

Dialogue Summary

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

22 November 2018



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**Dialogue Summary:
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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 the 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.

Authors

Cristina A. Mattison, PhD, Scientific Lead, Stakeholder Engagement and Systems Analysis,
McMaster Health Forum

Kaelan A. Moat, PhD, Managing Director, McMaster Health Forum

John N. Lavis, MD PhD, Director, McMaster Health Forum, and Professor, McMaster University

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Conflict of interest

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Table of Contents

SUMMARY OF THE DIALOGUE4

SUMMARIES OF THE FOUR DELIBERATIONS.....5

 DELIBERATION ABOUT THE PROBLEM5

 DELIBERATION ABOUT THE ELEMENTS OF A POTENTIALLY COMPREHENSIVE
 APPROACH.....8

 Element 1 – Enable self-management of IBD through better supports for patients.....8

 Element 2 – Strengthen primary care and emergency-department care of IBD and improve
 connections to specialty care9

 Element 3 – Introduce comprehensive alternative-service options for IBD specialty care10

 Considering the full array of elements11

 DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS12

 DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES.....12

SUMMARY OF THE DIALOGUE

Dialogue participants agreed on the importance of the issue and the general framing of the problem in the evidence brief. A number of participants questioned whether the title was optimally worded since it problematized the issue of emergency-department usage among those with inflammatory bowel disease (IBD), and some participants suggested a more positive framing and title. Overall, most participants agreed that while there isn't one framing of the issue that will get traction with all concerned policymakers, stakeholders and researchers, it is important to acknowledge that slight variations in how dimensions of the issue are framed – including the title – may need to be considered, depending on who is being engaged to discuss the issue. While generally agreeing with the specific contributions to the problem, participants emphasized and focused their discussion on four distinct aspects of the problem that exist: 1) patients face knowledge gaps and unhelpful perceptions of emergency departments as the default option; 2) providers lack strong connections and face challenges in adhering to 'one-size-fits-all' guidelines; 3) delivery and financial arrangements hinder integrated care; and 4) lack of system-wide leadership, coordination and action.

Dialogue participants supported the three elements of a potentially comprehensive approach to reducing emergency-department use in people with IBD as identified in the evidence brief: 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. Participants particularly emphasized element 1 and the role of an IBD care team in enhancing the capacity for self-management (e.g., mental health supports and system navigation) and supporting comprehensive IBD specialty care. Participants also looked to other chronic diseases when deliberating about ways to increase supports from health professionals (e.g., diabetes self-management education and support) and to introduce comprehensive alternative-service options for IBD care in element 3 (e.g., INSPIRED scale collaborative to reduce emergency-department visits and hospital admissions and stays for chronic obstructive pulmonary disease).

In deliberating on how to move forward with these elements, participants identified six overarching principles to guide efforts to reduce emergency-department use among IBD patients in provincial health systems in Canada: 1) leverage existing IBD-related initiatives to help get farther, faster; 2) strengthen collaborations and networks among key players within and across jurisdictions who can also help to raise the profile of IBD among others in health systems; 3) framing issues in ways that are more likely to garner support among policymakers; 4) position IBD as a 'way in' to broader system transformation; 5) consider system-level innovations that could have broad impacts; and 6) clarify roles among key players to establish clear goals to be achieved in the short, medium and long term.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Participants all agreed on the importance of the issue and the general framing of the problem in the evidence brief. However, as an overarching consideration, a number of participants questioned whether the title was optimally worded since it problematized the issue of emergency-department usage among those with IBD, despite the fact that in some cases this is the most appropriate care pathway for patients – particularly among those in the midst of an acute flare. Some participants suggested a more positive framing and title, such as ‘optimizing emergency-department usage’ would be more appropriate. In contrast, some participants noted that while the positive framing resonated with them, it may not be the most effective way of getting an issue on the radar to spark action among policymakers, who are more likely to feel compelled to act when something is positioned as a problem that needs to be addressed to improve patient care (and reduce unnecessary use of resources). Some participants even suggested that the positive framing of ‘optimizing’ may be viewed among some policymakers and stakeholders as suggesting the need for more use of emergency departments, which may end up discouraging them to act on the many challenges outlined in the brief. Overall, most participants agreed that while there isn’t one framing of the issue that will get traction with all concerned policymakers, stakeholders and researchers, it is important to acknowledge that slight variations in how dimensions of the issue are framed – including the title – may need to be considered, depending on who is being engaged to discuss the issue.

Throughout the deliberation about the problem – and despite the discussions about whether a positive or problematized framing of the issue was most appropriate – participants raised a number of reasons to justify why reducing emergency-department visits among patients with IBD is important. These include:

- patients receiving fragmented care that doesn’t align with the approaches preferred (or planned for) by their gastroenterologist;
- patients being tested unnecessarily; and
- patients being subjected to overcrowded emergency departments and long wait times, without getting the most appropriate care for their condition.

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

- 1) it addressed an issue currently being faced in Canada;
- 2) it focused on different features of the problem, including (where possible) how it affects particular groups;
- 3) it focused on three elements of a potentially comprehensive approach for addressing the policy issue;
- 4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three approach elements, and key implementation considerations;
- 5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible elements of an approach to addressing it;
- 6) it brought together many parties who would be involved in or affected by future decisions related to the issue;
- 7) it ensured fair representation among policymakers, stakeholders and researchers;
- 8) it engaged a facilitator to assist with the deliberations;
- 9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: “Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed”; and
- 10) it did not aim for consensus.

We did not aim for consensus because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors and others about detailed commitments.

Participants’ views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed 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. The dialogue was also designed 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.

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

More generally, some participants noted that avoiding individuals with chronic conditions (including but not limited to IBD) having to visit an emergency department for their urgent care would have system-wide benefits, including less crowding and shorter wait times for other patients with emergency-care needs.

In considering the main challenges with reducing emergency-department use among IBD patients in Canada, participants identified a number of contributions to the problem. Specifically, it was clear throughout deliberations that most participants agreed with the four presented in the evidence brief:

- 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.

Within the general agreement about these themes, participants emphasized and focused their discussion on the importance of four distinct aspects of the problem:

- 1) patients face knowledge gaps and unhelpful perceptions of emergency departments as the default option;
- 2) providers lack strong connections and face challenges in adhering to ‘one-size-fits-all’ guidelines;
- 3) delivery and financial arrangements hinder integrated care; and
- 4) lack of system-wide leadership, coordination and action.

Many patients face knowledge gaps and unhelpful perceptions of emergency departments as the default option

At the level of patients, participants focused their discussion on two unique challenges. The first challenge related to the point raised in the brief that individuals with IBD lack the necessary knowledge about their condition and how to manage it. Some participants suggested that the lack of knowledge among patients with IBD related to the fact that they aren’t always supported by their care providers (whether in primary- or specialty-care settings) to understand their condition and how to manage it, which negatively affects their ability to appropriately seek urgent care during a flare. In particular, some participants stated that many patients with IBD who present to the emergency department with acute symptoms aren’t able to engage in productive conversations with the health professionals there about what they need. One of the participants in attendance who works in an emergency department confirmed their own experience that, on average, patients with IBD can be a challenge to treat efficiently given the uncertainty they have about their symptoms during a flare, and about their condition more generally. On a related point, other participants noted that while there are a range of educational materials available to educate and support patients with IBD in Canada (e.g., through organizations such as Crohn’s and Colitis Canada and the Gastrointestinal Society/Canadian Society of Intestinal Research), most patients are not aware that these resources are available to them. Some participants noted that this was a key missed opportunity to improve patient knowledge and care. Another participant indicated that their own organization is increasingly receiving calls from patients about treatment options for IBD, despite that type of support extending well beyond their mandate, and for them this was an indication that patients are not being optimally supported with information about IBD management.

The second challenge discussed at the level of patients related to the culture within which IBD patients in Canada are accessing and receiving care. In particular, the following points were raised by participants:

- patients may have unrealistic expectations of the system’s ability to cater to their needs, and as such be unwilling to take a leadership role in managing their condition;
- patients may prefer visiting the emergency department when they are experiencing symptoms indicative of a flare (which could be because they’d rather be safe than sorry, but oftentimes is a reflection of how they’ve grown accustomed to accessing support);
- patients often feel intimidated by the specialists they engage with, which can erode trust, lead to more emergency-department visits, and hamper their ability to gain knowledge about their condition and how it can be managed; and

- the general public lacks awareness of IBD, which can detract from its perceived importance among patients (particularly when compared to other chronic conditions).

Taken together, many participants agreed that these points mean patients are often accessing care in a culture that has set the emergency department as the default option for patients, and isn't conducive to the successful management of IBD.

Providers lack strong connections and face challenges in adhering to 'one-size-fits-all' guidelines

At the level of providers, participants identified two pressing challenges that stand in the way of supporting the optimal management of IBD. The first challenge is that strong connections among healthcare providers are lacking in the treatment of IBD. Some participants stated that this was particularly obvious when comparing networks of specialty-care providers in the gastroenterology field with those in others such as cardiology, where networks are strong. Among participants who agreed with this point, some argued that when networks are strong, patients experience both direct benefits (better care coordination and continuity of care) and indirect benefits arising from their stronger collective identity (others in the system perceiving the care for their patients to be important). The second challenge identified at the level of providers was that, while practice guidelines and quality standards exist for the management of IBD, there are challenges in supporting their use among providers in both primary- and specialty-care settings. Several participants suggested that the complexity of IBD and its symptoms, as well as how patients perceive their own condition, make adopting and following a standardized approach to care a challenge. A number of participants noted that, while practice guidelines and care standards can be helpful, the need for truly patient-oriented care in managing IBD meant that it would never be easy to ensure their widespread adoption.

Delivery and financial arrangements hinder integrated care

In terms of problematic delivery arrangements, some participants stated (and many agreed) that in the delivery of care for IBD patients:

- care pathways are fragmented, referral systems aren't as streamlined as they need to be, and providers practise in siloes within and across sectors (or, as one participant noted, care is accessed and delivered in a "jagged line with many breaks in the chain");
- packages of care rarely emphasize a broad range of supports that could help to keep IBD patients out of emergency departments (e.g., mental health supports), which results in individual providers – often gastroenterologists who aren't always easy for patients to access – to 'put on many hats' when providing care; and
- electronic tools such as interoperable electronic medical records are not easily accessible to patients and providers, and patient data are often incomplete (within and across jurisdictions).

In terms of problematic financial arrangements, some participants noted that in most jurisdictions across Canada, how care is paid for reinforces the delivery-arrangement challenges, since financial arrangements prioritize the remuneration of physicians (rather than a broader range of healthcare providers) and funding of services provided in specialty-care settings (rather than in home- and community-care or in primary-care settings). Most participants agreed that these interrelated health-system challenges would need to be addressed if jurisdictions across Canada wanted to shift towards new models of care that aim to reduce the unnecessary usage of the emergency department among IBD patients.

Lack of system-wide leadership, coordination and action

Finally, at the level of health-system leadership, many participants noted that in most jurisdictions there was a clear lack of leadership related to IBD care. In particular, participants flagged three leadership-related issues that are problematic:

- 1) no strong system-wide vision for how to address unnecessary emergency-department use among patients with IBD;

- 2) little coordination or collaboration among the key players that could drive change within and across health systems in Canada; and
- 3) no priority placed on identifying and using the most compelling language and pursuing efforts to strategically frame the issue to spark action, despite the vital role that these efforts will play in getting traction among policymakers and stakeholders.

Additional considerations about the problem

Overall, while most participants agreed that the many aspects of the problem that were raised during deliberations and outlined above are relevant to different provincial and territorial health systems, there is a tension between discussing broader concepts that apply nationwide, and staying attuned to the unique nature of challenges that exist within each health system. A number of participants pointed out that the challenges manifest themselves in provincial differences across jurisdictions and settings (e.g., urban Manitoba differs from rural Alberta), and suggested that this should be acknowledged.

DELIBERATION ABOUT THE ELEMENTS OF A POTENTIALLY COMPREHENSIVE APPROACH

In deliberating about how to reduce emergency-department use in people with IBD in provincial health systems in Canada, dialogue participants generally agreed with, but offered complementary insights about, the range of elements presented in the evidence brief. These 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.

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

For element 1, participants deliberated about three broad approaches to enable self-management of IBD: 1) provide educational materials to support self-management for persons living with IBD, including knowing when to seek specialist care; 2) increase personal supports from health professionals with experience in IBD to enhance capacity for self-management; and 3) use electronic tools (e.g., apps) to support self-management.

Providing educational materials to support self-management for persons living with IBD

Participants agreed with the importance of providing educational materials to support self-management for persons living with IBD, however, they recognized that there is a lack of clarity around what constitutes self-management due to the complexity of IBD. During the deliberations, participants identified two key approaches in which educational materials can support self-management: 1) information provision about IBD following diagnosis; and 2) a checklist for when to seek specialist care. Regarding the first approach, some participants recognized the need to standardize information and create a provincially approved set of handouts to be made available to patients following diagnosis. The handouts could be created by the main non-governmental and stakeholder organizations involved in IBD and include consistent information with a customizable listing of local resources for patients to seek further supports. One participant raised concerns with non-governmental and stakeholder organizations coming together to create the set of handouts, recognizing that each organization has a unique identity. One example of educational materials was ibdmanitoba.org, which has 16 evidence-informed knowledge pieces (e.g., new biological medicines, corticosteroids and nutrition) that are available for download. An important consideration for providing educational materials to support self-management is that the literacy level of materials should be in accessible language.

Regarding the second approach (a checklist to help individuals understand when symptoms are manageable at home and when to seek specialist care), one participant provided the example of a rapid-access service at the IBD Centre at McGill University. There, patients are provided with a flyer that lists a set of criteria for when they should seek specialist care. If their symptoms meet the criteria, patients send an email to the rapid-access service and are triaged accordingly.

Increasing personal supports from health professionals with experience in IBD

In deliberating about the role of an IBD care team in enhancing capacity for self-management, participants focused primarily on mental-health professionals and IBD nurses. First, participants acknowledged that there is significant variation in terms of patient needs and that supporting mental health is a key component of self-management. Participants noted that while there is a great need for mental health supports, the psychiatric aspects of IBD are not well understood. Several participants shared positive experiences of having a psychiatrist embedded within the IBD unit, but cited funding limitations (e.g., hospital budgets) as a barrier to maintaining the service. Similarly, IBD nurses were viewed as central to supporting self-management and IBD care more broadly, however, due to barriers in funding, they are an exception rather than the rule. IBD nurses were identified by participants as an essential member of the IBD care team and as being well-suited to supporting system navigation and self-management for patients with IBD. Lastly, dietitians were recognized as an important support in the provision of nutrition counselling for improved self-management.

Participants also looked to other chronic diseases when deliberating about ways to increase personal supports from health professionals with experience in IBD. Diabetes self-management education and support was listed as an example that could be applied to the IBD context. Specifically, creating an IBD version of the diabetes educator certificate program for regulated health professionals could strengthen IBD education and build a knowledge base to support IBD self-management programs.

Using electronic tools to support self-management

Participants identified two types of electronic tools to support self-management. The first was the use of telehealth lines (e.g., a 1-800 number) that can provide education and system navigation supports for patients with IBD. Alberta Health Services' Dementia Advice Service was provided as an example of a nurse-led telephone support service available 24/7 for individuals and caregivers living with dementia. The service offers specialized dementia advice, including in-depth assessment. The second electronic tool was the Gi BodyGuard, which is a mobile app that was created by the Canadian Digestive Health Foundation. The app allows IBD symptom tracking and is set for a relaunch.

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

Participants agreed that this element was important to address and that the treatment of IBD is increasingly complex, which requires connections to and management by a gastroenterologist. Deliberation about the element focused on four approaches that could strengthen primary care and emergency-department care of IBD and improve connections to specialty care: 1) patient-care plans; 2) regional call systems for health professionals working in emergency-departments; 3) IBD management guidelines for emergency-department professionals; and 4) improving the interoperability of electronic health records (EHRs).

First, participants highlighted the importance of patients having an individualized care plan. Participants agreed that there is no standard approach to supporting patients with IBD, with each patient having unique needs. A patient-care plan or 'passport' was viewed as a key document that could be used to inform primary care and emergency-department care decisions. This care plan would be created in collaboration with the patient and their gastroenterologist and used by primary-care and emergency-department professionals. The

documentation was seen as a particularly important tool with respect to the opioid crisis and helping primary-care and emergency-department professionals make the best pain-management decisions for their patients.

Second, participants focused on ways to support quick access to specialty-care advice for emergency-department professionals. Some participants had experience with a regional call system, which includes a dedicated gastroenterologist to provide specialist advice to emergency-department physicians. Participants agreed that the approach offers a good ‘first line of defence’, while utilizing existing resources (e.g., gastroenterologists in the region being on call one day a month). The service facilitates streamlined access to a specialist opinion and transfer, if needed. Participants agreed that regional call systems are an example of ‘low-hanging fruit’ that can easily be pursued.

Third, participants looked to existing examples of management guidelines for emergency-department professionals. Posters and protocols for cardiac care, trauma and stroke (e.g., CorHealth Ontario) were recognized as effective examples of efforts to guide emergency-department professionals. Creation of an IBD-specific version was viewed by participants as a tool that could strengthen IBD care in emergency departments. Specifically, creation of a poster that could be used as a quick reference tool was preferred by participants.

Lastly, improving the interoperability of EHRs was raised as an important component of strengthening primary care and emergency-department care of IBD and improving connections to specialty care. Participants focused on two main ways in which interoperable EHRs could strengthen care for IBD. First, participants gave a number of examples of redundancies in performing medical imaging and concerns with the effects of some tests (e.g., radiation risks from multiple CTs). By allowing patients access to their results participants thought it had the potential to help to reduce the number of diagnostic tests performed, and also serve to empower patients to take charge of their care. Second, participants agreed that interoperable EHRs would improve communication between primary care and specialty care. Many participants described barriers to electronic communication of test results and treatment plans from specialty to primary care.

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

For element 3, participants deliberated on ways to support comprehensive IBD specialty care. Similar to element 1, much of the deliberation focused on creating interprofessional IBD care teams that can meet the full range of patient needs. Second, participants looked to existing chronic-disease initiatives for components that can be applied to the IBD-specific context.

Interprofessional care was viewed by participants as central to the provision of comprehensive IBD care. Key members of IBD care teams were identified as gastroenterologists, surgeons, IBD nurses, mental health professionals and dietitians. While participants agreed with the value of IBD care teams, most experienced funding barriers, which results in a highly variable approach. Often the teams consist of a patchwork of health professionals, with challenges to sustained and adequate funding for the roles (e.g., IBD nurses and mental health professionals). Participants emphasized that appropriate resources are needed to support IBD referral centres in particular, and that there are often gaps which can lead to a reliance on private-industry support. Pharmacological supports were provided as an example of private industry filling the gap through nurses working directly for pharmaceutical companies selling biological medicines. The pediatric IBD community was viewed as a good example of comprehensive care, which is presumably made easier by the smaller community size and their typical location in academic centres. In addition, the pediatric IBD research network has linkages to networked primary care, which facilitates communication between health professionals and across sectors.

In addressing ways to introduce comprehensive alternative-service options, instead of reinventing the wheel, participants preferred to explore existing chronic-disease initiatives as well as improving ways to share IBD best practices across provinces. The INSPIRED chronic obstructive pulmonary disease (COPD) scale

collaborative was listed as an opportunity to foster learning, which could be applied to the IBD context. The initial collaborative in 2014-15 consisted of the Canadian Foundation for Healthcare Improvement with 19 teams from healthcare organizations across the 10 provinces, and had as its aim to reduce emergency-department visits and hospital admissions and stays for COPD. The new 'scale collaborative' supports six teams across Canada to increase uptake by organizations, professionals and patients. Participants agreed that the IBD community is well poised to learn from the INSPIRE project and apply a similar approach. Second, the Promoting Access and Care through Centres of Excellence (PACE) network was identified by participants as an important effort to disseminate IBD best practices, and to identify and address gaps in care (e.g., servicing remote communities through telemedicine).

Considering the full array of elements

In considering the full range of elements, participants identified six overarching principles that should be embraced when pursuing any efforts to address the many problems related to emergency-department use among IBD patients in provincial health systems in Canada:

- 1) leverage existing initiatives to help get farther faster, such as the 16 strategic clinical networks in Alberta of which one is focused on digestive health;
- 2) strengthen collaboration among networks (e.g., IMAGINE and PACE networks) and key players within and across jurisdictions, which can help to raise the profile of IBD among others in health systems (e.g., primary-care and emergency-department professionals);
- 3) frame the key issues strategically so that they are more likely to garner support among policymakers (e.g., achieving the 'triple aim' through reduction of costly emergency-department use, 'reallocation of resources' versus 'additional funding', and improving the management of IBD);
- 4) position IBD as a 'way in' to broader system transformation;
 - a. e.g., focusing on a complex condition like IBD will teach us how to address other complex single conditions,
 - b. e.g., piggy-backing on other areas that are more broadly related to IBD, where there is attention being given and policy decisions being made (e.g., digestive health);
- 5) consider system-level innovations that could have broad impacts (e.g., self-referral systems such as those for mental health in the United Kingdom, and for physiotherapy for low-back pain in Alberta); and
- 6) clarify roles among key players (e.g., policymakers, IBD networks, non-governmental and stakeholder organizations, health professionals and researchers) to establish clear goals to be achieved in the short, medium and long term.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Discussion about the barriers to reducing emergency-department use in people with IBD in provincial health systems in Canada generally focused on two areas: 1) existing approaches are fit for purpose in each of the unique health systems; and 2) being attentive to financial constraints within health systems.

The first major barrier noted by participants was the existing approaches across each of the unique health systems. Participants acknowledged that common challenges exist across health systems in trying to improve care for IBD, however, implementing the elements and sub-elements warrants specific health- and political-system considerations. Both within and across jurisdictions, many participants highlighted the variability in patient needs, particularly with respect to equity considerations and access to IBD care. Many participants agreed that policy decisions need to be context-specific (e.g., taking into account ethnocultural diversity or geographic area) in order to improve access to and management of IBD, and reduce unnecessary emergency-department usage.

Second, participants recognized that, given attentiveness to the financial constraints in health systems across Canada, there is a general lack of financial supports for IBD-related care. Financial constraints include investments in training gastroenterologists, fellows and nurses, and providing competitive salaries for mental-health professionals. Related to the lack of funding, some participants discussed challenges in meeting with policymakers because IBD is not a high-profile policy issue or on political agendas.

In deliberating on the barriers, several participants highlighted important enablers that are essential for implementing the three elements, which are closely linked to the six overarching principles outlined in the preceding section (considering the full range of elements). Participants agreed that the current approaches to IBD are not sustainable, especially with the incidence and prevalence of IBD in Canada being amongst the highest in the world. Participants identified two key policy-focused enablers. First, the issue could be reframed to one that meets the health system 'triple aim' (improving the patient experience and population health while keeping per capita costs manageable) by focusing policy conversations on efficiencies through cost-effective allocation of resources and not asking for new funds. The second enabler identified by participants is to present the issue as one that can act as a powerful exemplar for policymakers 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. Some participants viewed this as a manageable chronic disease for policymakers to invest seed money in to demonstrate the success of the model, which could then be scaled up.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

During deliberations about next steps, five broad points emerged as participants considered what actions they could take in their roles as organizational and health-system leaders:

- 1) promote more collaborative, coordinated and proactive outreach efforts in order to educate patients in Canada, which can leverage the many existing resources and networks already available through the many diverse organizations represented at the table;
- 2) strengthen existing and establish new networks among the full range of healthcare providers who are in positions to improve care for IBD patients, including those in home- and community-care settings, primary-care settings, emergency departments, and specialty-care settings;
- 3) create a community of practice whereby individuals who are introducing and evaluating innovative models of care for IBD patients in particular settings (e.g., case management with a broad range of support from multidisciplinary teams) have a forum to:
 - a. share lessons learned,
 - b. provide practical guidance for others engaged in the community of practice and interested in adopting similar approaches in their own setting, and

- c. begin using evaluation results to build an evidence base that can be used to make the case for widespread change across the country;
- 4) take strategic action to raise the profile of IBD and its importance among other healthcare providers, as well as among policymakers and stakeholders who need to be on board to improve IBD care in Canada through concerted efforts to frame the conversation around the health-system goals most likely to get traction (e.g., reducing unnecessary use of the emergency department in order to achieve the ‘triple aim’ of improving patient experiences and outcomes while keeping per capita costs manageable); and
- 5) identify and take advantage of ‘windows of opportunity’ where small wins may create the impetus for broader system change (e.g., funding opportunities that enable the development, implementation and evaluation of an innovative model of care for IBD patients that if shown to be effective could be scaled up).



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>> Contact us

1280 Main St. West, MML-417
Hamilton, ON, Canada L8S 4L6
+1.905.525.9140 x 22121
forum@mcmaster.ca

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