



Topic Overview

Citizen Panels and Stakeholder Dialogue

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

The McMaster Health Forum convened two citizen panels on the subject of reducing emergency-department usage in people with inflammatory bowel disease in provincial health systems in Canada convened on 14 September and 12 October 2018, followed by a stakeholder dialogue on the same subject convened on 22 November 2018 that was informed by the insights captured at the panels. The panels and dialogue were organized with the support of the IMAGINE SPOR Network. The panels brought together a total of 23 citizens from across Canada, and the dialogue brought together 23 participants – 6 policymakers and managers, 2 healthcare professionals, 9 researchers, and 6 stakeholders – from across Canada to examine the problem, elements of a potentially comprehensive approach for addressing it and key implementation considerations.

Insights from citizens about the problem

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.



The views expressed in the panel summary are the views of panel participants and should not be taken to represent the views of the IMAGINE SPOR Network or the authors of the panels and dialogue summaries.



A total of 23 citizens from across the country gather during McMaster Health Forum citizen panels on 14 September 2018 (Saskatoon) and 12 October 2018 (Hamilton).

Photos include participants and McMaster Health Forum staff.

Insights from citizens about the elements

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.

Insights from citizens about the implementation considerations

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.



A total of twenty-three participants drawn from government and from health, professional and research organizations gather during a McMaster Health Forum stakeholder dialogue on 22 November 2018.

Photos include participants and McMaster Health Forum staff.

Stakeholders' deliberation about the problem

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.

Stakeholders' deliberation about an approach

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).

Stakeholders' deliberation about next steps

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.

Panels and dialogue deliverables

To learn more about this topic, consult our complete [set of products](#), which include: the citizen brief that was presented to citizens before the panels, the evidence brief that was presented to dialogue participants before the dialogue, the summary of the panel, the summary of the dialogue, and the video interviews with dialogue participants.

Products addressing other topics are also available on our website www.mcmasterforum.org. Click on 'Find evidence>Products' in the menu.