary, engaging patients and professionals, and functioning within a culture of organization that supports self-management.</p> <p>This review found that self-management is a crucial component of care among patients with long-term conditions. Strong leadership, engagement of professionals, appropriate training, support of resources, and ongoing evaluation are necessary to ensure organizational change in support of these interventions.</p>	2012	8/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/193	0/193
	Assessing the effectiveness of self-management	<p>The review examined 15 randomized controlled trials in order to assess the effectiveness of self-management interventions for patients with IBD.</p> <p>This review examined the components of structure and content of self-management interventions using content analysis. Programs varied in structure, ranging in mode of</p>	2014	9/11 (AMSTAR rating from McMaster)	0/13	0/13	13/13

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
	interventions for patients with IBD (54)	<p>delivery, material provided, provider, structure, and intensity. Interventions also varied in content, and included information provision, drug management, symptom management, psychological management and lifestyle management. The results indicated that self-management programs had a positive effect on health-related quality of life among patients with IBD, with distance interventions having a stronger effect size.</p> <p>In terms of structure, distance self-management interventions demonstrated significant strength. The use of internet-based learning should be capitalized on as most newly-diagnosed IBD patients are young people. However, the review noted a paucity of evidence on remote delivery of self-management programs; thus, further research in this area is needed.</p> <p>In terms of content, the review did not find evidence to suggest that specific content components lead to positive effects among patients with IBD. However, the authors note that patient education is central to the success of IBD management, as information provision may improve health-related quality of life.</p> <p>The review found that self-management interventions for patients with IBD had a medium effect on health-related quality of life, with distance management proving successful in this context. Future studies should test the feasibility, acceptability and efficacy of these programs.</p>		Health Forum)			
	Evaluating the skills and effect of self-management interventions among adults with IBD (55)	<p>The review examined six studies in order to evaluate the skills and effects of self-management interventions among adults with IBD. Outcomes of interest included self-management skills and health-related outcomes including quality of life, disease activity and symptoms.</p> <p>Self-management is defined by five core skills: problem solving, decision-making, finding and using resources, forming relationships with healthcare professionals and taking action. Only one study encompassed all five of these skills, with decision-making and relationship-forming being the most commonly cited skills among interventions. Most interventions focused on self-management of disease. Future research should emphasize the inclusion of all five self-management skills in order to evaluate positive outcomes and better understand the effects of these skills.</p> <p>Studies varied in reports of health-related quality of life. Five interventions used the IBD Questionnaire. Beyond a global score, this scale has four sub-scales: bowel symptoms, systemic symptoms, emotional function and social function. Two studies indicated that self-management resulted in the improvement of global scores, and three interventions found no difference. Two studies also examined generic health-</p>	2014	7/10 (AMSTAR rating from McMaster Health Forum)	0/6	0/6	6/6

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		<p>related quality of life scores with one finding positive effects and one finding no significant change.</p> <p>In terms of disease activity, four interventions found that self-management interventions had a positive effect. One study found no significant difference in disease activity.</p> <p>Three interventions examined the impact of self-management interventions on the symptoms of IBD. Findings varied, with one study of project management demonstrating improvements in bowel and systemic symptoms, one study of personalized self-management and open-access clinics finding no difference in anxiety and depression scores, and one study of a web-based intervention finding that the depression symptoms of the control group improved. There was a general lack of consistency among measures, limiting the authors' ability to draw conclusions.</p> <p>While this review found a number of positive outcomes resulting from self-management interventions, future research must address the importance of symptom management as this is a distressing aspect of IBD.</p>					
	<p>Examining the effects of self-management interventions on healthcare utilization for patients with chronic conditions (56)</p>	<p>Self-management interventions and supports are increasingly being considered to manage the healthcare utilization burden of chronic diseases. The systematic review aimed to determine the models of self-management and their effect on service utilization as well as health outcomes.</p> <p>The review included 184 randomized controlled trials on adults with chronic conditions who received a self-management intervention in any delivery format (digital, in-person, etc.).</p> <p>Majority of the studies reported reduced utilization and better health outcomes as displayed on a permutation plot. In addition, costs increase with interventions reporting better health outcomes. A meta-analysis produced statistically significant effect sizes above 0.2 for respiratory and cardiovascular conditions, which constitutes a relatively small impact of reduced service utilization, namely hospital use, due to self-management interventions.</p> <p>When reviewers considered the risk of bias in studies, they found that studies with higher risk of bias reported more significant health improvements and reduction in utilization than studies with lower risk of bias. Publication bias was also assessed and was not found to be a concern for health outcomes and cost data, but there was slight bias for hospital-use data.</p>	<p>2012</p>	<p>8/11 (AMSTAR rating from McMaster Health Forum)</p>	<p>7/184</p>	<p>0/184</p>	<p>0/184</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		Overall, the reviewers found that self-management interventions can be effective to a small extent for reducing hospital use with the strongest evidence present for cardiovascular and respiratory diseases. Reviewers also highlight that it is rare for interventions to have a negative impact on outcomes, and the effects on cost is variable.					
Electronic tools to support self-management	Evaluating the impact of electronic technologies on the management of patients with IBD (58)	<p>The review examined 17 studies in order to evaluate the impact of eHealth technologies on the management of patients with IBD. Results of interest were clinical outcomes and patient-reported outcome measures, effectiveness, cost-effectiveness and feasibility of self-management, and recommendations for future design and use.</p> <p>Electronic interventions were found to have an impact on disease activity, but the authors note that disease sub-type and severity were important factors on activity. The majority of studies focused on patients with ulcerative colitis, which may have had an impact on clinical outcomes as Crohn's disease is more complex.</p> <p>The review found that patient-reported quality of life improved after the use of web-based interventions. The extent of the impact depends on a number of factors, potentially including culture, disease sub-type, and baseline quality of life among patients.</p> <p>The eHealth interventions examined by the studies in this review were found to sometimes increase healthcare costs. Future research must encapsulate both the direct and indirect costs of this form of care.</p> <p>Electronic interventions often rely on self-reported data, therefore feasibility and accuracy are sometimes called into question. However, the review found that while patient knowledge is an important factor in accurate reporting, the strength of qualitative data may overcome these limitations.</p> <p>There is strong evidence to suggest that eHealth interventions have a positive impact on patient behaviour, knowledge, self-management and clinical outcomes. Success relies on adherence, therefore interventions should be designed with this in mind. The authors of this review suggest the development and application of a standardized framework for the design of eHealth solutions. Future research should focus on understanding limitations to design and developing a framework that integrates a range of factors, while keeping patients engaged and involved.</p>	2015	7/10 (AMSTAR rating from McMaster Health Forum)	1/17	0/17	17/17
	Assessing the quality of online resources	The review examined 25 sources in order to assess the quality of online resources used by patients considering surgery for ulcerative colitis.	Not reported in detail	5/9 (AMSTAR rating from	0/9	0/9	9/9

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
	used by patients considering surgery for ulcerative colitis (60)	<p>This review found a paucity of online decision-making resources for patients with ulcerative colitis. The quality of information on selected websites was assessed using a number of validated instruments. Despite recommendations that internet use be utilized alongside shared decision-making, there is a lack of resources. The websites under review did not meet minimum decision-making standards, and do not cover important information for patients such as comparing surgery with ongoing medical treatment.</p> <p>The lack of internet decision-making resources points to an important gap in shared decision-making. New content and decision aids must be developed to support this process as patients consider surgery for ulcerative colitis.</p>		McMaster Health Forum)			
	Reviewing randomized control trials on improving quality of health services through electronic symptom reporting by patients to providers (59)	<p>An increased focus on electronic communication between patient and providers is prompting a need to understand the effects on health-service quality. The systematic review focuses on randomized controlled trials evaluating the effects of electronic symptom reporting; this approach has been primarily researched with the following conditions: cancer, respiratory and lung diseases, cardiovascular diseases, psychiatry, and diabetes. In addition, the varying purposes of electronic symptom reporting as categorized by the reviewers include consultation support for physicians, supporting monitoring of symptoms, and self-management for patients.</p> <p>The reviewers included 32 papers with 29 studies, but only drew conclusions from 20 higher-quality studies with a combined total of 3,991 patients, after conducting a quality assessment. The results from 13 of the studies supported their respective hypotheses and reported that electronic symptom reporting was either just as effective or better than the control of standard care.</p> <p>With regards to consultation support, studies highlighted that electronic symptom reporting prior to the clinical visit reduced patient distress, enabled patient-centred conversation, and was associated with better symptom management and health-related quality of life. The visit duration was similar, but communication between the patient and provider was perceived to be enhanced.</p> <p>Two studies focused on asthma supported the use of electronic symptom reporting for monitoring purposes as it improved quality of life and symptoms. There were limited positive outcomes for cardiovascular conditions reported.</p> <p>The reviewers found eight out of nine studies of higher quality on self-management supporting the use of electronic symptom reporting. Improved health outcomes were reported for patients with asthma, chronic obstructive pulmonary disease, diabetes, lung transplantation, certain psychiatric conditions, and to some extent for irritable bowel syndrome. Reduced resource utilization in the form of fewer physician visits</p>	2011	8/10 (AMSTAR rating from McMaster Health Forum)	0/32	0/32	0/32

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		<p>were also reported as self-management improved symptom control in conditions such as asthma.</p> <p>Overall, the reviewers contend that the randomized controlled trials found were of relatively low methodological quality and higher-quality research is needed to recommend the use of electronic symptom reporting more broadly. At the same time, there is some evidence to suggest that electronic symptom reporting may have benefits for self-management and supporting clinical consultations.</p>					



**Appendix 2: Systematic reviews relevant to Element 2 – Strengthen the role of primary and emergency-department care and improve connections to specialty care**

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
Training and supports for primary and emergency-department professionals	Examining the impact of specialist-nursing interventions on patients with IBD (61)	<p>This review examined one randomized controlled trial in order to examine the impact of specialist-nursing interventions on patients with IBD. The primary outcome of interest was the proportion of patients who entered remission. Secondary outcomes included a range of factors such as patient compliance, clinical outcomes, duration of remission, use of medical services, psychosocial outcomes and patient satisfaction.</p> <p>The study under review did not present data on the proportion of patients entering remission.</p> <p>Health-related quality of life was examined following a nurse-led counselling program for patients with IBD, finding positive outcomes six months post-intervention. However, this study had a high risk of bias, and the authors of the review caution against forming conclusions from these results.</p> <p>The review found a striking lack of research in the area of specialist-nurse interventions for patients with IBD. While positive outcomes were seen among measures of health-related quality of life, the risk of bias in the selected study limits conclusions. Future research should assess the impact of these interventions on a range of outcomes, focusing on methodological rigour.</p>	2008	10/11 (AMSTAR rating from McMaster Health Forum)	0/1	0/1	1/1
	Exploring the effectiveness of telemedicine and mobile health technologies in the management of digestive diseases (62)	<p>The review examined 20 articles in order to explore the effectiveness of telemedicine and mobile health technologies in the management of digestive diseases. Outcomes of interest were patient compliance, patient satisfaction, disease activity and quality of life.</p> <p>There was a wide range of patient compliance for the telemedicine systems examined by the review. Compliance varied largely based on intervention type, and authors also noted that study power and study design played a key role in the measurements of compliance.</p> <p>Patient satisfaction was high among the studies examined in the review, with the lowest satisfaction measure sitting at 74%.</p> <p>Disease activity varied based on the disease being studied, but results from a number of studies indicated that symptom severity and physiological</p>	2017	5/11 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/20	12/20

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		<p>biomarkers improved among groups engaged with telemedicine interventions. While half of the studies reported statistically significant findings, the authors note that sample sizes may have compromised statistical power.</p> <p>In terms of quality of life, the studies included in the review largely demonstrated positive outcomes among both generic and disease-specific measures. The IBD quality-of-life questionnaire was commonly cited, with most studies indicating improvements in post-treatment groups. One study reported a decrease in this measure from pre-treatment to post-treatment.</p> <p>The review found positive evidence for the use of telemedicine interventions among patients with digestive diseases. Moving forward, researchers should focus on understudied areas of mobile health technology in order to explore potential benefits to patients.</p>					
	<p>Reviewing qualitative and quantitative research on acceptance of telehealth technologies by nurses (63)</p>	<p>The review examined 10 qualitative, two quantitative and two mixed-method studies to determine factors affecting the acceptance of telehealth technologies by nurses for chronic obstructive pulmonary disease and chronic heart failure patients. The methods include surveys, focus groups, observations, interviews and document analysis.</p> <p>The idea that staff acceptance of technology plays a critical role in the ability of nurses to deliver quality care was reflected in all studies. However, there are many challenges to acceptance such as a perceived loss of autonomy and potential concerns about the staff-patient relationship as reported by several qualitative studies.</p> <p>The quality of the technology in terms of its ease of use, reliability and support available is identified as a key component contributing to the acceptance. The reviewers suggest that it may be important to include front-line staff in the service design and development involving telehealth technologies to facilitate the change process.</p> <p>The reviewers found limited data on staff acceptance specifically, as many studies were part of larger investigations. Further research is needed to develop concrete solutions to the challenges front-line nurses experience in accepting and integrating telehealth technologies into routine practice.</p>	<p>2012</p>	<p>6/0 (AMSTAR rating from McMaster Health Forum)</p>	<p>1/14</p>	<p>0/14</p>	<p>0/14</p>

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
Proactively identify those patients at risk	Examining the value of patient-reported outcome measures for diagnostic support in IBD (64)	<p>Patient-reported outcomes (PROMs) are becoming more prevalent in clinical environments to support monitoring of conditions such as IBD. It is important to understand how these measures are designed and provide value to patients. The review examines PROMs created for IBD and considers their utility in supporting disease monitoring by considering content, construct and criterion validity.</p> <p>The reviewers included 17 studies with 20 IBD-related PROMs, largely for adult patients. The PROMs included ones adapted from other clinical conditions and others that were created specifically for IBD. As PROMs are intended to focus on patient perspectives, their input is important during the design process for content validity. Only two articles highlighted that patients' experiences were considered in PROM development, with one conducting qualitative interviews to facilitate the process. Hence, reviewers suggest that there may be a need to further include patients in PROM development.</p> <p>For validating the constructs of PROM instruments, seven studies compared clinician-reported tools and patient-reported ones. They found good agreement for physical symptom-related measures such as blood in stool, but less agreement for items such as urgency, well-being and extra intestinal manifestations.</p> <p>Four of the studies compared PROMs to the gold standard of measuring disease activity with endoscopy. The six PROMs evaluated showed moderate accuracy for identifying key issues such as mucosal inflammation in patients with ulcerative colitis, and low accuracy for those with Crohn's disease. Further research in this area may allow for the development of PROMs more in line with endoscopic findings.</p> <p>In terms of reliability of using the same instrument over time, several of the PROMs showed strong retest ability when re-administered a week later, or even after two to six weeks. There was good agreement between the scores taken at different time periods.</p> <p>The responsiveness of the test to changes in disease activity varied depending on the PROM. Most PROMs were able to detect if a patient's condition had improved or deteriorated with good confidence as evaluated by the mean paired difference and compared to physician assessment.</p>	2016	5/10 (AMSTAR rating from McMaster Health Forum)	0/17	0/17	17/17

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		<p>Overall, the reviewers suggest that PROMs need more rigorous evaluation by correlating outcomes with standards such as endoscopy for widespread clinical use. Few studies considering criterion validity demonstrate low-to-moderate ability to detect patients at risk for active disease. More patient involvement is also needed to facilitate content validity and uptake.</p>					
	<p>Evaluating the evidence for interventions in primary and community care for patients with multimorbidity (65)</p>	<p>Multimorbidity is defined as individuals with multiple chronic conditions. The review includes 18 randomized controlled trials with interventions in primary and community care for patients who have multimorbidities. The disease conditions primarily considered in nine studies included depression, diabetes and cardiovascular disease, and the majority of the studies focused on older adults.</p> <p>Interventions in 12 studies centred around case management and collaboration of healthcare professionals to support care delivery. The other six studies focused on direct patient interventions such as educational or self-management tools.</p> <p>The authors considered the impact on clinical, mental health and patient reported outcomes as well as health-service utilization, medical use and adherence, and patient and provider behaviours.</p> <p>They found limited evidence to suggest interventions improved clinical outcomes unless they targeted specific risk factors. The quality of evidence was rated as moderate. Mental health outcomes based on high-quality evidence saw some improvement, especially when targeting depression in a comorbid condition. Four of seven studies had significant effect sizes (above 0.5).</p> <p>Patient-reported outcomes had variable effects with half of reporting studies highlighting positive results with small effect sizes. No effects were demonstrated for health-service utilization, while medication adherence, health-related patient behaviours and provider behaviours saw slight improvements with low- to moderate-quality evidence.</p> <p>Overall, the reviewers highlight that there is limited evidence on the effectiveness of interventions for multimorbidity. Larger trials with well-defined interventions are needed in the future. There is some evidence to suggest that interventions could be effective when targeting specific issues such as depression.</p>	<p>2010</p>	<p>10/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>1/18</p>	<p>0/18</p>	<p>0/18</p>

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
	Evaluating the effectiveness of patient-initiated follow-up care in secondary outpatient settings (67)	<p>The review examined six studies evaluating the use of patient-initiated follow-up appointments for outpatient specialist or secondary-care services. The aim of this intervention is to allow patient to direct care while potentially reducing unnecessary follow-up appointments.</p> <p>Three studies on a randomized controlled trial following the same cohort of patients with rheumatoid arthritis over six years found no negative impact associated with patient-initiated follow-up. Instead patients initiating follow-up tended to report higher satisfaction and quality of life and had lower management costs than the control group. The clinical outcomes between the two groups did not differ significantly.</p> <p>Two multi-centre randomized controlled trials focused on patients with IBD by providing the intervention group with self-management training and the option to follow up as needed, while the control received standard care. Both studies reported that the intervention group had fewer hospital visits and outpatient visits as well as an improved ability to manage their care. The health-service-utilization costs were also significantly lower for the intervention group. There was limited difference between quality-of-life and patient-satisfaction measurements in the groups.</p> <p>One randomized study with breast cancer patients also reported no difference in quality of life, and had high rates of satisfaction in both standard care and patient-initiated follow-up groups.</p> <p>In regards to limitations, the authors highlight that studies are limited in generalizability as patient selection and context plays a role. The studies also did not do a full cost-benefit analysis and may not have considered other costs such as keeping a reserve of appointments associated with patient-reported follow-up.</p> <p>Overall, there is some evidence to suggest that patient-initiated follow-up systems may reduce number of visits while maintaining quality of life and clinical outcomes. Further research is needed to establish the cost-effectiveness and contexts as well as patient populations in which the intervention may work best.</p>	2013	5/10 (AMSTAR rating from McMaster Health Forum)	0/6	0/6	2/6
	Examining the interventions for furthering access to primary care in areas of prevention,	The review included 121 studies on interventions furthering access to primary healthcare in areas of prevention, chronic-disease management and episodic care. The included studies were mostly rated as being of medium quality with some being high quality and a few of low quality.	2009	7/10 (AMSTAR rating from McMaster)	3/121	0/121	0/121

*Reducing Emergency-department Usage in People with Inflammatory Bowel Disease in Provincial Health Systems in Canada*

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
	chronic-disease management and episodic care (66)	<p>The primary outcomes considered by these studies included use of services such as attendance to a pap test, follow-up or continuity of care in chronic-disease management and wait times.</p> <p>Strategies used to further access were categorized by the reviewers as: practice-reorganization such as establishing condition-specific clinics, patient support including education and reminder systems, provision of services by extending hours or outreach initiatives, workforce development by supporting training for expanding skills and competencies, and financial incentives for providers.</p> <p>The utility and effectiveness of a strategy for increasing access depended on the given domain and country's health system. For example, financial incentives and practice re-organization were found to be effective for chronic-disease management while patient support and workforce development furthered prevention initiatives. Countries which already have public primary healthcare such as the U.K. focused on decreasing wait times to episodic care while U.S. policy focused on issues such as access to procedures in general.</p> <p>Fifty-two of 75 interventions evaluated resulted in positive outcomes such as statistically significant increases in use of services and those receiving care. Combination of strategies that considered patient demand and provider capacity were demonstrated to be more effective.</p> <p>Overall, the reviewers suggest that multiple strategies are needed at all levels of the health system to facilitate access to primary healthcare.</p>		Health Forum)			

**Appendix 3: Systematic reviews relevant to Element 3 – Introduce comprehensive alternative-service options for IBD specialty care**

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
Remote consultations with an inflammatory bowel care team	Assessing the effectiveness, acceptability and costs of interactive telemedicine (68)	<p>The review examined 93 studies in order to assess the effectiveness, acceptability and costs of interactive telemedicine in comparison to usual care.</p> <p>The studies included in the review covered a broad range of clinical conditions, including cardiovascular disease, diabetes, respiratory conditions, mental health and conditions requiring a specialist. Telemedicine was used for either remote monitoring or real-time videoconferencing.</p> <p>In terms of health outcomes, studies examining patients with heart failure found a broad range of impact of telemedicine. Hospital admissions ranged from a relative decrease of 64% to an increase of 60%, and authors note that this variation may be partially due to the varying severity of disease among participants. Patients engaged with telemedicine reported an improvement in quality of life. Among patients with diabetes, there was evidence that clinical outcomes such as blood pressure and cholesterol improved among patients engaged with telemedicine. Patients with mental health or substance abuse problems reported cost savings when engaged with telemedicine, but did not report differences in treatment effects.</p> <p>While the reporting of costs varied widely among studies, a number of studies reported a decrease in cost among patients receiving telemedicine care. Decreased costs were observed in follow-up care and hospital admission charges. Ten studies found no difference in cost between telemedicine groups and usual care groups. Five studies reported an increase in costs when using telemedicine, and this may have been partially due to travel costs of healthcare professionals or intervention cost.</p> <p>As telemedicine evolves, updated research is essential. The effectiveness of this tool must be assessed in a range of contexts, and future research should build on promising evidence to further develop this field of study.</p>	2013	11/11 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/93	0/93
	Examining the effectiveness of distance management	The review examined six randomized controlled trials in order to examine the effectiveness of distance management among adults with IBD. These studies compared outcomes of distance management and	2013	10/11 (AMSTAR rating from	0/6	0/6	6/6

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
	on outcomes among adults with inflammatory bowel disease (69)	<p>standard clinic follow-up care. The primary outcome of interest was the quality of life of patients, with secondary outcomes being relapse rate, the number of clinic visits by a patient in a year and hospital admission rates.</p> <p>All studies included in the review demonstrated positive effects of distance management on quality of life among patients with inflammatory bowel disease. While these results were not statistically significant, the authors note that any improvement in quality of life may be important. The improvements on quality of life varied depending on the mode of distance management, with the ulcerative colitis home-management system yielding significantly improved scores. The authors of this review speculate that this improvement may have been due to the interactive nature of this system, or due to the baseline characteristics of participants.</p> <p>There was a decrease in clinic visits by patients across studies. However, telemedicine still requires a time commitment from health professionals. There were conflicting findings on relapse rates, with one study reporting increased relapse rates among patients engaged with distance management, and others reporting insignificant difference between groups. These differences may be due to varying definitions of “relapse”. There was no difference in hospital readmission rates between groups.</p> <p>The use of distance management was found to have significant effects on clinic visits, as patients with IBD used these services less. There were no statistically significant impacts on the other outcomes of interest. Future studies should explore the different types of distance management and how these methods can help specific groups of patients.</p>		McMaster Health Forum)			
	Examining the evidence on telemedicine in the management of patients with IBD (70)	<p>The review examined 16 studies in order to evaluate the evidence on telemedicine in the management of patients with IBD. Most studies examined either tele-monitoring (home systems or online portals) or telecare (real-time phone use and images) as applications of telemedicine. Outcomes of interest included feasibility and acceptance, adherence, quality of life, and patient knowledge.</p> <p>In terms of tele-monitoring, one study found that the use of this system among patients with IBD was highly feasible and acceptable. The implementation of a web-based tele-management system was</p>	2014	3/10 (AMSTAR rating from McMaster Health Forum)	Not reported in detail	0/16	16/16



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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		<p>found to be cost effective in another study, where improvements were also seen in quality of life, disease activity and disease knowledge. Other studies examined the development of tele-consulting systems which bridged the communication gap between patients and healthcare professionals. Acceptance and satisfaction with this method of care was high among patients. Telemedicine demonstrated a range of other benefits, including cost-effectiveness, patient empowerment and treatment adherence.</p> <p>While there are a range of advantages to the implementation of telemedicine, there are a number of barriers as well. Lack of confidence and knowledge pose obstacles, and initial cost of installation may be high. Some systems may pose difficulties to users initially – training must be given to patients. Taken together, tele-monitoring and tele-consulting are highly effective and accepted methods of care among patients, which can be used to monitor disease activity among persons with IBD. Future studies must evaluate efficacy among larger sample sizes, taking financial impact into account.</p>					
	<p>Evaluating the outcomes of internet-based eHealth technology in the field of gastroenterology (71)</p>	<p>The review examined 17 studies in order to evaluate the outcomes of internet-based eHealth technology in the field of gastroenterology.</p> <p>Two trends in eHealth studies were found by the review: eHealth studies examining gastrointestinal symptoms and mental health; and eHealth studies in disease management.</p> <p>Seven studies examined eHealth interventions in relation to gastrointestinal symptoms and mental health, with six studies examining irritable bowel syndrome and one study examining IBD. Among patients with IBS significant improvements in quality of life and symptoms were observed. Among the adolescent IBD group, there were no significant differences between intervention and control groups, with the exception of parent-reported approach on the pain coping questionnaire. Within the intervention group, there was a significant reduction in somatic symptoms. However, the intervention was still found to be beneficial.</p> <p>Eight studies examined eHealth interventions targeting disease management, with seven studies evaluating IBD and one study evaluating celiac disease. Studies examined a range of disease management techniques including the monitoring of disease activity,</p>	<p>2013</p>	<p>7/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>0/17</p>	<p>0/17</p>	<p>8/17</p>

Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		<p>treatment adherence, diet adherence and overall management. In two studies, the intervention group had significantly improved disease knowledge and compliance with both treatment and diet. Participants reported satisfaction, acceptance of eHealth, improved quality of life, knowledge, adherence and reduced costs.</p> <p>The findings of the review indicate that eHealth may be a potentially strong tool in the field of gastroenterology. Participants reported positive outcomes following engagement with this technology. However, future research is needed to identify appropriate treatment forms and factors affecting engagement and success.</p>					
	<p>Evaluating the impact of electronic technologies on the management of patients with IBD (58)</p>	<p>The review examined 17 studies in order to evaluate the impact of eHealth technologies on the management of patients with IBD. Results of interest were clinical outcomes and patient-reported outcome measures, effectiveness, cost-effectiveness and feasibility of self-management, and recommendations for future design and use.</p> <p>Electronic interventions were found to have an impact on disease activity, but the authors note that disease sub-type and severity were important factors on activity. The majority of studies focused on patients with ulcerative colitis, which may have had an impact on clinical outcomes as Crohn's disease is more complex.</p> <p>The review found that patient-reported quality of life improved after the use of web-based interventions. The extent of the impact depends on a number of factors, potentially including culture, disease sub-type, and baseline quality of life among patients.</p> <p>The eHealth interventions examined by the studies in this review were found to sometimes increase healthcare costs. Future research must encapsulate both the direct and indirect costs of this form of care.</p> <p>Electronic interventions often rely on self-reported data, therefore feasibility and accuracy are sometimes called into question. However, the review found that while patient knowledge is an important factor in accurate reporting, the strength of qualitative data may overcome these limitations.</p> <p>There is strong evidence to suggest that eHealth interventions have a positive impact on patient behaviour, knowledge, self-management and clinical outcomes. Success relies on adherence. Therefore,</p>	<p>2015</p>	<p>7/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>1/17</p>	<p>0/17</p>	<p>17/17</p>

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Element	Focus of systematic review	Key findings	Year of last search	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada	Proportion of studies that deal explicitly with one of the prioritized groups	Proportion of studies that focused on IBD
		<p>interventions should be designed with this in mind. The authors of this review suggest the development and application of a standardized framework for the design of eHealth solutions. Future research should focus on understanding limitations to design and developing a framework that integrates a range of factors, while keeping patients engaged and involved.</p>					
<p>Create clinics to address multiple chronic conditions</p>	<p>Evaluating patient-initiated clinics in secondary care (72)</p>	<p>The review examined seven studies in order to evaluate patient-initiated clinics compared to traditional consultant-led clinics in secondary care. Studies examined included patients with breast cancer, IBD, or rheumatoid arthritis. Patient reported outcomes of interest included psychological outcomes, health-related quality of life and satisfaction.</p> <p>Three studies examined patients with IBD. Among these studies, there were mixed outcomes of psychological measures and health-related quality of life. In one study, people engaged with a patient-initiated clinic had improved mental health scores at 12 months versus the control group. However, another study demonstrated better scores among the control group at 24 months. Similar conflicting results over time were found for the general health perception of patients with IBD. One study found that patients in the intervention group changed the way they thought about and managed their disease and their healthcare professional.</p> <p>Among all disease groups, the best outcomes were seen when patients had positive relationships with their consultant. Positive relationships yielded higher satisfaction. Patient-initiated clinics are effective when patients are able to identify a clinical problem, thus they are appropriate in the current diseases under study. Future research should explore other disease models and address the safety, effectiveness and efficiency of the implementation of these clinics.</p>	<p>2013</p>	<p>9/10 (AMSTAR rating from McMaster Health Forum)</p>	<p>Not reported in detail</p>	<p>0/7</p>	<p>3/7</p>



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