

Panels Summary

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

14 September & 12 October 2018



McMaster
HEALTH FORUM



EVIDENCE >> INSIGHT >> ACTION

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

McMaster Health Forum

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

About citizen panels

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

About this summary

On the 14th of September and 12th of October 2018, the McMaster Health Forum convened citizen panels on reducing emergency-department usage in people with inflammatory bowel disease in provincial health systems in Canada. This summary highlights the views and experiences of panellists about:

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

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among panellists and (where possible) identifies the values underlying different positions.

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Summary of the panels

Panellists identified six challenges related to living with (and caring for people with) inflammatory bowel disease (IBD): 1) stigma associated with IBD exists at both the individual and societal levels; 2) there is limited understanding about IBD among the general public and health professionals; 3) patients experience inconsistent and multiple diagnoses before being diagnosed with IBD; 4) patients have trouble accessing primary and specialist care; 5) emergency departments do not have adequate facilities and supports for IBD patients; and 6) there are significant costs associated with the sub-optimal management of the condition.

In discussing the elements of a potentially comprehensive approach to address the problem, panellists expressed the desire to empower patients to better manage their IBD (element 1). To achieve this, they called for greater access to reliable and trustworthy sources of information and to patient-held records that include information on IBD (including the latest evidence on treatment options and decision aids) and a repository of diagnostic results. Most panellists were skeptical about the capacity to help current primary-care and emergency-department staff better support IBD patients during flares (element 2). When discussing alternative ways for specialists to support patients during IBD flares (element 3), panellists supported the use of remote consultations (by email, telephone or web-based platforms) with an IBD care team as an option for those living in rural and remote communities, but also for those experiencing an IBD flare who may not be physically able to attend an in-person consultation.

Panellists identified the lack of timely access to specialist care and the variations across regions in access to specialist care as the most fundamental obstacles to timely diagnosis and to reducing the use of emergency departments. The limited visibility of (and perceived lack of an advocacy coalition) of IBD organizations at the national level was also identified as a key obstacle to raising public awareness about IBD. In discussing potential strategies to move forward, panellists emphasized the need to empower patients to be able to self-manage and to become strong advocates for their care and system changes. Panellists also proposed a reframing of the conversation from IBD to auto-immune conditions more broadly would help to raise public awareness and get the attention of key decision-makers.



“It’s a long road from misdiagnoses to correct diagnosis.”

Discussing the problem:

Why is it challenging to reduce emergency-department use by people with IBD?

During the deliberation about the problem, citizens were asked to share what they perceived to be the main challenges contributing 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: 1) getting a timely diagnosis; 2) managing their IBD; 3) accessing timely and appropriate specialty care; and 4) accessing urgent care.

They individually and collectively focused on the following six challenges:

- stigma associated with IBD exists at both the individual and societal levels;
- there is limited understanding about IBD among the general public and health professionals;
- patients experience inconsistent and multiple diagnoses before being diagnosed with IBD;

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- patients have trouble accessing primary and specialist care;
- emergency departments do not have adequate facilities and supports for IBD patients; and
- there are significant costs associated with the sub-optimal management of the condition.

We review each of these challenges in turn below.

Stigma associated with IBD exists at both the individual and societal levels

Most panellists indicated that they experienced stigma associated with IBD. They highlighted that stigma was perceived at both the individual and societal levels, and suggested that stigma affected the decisions of people with IBD to talk about their symptoms and seek care.

At the individual level, panellists indicated that the stigma associated with IBD had an impact on their intimate relationships, but also their social, academic and professional lives. They shared that they were often unable to attend social events and if they did, they often needed special accommodations (which exacerbated the perception that they were a burden). They also described stigma in the workplace and difficulties with maintaining employment. Some panellists recounted co-workers questioning their frequent use of the washroom or numerous medical

Box 1: Key features of the citizen panels

The citizen panels about reducing emergency-department use by people with IBD had the following 11 features:

1. they addressed a high-priority issue in Canada;
2. they provided an opportunity to discuss different features of the problem;
3. they provided an opportunity to discuss three elements of an approach for addressing the problem;
4. they provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. they provided an opportunity to talk about who might do what differently;
6. they were informed by a pre-circulated, plain-language brief;
7. they involved a facilitator to assist with the discussions;
8. they brought together citizens affected by the problem or by future decisions related to the problem;
9. they aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. they aimed for open and frank discussions that will preserve the anonymity of panellists; and
11. they aimed to find both common ground and differences of opinions.

appointments (some implying that they were suffering from an eating disorder or drug addiction). In some instances, panellists lost their job because their employers claimed that their condition affected their performance. Thus, given the nature of IBD symptoms, most people were not comfortable discussing their condition, which often led to social isolation. Many panellists indicated that they felt ‘on their own’. This situation could contribute to anxiety and depression among people living with IBD. As one panellist said, “you get sick and tired of being sick and tired.” As a second panellist said, “we hide because we are embarrassed. I prefer to suffer in silence.”

At the societal level, panellists said they felt there was a general lack of public awareness about IBD and general confusion with irritable bowel syndrome (IBS). As one panellist said, “IBS has done a disservice to IBD. [...] They are apples and oranges, but people out there don’t know the difference and they don’t take us seriously.” 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.

There is limited understanding about IBD among the general public and health professionals

The discussion then focused on the limited understanding (among the general public and health professionals) about the causes of IBD and new treatment options. Most panellists shared concerns about the prevalence of IBD in Canada and the limited understanding of the factors that may cause the condition (including genetics, environmental factors and geographic location). Panellists noted they were concerned that the limited understanding of the causes of IBD may reduce the ability to appropriately manage their condition.

All panellists expressed concerns that health professionals had limited understanding and experience with IBD (in both primary-care and emergency-department settings). This was identified as a significant obstacle to timely diagnosis and optimal management of IBD.

In elaborating on these concerns, panellists shared experiences with physicians not prescribing treatment options, such as biological therapies, that were best suited to their condition and that aligned with the best available research evidence. Others voiced challenges related to the types of dietary advice received by dietitians who are unfamiliar with how to manage flares. As one panellist pointed out, “we have access to [dietitians] but

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they don't have the IBD experience. They give you [advice based on the] Canada Food Guide, not IBD-related help." Panellists indicated they were concerned that professionals lacked evidence-based training and protocols to deal with IBD.

They also indicated that health professionals in urgent-care centres and emergency departments had a limited understanding about IBD, which was particularly challenging during IBD flares. Some panellists indicated that they favoured emergency departments over urgent-care centres because many had experiences with being referred from urgent-care centres to emergency departments. As one panellist said, "urgent-care centres will just send you to the hospital because they don't know how to handle it." Others emphasized that the lack of understanding about IBD was frequent in emergency departments. Many panellists reported problems with triage within emergency departments, particularly when staff were not recognizing the severity of their symptoms, which led to long and painful wait times.

These experiences fuelled a lack of confidence in health professionals and the system more broadly. Thus, many panellists said they felt that they need to be their own advocates and have learned by experience to be much more direct, telling primary-care providers and emergency-department staff the care they need. However, many panellists noted that they lacked trusted information sources about IBD (both about the causes of IBD and new treatment options) and were unsure where to look for reliable information. This limited their capacity to play an active role in their own care. Several panellists indicated that they received very limited information (if any at all) from their health professionals: "They send you home with nothing, not even a handout." Panellists were forced to look for information on their own. Most panellists said they were not familiar with existing information sources (including Crohn's and Colitis Canada's website, webinars, brochures, etc.), despite their relevance to them. One panellist indicated that getting information was important, but it was essential that this information be applicable to their individual care: "[It's about] knowing what works for you and what doesn't." Panellists also described having limited connections with their peers and/or support networks, with the exception of one panellist who had extensive experience with a local Crohn's and Colitis Canada chapter.

Patients experience inconsistent and multiple diagnoses before being diagnosed with IBD

The majority of panellists expressed deep frustration with the process of getting an IBD diagnosis, as well as challenges with multiple misdiagnoses. As one panellist put it, “it’s a long road from misdiagnoses to correct diagnosis.”

The experiences shared by panellists ranged from misdiagnoses (for example, appendicitis and gastroenteritis) to inconsistent diagnoses (between Crohn’s disease and ulcerative colitis) and lack of diagnostic certainty (for example, due to limitations in endoscopy), all of which led to delays in receiving appropriate care for their condition.

Some panellists described being dismissed by their primary-care provider when presenting with significant symptoms, or experiences with their child’s symptoms not being taken seriously. One example included primary-care providers dismissing significant energy and weight loss as a normal process of growing up, without ordering diagnostic tests.

The long process of getting to the right diagnosis was highlighted by panellists as a source of frustration, which they also indicated led to increased levels of anxiety and stress, and an overall distrust of health professionals’ ability to manage IBD. A number of panellists

Box 2: Profile of panellists

The citizen panels aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panellists:

- **How many panellists?**
Saskatoon panel (10) and Hamilton panel (13)
- **Where were they from?**
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)
- **How old were they?**
25-34 (2), 35-49 (5), 50-64 (9), 65 and older (7)
- **Were they men, or women?**
Men (8) and women (15)
- **Were they living in urban, suburban or rural settings?**
Urban (10), suburban (8), and rural (5)
- **What was the perspective of panellists?**
Diagnosed and living with IBD (13)
Member of their family living with IBD/or caregiver for someone with IBD (10)
- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panel

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reported that these feelings persisted for years after their diagnosis. As one caregiver indicated, “my son was diagnosed with Crohn’s at a young age. He has been symptom free for four years, but each time I get a call from him, I worry he got a relapse.”

Patients have trouble accessing primary and specialist care

Many panellists expressed frustrations with the lack of access to both primary care and care provided by specialists. Starting with primary care, many panellists discussed challenges in their region in terms of primary-care physician shortages, which is troublesome given their role as gatekeepers to specialists.

Turning to specialist care, 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 roster. However, panellists felt this was an inefficient use of resources and not an effective approach given the unpredictable nature of IBD symptoms. As one panellist indicated, “I can’t call up my GI [gastroenterologist]. I’d go to my family doc and try the never ending ‘*try this or try that*.’” A second panellist highlighted that, in his jurisdiction, access to the gastroenterologist is based on pre-scheduled semi-annual visits: “In Quebec, we need to see our GP before seeing the GI, even if we have a prior relationship with that GI. The loophole is that I asked to book appointments with my GI every six months.” Without such regular appointments, you will be ‘dropped’ from the list of patients seen by the gastroenterologist and require a new referral from your primary-care provider.

Many panellists also expressed concerns with the general shortage of gastroenterologists in Canada, but also with the regional variations in access to specialist care (including gastroenterologists and IBD nurses, as well as surgeons with IBD experience). For example, some panellists from Prince Edward Island expressed concerns with having only one gastroenterologist in their province. Yet, despite the shortage of specialists, panellists from P.E.I. indicated that they had a close bond with (and flexible access to) their GI: “[My GI said] you contact me when you need to see me.”

The majority of panellists indicated that, within specialty care, 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, dietitians, social workers, psychologists and others). Some panellists referred to this type of care team as a “dream team.” When discussing what other professionals should be included as part of the IBD care team, panellists indicated that pharmacists, surgeons and peers with IBD (for example, local support groups) should be included. As one panellist indicated, people with IBD must find ways to build their own IBD care team: “In this era of specialization, there’s not one [person] that can help you with everything.” The idea of having an actual team also appeared to resonate with some panellists who indicated that the frequent staff turnovers in primary-care settings and emergency-departments often created gaps in information. It also made it more difficult for people with IBD to establish a personal bond with their health professionals (who could then become an advocate for them). Emphasizing the importance of having close relationship with their care team, one panellist said, “my regional hospital is so small that everybody knows each other. That’s the beauty of small communities. I know it can’t be replicated in Toronto, but it could be replicated in other communities across Canada. In the tertiary care [sector], it’s a revolving door of new GIs and new residents every day.”

Emergency departments do not have adequate facilities and supports for IBD patients

Panellists shared their negative experiences with emergency departments and categorized their experiences in two distinct phases: pre-diagnosis and post-diagnosis.

The pre-diagnosis phase was described by many panellists as a very scary period in which they had repeated visits to emergency departments without being able to obtain proper care. These repeated visits were attributable to severe, long-lasting symptoms (for example, significant weight loss, intense abdominal pain, and blood in the stools), the lack of diagnosis to explain those symptoms, the inability of primary-care physicians to provide adequate support, and the pain, anxiety and fear experienced by patients.

In the post-diagnosis phase, although they were by then becoming more knowledgeable about their condition, panellists shared their frustrations with the inadequate supports provided to them by both primary-care providers and emergency-department staff. Many explicitly mentioned that they preferred avoiding the emergency department during IBD flares, unless they felt the situation to be critical. Panellists gave four reasons why they avoided emergency departments and considered them the last resort: 1) inappropriate

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facilities for someone experiencing an IBD flare (for example, only one bathroom in a crowded waiting room); 2) long wait times to be admitted and receive the needed interventions (for example, fluids and pain management); 3) inappropriate interventions; and 4) the loss of control over diet once admitted. As one panellist with Crohn's disease indicated, "once you're diagnosed with Crohn's, you tend to avoid ERs [emergency departments] unless necessary. Your routine is in place. You know when to go."

Many panellists indicated that they preferred the relative comfort and privacy of their own home (or bathroom) when experiencing a flare. They also emphasized that they are generally unable to move during an IBD flare (and thus unable to go on their own to the emergency department to wait for hours to receive care). As one panellist said, "when you're on a toilet [with] a garbage can, you can be there for hours. I just ride it for a few days at home because all they do is give you a shot for the pain." This resonated with a second panellist: "You take your blanket and your pillow, and you sleep on the floor of the bathroom."

There are significant costs associated with the sub-optimal management of IBD

Many panellists voiced their concern that the delivery of care is not optimal for IBD, which can lead to increased costs to the health systems, as well as out-of-pocket costs for patients. At the patient level, the high cost of biological therapies was listed as a significant barrier to managing IBD. Panellists also noted the high out-of-pocket costs for food in order to meet dietary restrictions. In addition, a number of 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.



“Self-care and self-management are the most constructive and best ways to go.”

Discussing the elements:

How can we address the problem?

After discussing the challenges that together constitute the problem, panellists were invited to reflect on three elements of a potentially comprehensive approach to reduce emergency-department use by people with IBD:

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

The three elements can be pursued together or in sequence. A description of these elements, along with a summary of the research evidence about them, was provided to panellists in the citizen brief that was circulated before the event.

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

The discussion about the first element focused on ways to support patients to play a more active role in managing their condition. As outlined in the citizen brief, this could include strategies to enable people with IBD to self-manage their condition, such as:

- providing educational materials for persons living with IBD;
- introducing in-person support to enhance their capacity for self-management; and
- providing electronic tools that can support self-management (for example, smartphone or computer applications allowing individuals with IBD to track information about their health, symptoms, medications, food and exercise, or applications allowing continuous home monitoring).

Box 3: Values-related themes about supporting patients to play a more active role in managing their condition (element 1)

Four values-related themes emerged across both panels during the discussion about element 1:

- empowerment of patients to better manage their IBD;
- competence of patients to manage their IBD;
- trusting relationships between patients and the health professionals and organizations within the system; and
- appropriateness/convenience of tools that enable self-management.

Of the three elements under discussion, element 1 was the one that resonated the most with panellists. Four values-related themes emerged during the deliberations about element 1 across both panels: 1) empowerment of patients to better manage their IBD; 2) competence of patients to manage their IBD; 3) trusting relationships between patients and the health professionals and organizations within the system; and 4) appropriateness/convenience of tools that enable self-management.

Element 1 was consistent with the desire described by panellists to empower patients to better manage their IBD (which was the first values-related theme to emerge), and also with the perception that they have the competence to manage their IBD (the second values-related theme). One panellist summarized this point as, “self-care and self-management are

the most constructive and best ways to go.” A second panellist agreed saying, “I want to learn how to be more proactive, to take care of myself.” Two strategies were proposed to better empower patients and develop their self-management competencies: 1) establishing peer supports; and 2) creating opportunities for one-on-one consults with health professionals trained to provide IBD care. Some panellists saw great value in engaging peers with lived experiences who could provide targeted training (for example, training about ileostomy care as well as training people with IBD to develop a proper language to communicate complex and sensitive issues). The importance of developing a common language was highlighted by a panellist who stated, “most people in the ER are in pain and angry. They don’t know what you have. People can’t tell you what’s wrong. [We must find a way to develop] a common language, and accurately engage patients when they are in pain. We have a personal responsibility to not just be sick and upset, but to be working in partnership with the care team.”

Regarding the third values-related theme, panellists highlighted the need to develop and strengthen more trusting relationships between patients and the health professionals and organizations within the system. As mentioned earlier, many panellists had negative experiences with multiple and inconsistent diagnoses and with getting timely access to optimal care during flares. These negative experiences have fuelled distrust in the capacity of the system to meet their potential needs, and the perception that patients are sometimes best positioned to take care of themselves. Since it can take a long time to restore trusting relationships, panellists emphasized the need to enhance access to reliable and trusted sources of information (including pamphlets in primary-care clinics and emergency departments, websites and/or 1-800 numbers). They indicated that they envisioned the use of patient-held records (either digital records or physical binders), which would include information on IBD, including the latest evidence on treatment options and decision aids, and provide a repository for diagnostic results. These patient-held records could help them when they seek care from a primary-care setting or emergency department.

Panellists had mixed views regarding the appropriateness and convenience of electronic tools (for example, downloadable apps for mobiles) to support self-management - which related to the fourth values-related theme to emerge. Some panellists saw these electronic tools as a great opportunity to monitor their health in real time, with one panellist suggesting that it would be helpful to have “an external set of eyes that could see patterns in the data that you don’t see.” These electronic tools could also be quite useful when people with IBD meet their specialists, as noted by one panellist: “If you see your GI every six

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months, how can you remember everything that happened. You need a way to document and monitor things. This is information that you can take to your doctor.”

However, most panellists remained skeptical about the use of electronic tools for six reasons: 1) there is a generational gap in using electronic tools (and the learning curve required to effectively use these apps may be steep for older adults); 2) there are concerns about the confidentiality and security of the information being shared; 3) there is uncertainty whether there would be someone competent on the ‘receiving end’ to analyze and appropriately respond to the data; 4) health professionals may be reluctant to adopt these tools; 5) some users may have limited internet access (or limited data packages); and 6) users may not be well enough to use these apps during flares (“when you have cramps, your eyes are crossed.”)

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

The discussion about the second element focused on helping professionals working in primary-care settings and emergency departments to better support patients during IBD flares. As outlined in the citizen brief, this could include:

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

Box 4: Values-related themes about helping primary-care and emergency-department staff better support patients during IBD flares (element 2)

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

- trusting relationships between patients and the health professionals and organizations within the system; and
- competence of professionals in primary-care settings and emergency-departments.

Of the three elements under discussion, element 2 was the one that resonated the least with panellists. Two values-related themes emerged during the deliberations about element 2 across both panels: 1) trusting relationships between patients, health professionals and organizations within the system; and 2) competence of professionals in primary-care settings and emergency departments.

Most panellists were skeptical about the health system's capacity to help current professionals in primary-care settings and emergency departments better support IBD patients during flares. Again, the negative experiences mentioned earlier (for example, getting multiple and inconsistent diagnoses, and difficulties in timely access to optimal care

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during flares) have fuelled distrust in the system's ability to meet their needs (which was related to the first values-related theme for element 2), and the competence of primary-care and emergency-department staff to care for people with IBD (which was related to the second values-related theme for element 2). As one panellist highlighted, "it's bitter experience speaking here."

Yet, panellists could envision ways to improve competencies, such as introducing educational programs for new health professionals that integrate material focused on IBD, and creating 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). They also believed that newly diagnosed IBD patients should be automatically connected with an IBD nurse or a patient navigator (for example, someone living with IBD who is available either in-person or by telephone). The IBD nurse or patient navigator could then use a checklist to ensure that all the patients' information and care needs are met (for example, making referrals or contacting a local IBD group to obtain peer support).

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

The discussion about the third element focused on providing alternative ways for specialists to support patients during IBD flares, which could reduce unnecessary emergency-department use. As outlined in the citizen brief, this could include:

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

Box 5: Values-related themes about providing ways for specialists to support patients during IBD flares (element 3)

Three values-related themes emerged across both panels during the discussion about element 3:

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

Three values-related themes emerged during the deliberations about element 3 across both panels: 1) fairness/equity; 2) trusting relationships between patients and health professionals; and 3) collaboration among patients, health professionals and organizations within the health system

Issues related to fairness and equity (which was the first values-related theme related to element 3) were discussed at length by panellists, who worried about the lack of access to specialist care for those living in rural and remote communities. Panellists were in favour of the use of remote consultations (for example, by email, telephone or web-based platforms) with an IBD care team as an option for those living in rural and remote communities, but also for those experiencing an IBD flare who may not be physically able to attend an in-person consultation. They also supported the idea of introducing mobile diagnostic clinics (similar to mobile clinics for breast cancer screening) to ensure access to IBD diagnostic

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services in underserved areas (while also raising awareness and providing education). Some panellists also envisioned a national, 24/7 specialty team accessible via email, telephone or web-based platforms, which could provide care and support for patients during IBD flares.

Regarding the second values-related theme (trusting relationships), some panellists did not think that sufficient trust could be developed in the proposal of creating urgent-care clinics focused on supporting gastrointestinal care. Although they appreciated the idea of having timely access to specialized care, several panellists indicated that they did not trust that an ‘urgent-care clinic’ model could effectively support patients during IBD flares. This lack of trust was based on poor care experiences with traditional urgent-care centres that can be found across the country (and that are not specialized in gastrointestinal care). Yet, panellists supported the idea of creating clinics for patients with multiple chronic conditions. Such clinics appeared like a novel idea that was possibly relevant given that many patients with IBD have more than one chronic condition.

Lastly, regarding the third values-related theme (collaboration among patients, professionals and organizations), panellists emphasized the need for greater collaboration among health professionals who could support patients during IBD flares (including some professionals who are not part of the IBD care team as described in the citizen brief). For instance, panellists discussed the need to expand the roles of paramedics and pharmacists to support patients during IBD flares. Given the mobility limitations of patients experiencing IBD flares, panellists proposed to expand paramedics’ scope of practice to include providing home-based care for pain management during flares. They also proposed creating 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.



“[Stigma is] huge. It delays people seeking care and getting a diagnosis.”

Discussing implementation considerations:

What are the potential barriers and facilitators to implementing these elements?

After discussing the three elements of a potentially comprehensive approach to reduce emergency-department use by people with IBD, panellists examined potential barriers and facilitators to moving forward. Panellists identified the lack of timely access to specialist care and the variations across regions in access to specialist care as the most fundamental obstacles to timely diagnosis and to reducing the use of emergency departments. The limited visibility of (and perceived lack of an advocacy coalition) of IBD organizations at the national level was also identified as a key obstacle to raising public awareness about IBD. Panellists also emphasized the significant challenge of stigma associated with IBD. As one panellist indicated, “[stigma is] huge. It delays people seeking care and getting a diagnosis.”

When turning to potential facilitators to moving forward, panellists emphasized that patients are increasingly willing to self-manage their condition, as well as to become strong advocates for themselves and for system changes. As one panellist said, “[people with IBD must also become] informed citizens that can have conversations with our MPs [members of parliament] and decision-makers. It has probably never been brought to their attention

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before.” Panellists also proposed a reframing of the conversation from IBD to auto-immune conditions more broadly would help to raise public awareness and get the attention of key decision-makers. As one panellist indicated, “auto-immune diseases are out there and can affect everyone, at any age.” This strategy could help to change the conversation about IBD by broadening the scope of the conversation, which may help to raise public awareness and get the attention of those in and around government.

Acknowledgments

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the panels summary. The members of the IMAGINE SPOR Network reviewed a draft of the panels summary, but the authors had final decision-making authority about what appeared in the panels summary.

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