

Stakeholder Perspectives on Access to IBD Care: Proceedings From a National IBD Access Summit

Sonja MacDonald, BScN¹, Courtney Heisler, MSc², Holly Mathias, MA³, Raza Mirza, PhD^{4,5}, Mark MacMillan, MD¹, Mark Borgaonkar, MD⁶, Noelle Rohatinsky, PhD⁷, Jennifer L. Jones, MD, MSc^{1,2}

¹Dalhousie University School of Medicine, Halifax, Nova Scotia, Canada

²Division of Digestive Care & Endoscopy, Nova Scotia Health Authority, Halifax, Nova Scotia, Canada

³School of Health and Human Performance, Dalhousie University, Halifax, Nova Scotia, Canada

⁴National Initiative for the Care of the Elderly, Toronto, Ontario, Canada

⁵Institute for Life Course and Aging, University of Toronto, Toronto, Ontario, Canada

⁶Memorial University, St. John's, Newfoundland, Canada

⁷University of Saskatchewan College of Nursing, Saskatoon, Saskatchewan, Canada

Correspondence: Jennifer Jones MD, MSc, FRCPC, Victoria Building, QEII Health Sciences Center, 1276 South Park Street, Halifax, NS B3H 2Y5, Canada, e-mail: jjones@dal.ca

Abstract

Background: Canada has among the highest incidence and prevalence rates of inflammatory bowel disease (IBD) in the world. While access to IBD specialty care can have a direct impact on health-related outcomes, the complexity of accessing IBD specialty care within Canada is not well understood and presents a barrier to implementation and evaluation of IBD specialty care.

Aim: The IBD Summit was held in partnership with Crohn's & Colitis Canada to identify barriers and facilitators of IBD specialty care by exploring the perceptions and experiences of key stakeholders of IBD care across Canada.

Results: A total of 20 key stakeholders attended, including gastroenterologists, patients, researchers and policymakers. Perceptions and experiences of stakeholders were transcribed, coded and thematically analyzed. Three key categories relating to access to IBD care arose: (1) *inadequate system structure*, (2) *process inefficiencies* and (3) *using outcomes to guide system change*. The IBD Summit identified similar perceptions and experiences among stakeholders and across provinces, highlighting common barriers and facilitators that transcended provincial and health care system boundaries.

Conclusions: Key suggestions identify the clinical importance of comprehensive integrated multidisciplinary care approaches with enhanced communication between patient and health care providers, greater information sharing among team members, streamlined referral and triage processes, and improved incorporation of best practice into clinical care. Stakeholders across Canada and in other countries may benefit from the suggestions presented herein, as well as the successful use of collaborative and inclusive methods of gathering the perceptions and experiences of key stakeholders from diverse backgrounds.

Keywords: *Access to care; Health systems research; Inflammatory bowel disease; Multidisciplinary; Patient-centred care*

BACKGROUND

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC) are chronic, immune-mediated diseases that affect the gastrointestinal tract (1,2). Patients are most often diagnosed in late childhood and early adulthood, though symptom presentation and diagnosis can also occur in late adulthood (2,3). Persons living with IBD require lifelong treatment and, therefore, lifelong interactions with health care system to manage the disease and its associated symptoms, and complications. IBD can have a significant impact on a person's employment, education, social and psychosocial well-being, thus increasing the overall burden of this chronic disease (2,4,5). Canada has the highest age-adjusted incidence and prevalence rates of IBD in the world, with 270,000 Canadians diagnosed with IBD in 2018 (1,2,6–8). Due to compounding prevalence and the need for long-term repeated access to the health care system (2,8,9) persons living with IBD will face longer wait times and

additional visits to emergency departments or general practice which may not be appropriate for addressing IBD-related health issues.

Access to care is a key dimension in health care improvement and may include reducing wait times, creating equitable access for all individuals regardless of background and improving access to specialty care (7,8). Timely access to specialty care is important for patients living with a chronic illness, as limited access can affect patient outcomes (2,10,11). However, health care access for individuals with IBD in Canada is not well understood (3). Within Canada, the design of the health care system across provinces and territories varies relating to specialty care delivery (12,13). In most provinces and territories, a referral is made from a primary health care provider to the specialist, clinic, or department. Once a referral is received, the triage process often varies. To date, there are currently no nationally accepted or standardized triage processes, guidelines, or criteria in place

for gastroenterology referrals (14). Once a patient is connected with an IBD specialist, provincial and locoregional resources available for patients, including advocacy initiatives and community supports, vary. Place of residence influences access to IBD specialty care, adding to the complexity of accessing IBD specialty care in Canada (12–17). The literature lacks depth in understanding access through incorporation of stakeholder perspectives on factors that influence access to IBD specialty care. Bray et al. identified the need for further research on optimal models of care for IBD patients within Canada following a 2015 Summit hosted by Crohn's & Colitis Canada (CCC). Through this patient-centred initiative, it was concluded that CCC-funded research should focus on overall need to improve quality of life for patients living with IBD, as well as improving access to IBD specialist care through specialized and multidisciplinary IBD clinics (5). The Canadian Association of Gastroenterology has determined standards of access, mostly relating to maximum wait times (10). It is important to recognize the influence of system structure and process variation and the impact this might have on access to IBD specialty care across Canada. The typical entry points into the system (e.g., for diagnosis, for treatment, or for monitoring) may need to be re-imagined. It is equally important to incorporate concepts relating to patient-centred health care access dimensions when defining and developing effective solutions to improve access to care.

What follows is a proceedings report from the first Canadian IBD Access Summit.

Application of Theoretical Frameworks

To understand the components of health care access that are important for IBD patients, two existing frameworks, the Donabedian Model and Bodenheimer's Chronic Care Model (18,19) were applied to better understand access in the context of the organization and delivery of IBD care as a chronic illness within the Canadian health care system. A patient-centred approach to access was facilitated by defining access a priori for summit participants through the Levesque et al.'s framework of access to care (5,20).

Aim

In November 2017, the first national IBD Access Summit (the 'IBD Access Summit') meeting was held in Toronto, Ontario (Canada). The aim of the Summit was to engage multiple stakeholders (beginning with patients and clinicians) in a round table discussion aiming to better understand the barriers and facilitators of access to IBD services in Canada, with the ultimate goal of using this knowledge to improve access to IBD services for Canadians, provincially and nationally. Knowledge translation questions that helped guide this project were: (1) What are the barriers and facilitators of access to IBD services in Canada? (2) What are the potential solutions to identified barriers and facilitators to access to IBD services in Canada?

SUMMIT STRUCTURE AND QUALITATIVE METHODS

What follows is a report of the proceedings of The IBD Access Summit, funded by SPOR-CIHR catalyst funding, in partnership with CCC, invited attendees, including clinicians (gastroenterologists and a nurse providing care), administrators

(policymakers) and patients. Clinicians and patients were invited from British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia and Newfoundland to ensure reasonable geographic representation. The meeting was co-facilitated by a gastroenterologist (J.L.J.) and research associate (C.H.) with presentations by gastroenterologists with particular interest in access to GI specialty services (GN, KN and GK). The Summit involved two stakeholder dialogue sessions held over 1 day. Participants were invited to join via teleconference if they were unable to be present in person, to ensure full inclusion of relevant stakeholders. The focus of this summit was on a discussion of access to specialty care for IBD.

Thematic Data Analysis

The stakeholder dialogue sessions were audio-recorded and transcribed verbatim. Coding and analysis were done using Qirrkos software. Inductive thematic analysis was performed with the data to generate themes (21). The primary analysis started with 'immersion' into the data and included multiple readings of the transcripts to create initial codes from the data. Initial codes that showed similar patterns across the dataset were sorted and collated into categories and subsequently potential themes. Data were reviewed, and themes were defined and refined. Due to the comprehensive, multidimensional nature of each theme, subthemes were developed and are described in greater detail below.

RESULTS

Twenty attendees from across Canada were present at the Summit (Supplementary Table 1). These included clinicians (1 nurse and 10 physicians) from Nova Scotia, New Brunswick, Newfoundland, Quebec, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia; patient representatives from Nova Scotia, Ontario and Alberta; 2 policymakers from Nova Scotia and Ontario; 1 patient research partner (SZ) and 1 qualitative researcher (OK). Three major thematic categories for consideration emerged from the data: *inadequate system structure*, *process inefficiencies* and *the need for outcomes to guide health system change* (please see Supplementary Figure 1). Within these themes were subthemes that illustrate the complex and multidimensional nature of access to IBD care. Supporting quotes for each of the themes are summarized (Supplementary Table 2, Themes and Supporting Quotes) and presented visually (Supplementary Figure 1). Themes and solutions are presented in Supplementary Table 3.

Theme 1: Inadequate System Structure

Participants perceived that they understood how the health care system was structured and how care was delivered within this structure and was aware of the challenges associated with access in general, particularly access to specialist care and multidisciplinary approaches to care (Supplementary Figure 1).

Excessive Wait Times

Participants identified wait times as a major barrier to care and referred to the volume of patients in the system and demand for available services as a challenge. Participants acknowledged that wait times could have detrimental effects on patients and that the referral process and structure created

additional hurdles for patients to overcome. Additionally, there was concern that wait times were exceeding the wait times agreed upon by consensus through the Canadian Association of Gastroenterology practice audit paper (13,22). Wait time barriers were also discussed in the context of traditional clinical practice silos and having providers (primary health care providers and specialists) working more effectively together to ensure that patients were seen in a timely manner. Some clinicians described the benefits of being able to tell patients their actual wait time using new innovative web and software applications, and to address wait time issues if it was deemed that patients were waiting too long. In many instances, structural access barriers were related to referral volume and quality (inadequate resourcing to accommodate volume and format of incoming referrals) and appropriateness (accessing care with the appropriate clinician in the appropriate setting for the health challenges that patients were dealing with). For example, the emergency department was not felt to be a place where IBD care could be optimized and was identified as a barrier to appropriate care. The ability to access IBD care was perceived to be dependent on geography (rural availability of care) and the available care provider (primary health care providers, specialists, or another type of provider).

Limited Availability and Accessibility of Specialist Care

A large amount of discussion centred around the availability of specialist care. Common themes were (a) the need for more trained specialists given the number of persons living with IBD (population need), (b) long wait times, and (c) the expected growth in the IBD patient population (compounding prevalence). More importantly, given the limited number of IBD specialists, some patients worried that if they had 'exhausted all options' with one specialist, that a patient would have to 'start again' with a new specialist. A few of the IBD patients described feeling 'compelled' to see their specialist, even if they did not need to, in order to avoid having to be re-referred in order to remain on their active patient roster and avoid being re-referred. There was a recognition of the importance of innovation in specialty care delivery. For example, it was suggested that primary health care providers could be a facilitator of care and in some settings shadowing or working together with specialists to take care of 'complex patients' and in a shared care model. In this way, the patients were seen by the primary health care providers and the specialist without having to wait through a referral process. This strategy would also afford the opportunity for primary health care providers to build capacity and learn about IBD health challenges from patients and specialists.

Lack of Access to Comprehensive Collaborative Care Models

Stakeholders described comprehensive care with respect to the need for better system integration between primary care and specialist care (and associated allied health care providers including nurses, dietitians and psychologists, etc.) within or outside of the community and was seen as a 'cycle of care'. Comprehensive care was felt to extend beyond the clinical setting and was inclusive of the IBD patient's families, caregivers and others who worked together to address a common problem. Access to comprehensive care models was a concern for both patients and clinicians.

Support for primary care physicians within the community was identified as a potential facilitator for IBD care. For example, in Alberta, a non-urgent phone line was developed as a resource for primary care physicians to access support and resources through IBD specialists and to provide non-urgent guidance to help primary care physicians support their patients. Additionally, the phone line has helped to develop a more collegial relationship between IBD specialists and primary care providers. Similar to e-advice, this strategy also allowed for greater geographical access for primary care providers and patients, and improved access with a simplified strategy. Patients identified community supports as a facilitator to improve overall IBD care. Community supports can include community-based allied health professionals with knowledge and expertise in IBD, improved access in the community to nursing support for education, as well as interventions for mental health, nutrition and chronic pain management. The need for community support development for those diagnosed with IBD and their care providers has been well documented (2,15,23).

Barriers to Health Information Sharing and Integration

Interestingly, a common structural solution to all of these barriers was the uptake and implementation of eHealth and health information sharing systems in order to overcome geographic, resource and practice-based structural barriers. Limitations in information sharing was a commonly cited issue, and an important concern was that information sharing had not evolved to be aligned with the digital nature of the present world. Most of the information shared within the system as part of the process of interaction between clinicians, various settings of care, and between clinicians and patients was described as paper-based (for example, the use of fax machines to relay information or physicians having to physically sign medical orders). Paper-based information sharing was not only seen as 'archaic' and slow but also at risk for being misplaced or lost. Provincial electronic health records (EHRs) were seen as a step in the right direction, but still potentially presenting a barrier for information sharing between clinicians if using electronic medical record (EMR) platforms that are not integrated or interfaceable with provincial EHRs. Shared patient and physician portals (PHRs) were discussed in terms of their potential to allow for patients and clinicians to access their health care information.

Theme 2: Process Inefficiencies

When discussing system processes, specifically the steps involved in interactions between patients and clinicians, participants recognized the importance of information sharing, streamlined referrals, centralized care coordination, virtual care provision, and the concept of an IBD medical home (Supplementary Figure 1).

Need for Innovation in the Referral and Triage Process

Referral and triage processing is often viewed as an initial step in the process to accessing specialty care. There are currently no nationally accepted or standardized guidelines in place for IBD consults or referrals (14). Clinicians at the Summit identified the ongoing challenges that remain with the fundamental principle of prioritizing the acutely ill patients first, while

recognizing the burden of disabling symptoms patients with chronic disease experience. Through a recent review of triage processes in Alberta, a priority has become understanding the data as it relates to referrals/triaging and modifying pathways and guidelines to reflect the current population need. Understanding how to manage long wait times, how to properly manage patients with less urgent functional conditions like irritable bowel syndrome (IBS) as well as patients who remain undiagnosed but with ongoing disabling symptoms has helped guide process mapping to optimize their triage processing system. Physicians also noted the challenges pertaining to dissatisfaction of primary health care providers with referral rejections and how to navigate this and still support and optimize working relationships with primary health care providers in the community. Within Alberta and Nova Scotia, there has been a transition from general physician-specific referrals to a centralized referral and triage process. This process has allowed for positive modifications in relation to shared workflow, adjustments to overcome geographical barriers, reviewing referral guidelines, as well as the ability to leverage a centralized referral system in order to innovate and to provide more timely access to specialist-facilitated advice.

Improving Centralized Care Coordination

All participants recognized that centralized care coordination can be an important facilitator for access. Centralized care coordination, from the perspective of IBD patients, meant that someone could help them navigate the system but also provide clinical advice and direction. Nurses with IBD expertise (i.e., nurse practitioners or nurse navigators) were referred to as individuals with whom participants had had positive experiences. Patients found it reassuring to have a consistent 'contact person'. Centralized care coordination was also discussed in the context of patient advocacy, and that it sometimes meant that a contact person would liaise between patients and health care providers to help relay information about patient needs, severity of illness and urgency.

Facilitating IBD Care Through the Use of eHealth Technology

Summit clinicians felt that utilizing eHealth solutions was a facilitator for IBD care, specifically as it relates to overcoming geographic and communication barriers and to improve accessibility and integration of patient information. However, at the time, challenges with availability and implementation of eHealth platforms remained a concern for some stakeholders, and was a common shared perception with other health care providers (24,25). In AB, various technological changes have been implemented within their provincial health care system. One access facilitator noted by Alberta gastroenterologists was Alberta Net Care, a provincial EHR and E-advice platform. In Nova Scotia, a patient recognized the lack of a shared EHR in their province as a barrier, thus having to advocate for all medical records to be sent to all of their specialists after every emergency visit, clinic or hospital appointment to ensure their medical information was accessible and available to their various health care providers. In Ontario, telemedicine was highlighted by patients at the Summit as an important support for overcoming geographical barriers to access of IBD specialty care. Telemedicine was noted to positively impact patient experience by providing timely patient care and reassurance in addition to removing

the financial costs associated with travel in order to access IBD specialty care (26). E-consults (asynchronous digital consultation between providers) and e-referrals (referrals to specialists received digitally via EMRs) were discussed by various physicians, noting the trend to move away from paper copies to optimize efficiency of online organization.

Integration of IBD Patients into a 'Medical Home'

The concept of the evolution from traditional solo private practice in primary care to the medical or integrated health home was discussed by a few of the participants. A primary care health home houses the resources to provide patients with a consistent, integrated, holistic approach to meet their primary care needs (including chronic disease management). There was a perception that once patients were 'labelled' with an IBD diagnosis, that this served as a barrier to them receiving care anywhere other than with a specialist (versus care received within the primary care medical home). The ideas relating to a medical home were focused on the primary care setting as the appropriate site for collaboration between primary health care providers and specialists to ensure that the provision of timely care was not hindered by labels, inaccurate provider beliefs, or lack of knowledge related to IBD. The medical home was seen as a 'culture shift' and a way forward for providing comprehensive, specialist-facilitated care in primary care settings.

Theme 3: The Need for Outcomes to Guide Health System Change

Patient outcomes, or what happens to patients as a result of the system and the processes embedded within the system, were discussed and stakeholders focused on four important subthemes: the high prevalence of IBD, rurality, the importance of evidence-based decision making and system inefficiencies that needed to be addressed (Supplementary Figure 1).

Impact of Population Need on IBD Outcomes

Understanding that the high prevalence of IBD can lead to poor outcomes was an important point of consideration. The compounding prevalence modelling that stakeholders referred to during the Summit suggests that almost 1% of the Canadian population will have IBD in the near future (8,27), and also that the current 'bottleneck' of patients sitting on wait lists was delaying access. The high prevalence rate of IBD combined with existing system inefficiencies has exposed the inadequate supply of clinicians specialized in or knowledgeable about IBD to meet population need. Also, patient interactions with other providers in other parts of the system (i.e., primary health care providers, ER physicians) were described as often unproductive, and in some ways leading to delays in care or resulting in unnecessary tests and procedures.

Rurality as a Determinant of Health Outcomes

In the context of care delivery in rural settings, health outcomes were discussed as being influenced by a 'lack of medical management options'. For example, with limited access to specialty care in rural settings, surgery and other invasive treatment options were sometimes the only management options presented to patients. Living in a rural setting without access to specialist care also meant that individuals had to drive for significant distances to specialized centres in larger cities (e.g., Halifax, Toronto) and were often dependent on

caregivers for transportation logistics. This distance to care presents significant logistical challenges and financial burden for persons living with IBD from rural settings.

Unintended Consequences of Evidence-Based Wait List Prioritization

Data-driven decision making relating to triage and access was seen as advantageous for the sickest patients, as they would be seen first. Alternatively, this prioritization process also meant that patients who were deemed ‘healthy’ enough to wait, but with chronic symptoms (i.e., pain or chronic luminal symptoms in the absence of red flags), were not seen as soon as they potentially would have wanted to be. Clinicians traditionally described and understood access as subjective and determined by medical need, urgency, and whether they felt that a patient could wait for care or not. Alternatively, patients understood access from the perspective of their unique personal needs (medical and non-medical). Many patients indicated they would feel comfortable suggesting to a clinician that their condition was urgent, even if they did not meet the medical criteria for an urgent appointment. The issue of perceived access was raised by participants in the context of whether they were waiting too long (actual wait times), or whether IBD patients were seen as expected to be able to wait longer. Overall, evidence-based decision making was seen as a facilitator for opening up access to those who need it the most urgently, and also as a means of assessing whether certain tests or procedures actually yield useful outcomes. However, for the patient participants, this data-driven approach to triage and access to specialist care often led to excessive wait times and impaired access for those with chronic symptoms which, although not life-threatening, do severely affect the quality of life.

Impact of Health System Inefficiency on Outcomes

There was a substantive amount of discussion related to health system inefficiencies that could impact health outcomes (i.e., referral/triage, siloed care). In addition, the lack of information sharing and inefficiencies in data management meant that if patients were seen in the ER or in other settings, clinicians would not have access to their health or medication history, and that this may pose a challenge for accessing optimal care and could potentially delay care.

DISCUSSION

The results stemming from the IBD Access Summit highlight many important barriers and facilitators for understanding access issues related to IBD specialty care in Canada. Due to funding and feasibility, we focused primarily on clinicians and patients for this summit meeting. Plans to engage the critical perspectives of a more representative group of nurses and other allied health care professionals (dietitians, psychologists, social workers) and family members are underway. Some findings observed in this proceedings report are consistent with those of previous research, including inconsistencies in access that are experienced by IBD patients and inefficiencies in the referral process. Also, it was noted that comprehensive care delivered by a multidisciplinary team may help create greater efficiencies in the health care system (5,28–30). EMRs and patient–physician portals were seen by participants as ways to address barriers to information sharing. However, in contrast to studies where the focus has been exclusively on

patient-related factors that pose a challenge to accessing IBD care, the themes from this Summit meeting highlight macro and meso system-level process and structural issues that influence access such as the need for collaborative care models like a medical home as well as care delivery and communication through eHealth platforms. These areas have the potential to improve access to and act as facilitators of optimal care, as previously demonstrated by Habashi et al. (31) Although this Summit was conducted in the pre-COVID era, and although large system-wide transformation has taken place with respect to the rapid and widespread implementation of synchronous virtual care delivery (medical appointments delivered by telephone call or video visit) most of the perspectives derived from stakeholders in this IBD Access Summit are still highly relevant. For example, although synchronous virtual care has provided a much-needed alternative to traditional, in-person clinic visits, this type of synchronous virtual care option alone will not significantly impact access overall or bend the cost-effectiveness curve associated with health care delivery. Although geographic distance and patient cost are reduced, delivery of synchronous care virtually takes just as much time for health care providers as in-person care delivery. Additionally, it is not known yet to what extent virtual care delivery will continue to be supported by provincial governments. Rather, the structural and process health system innovations that stand to improve access to care for chronic diseases like IBD the most, are those which focus on leveraging virtual technology to streamline referral and triage processes and integrate specialists, primary health care providers and allied health professionals to facilitate collaborative, specialty-level care within the primary health medical home and patient’s community.

With the anticipated rise in the number of individuals living with IBD over the next decade, results from the Summit suggest that IBD care, as a health care system priority, lacks clarity and consistency across health regions and provinces. Although participants spoke of the concept of the primary care medical home and recognized the comprehensive nature of care that could be delivered within this context, it was unclear where an IBD patient’s care was most appropriately delivered or how resources for the care would be accessed or shared between the medical home and what a specialist could provide. The concept of the medical home, better understood in the primary care literature as a patient-centred collaborative health home (32,33), can also be viewed not just as a physical space, but a conceptual approach to care, inclusive of care that can be shared by primary health care providers and specialists. Within the context of IBD care, the medical home model should include the presence of specialist care providers (i.e., gastroenterologists and nurse specialists), a multidisciplinary team of providers, to provide ‘holistic’ patient care facilitated by eHealth technology (34). Perhaps the most important point about IBD care made by a Summit participant was that it was ‘shared work’, between patients and a number of providers. But how exactly the work gets shared will be influenced by structural, process and cultural factors.

The uncertainty of where and how specialty care for a condition like IBD is delivered makes innovation complex and open to resistance. Understanding the scope of complex access issues IBD patients are managing is a critical first step in determining how systems can improve and strengthen. The chronic nature of IBD can add to the volume of interactions within the health care system, and virtual medicine may offer

some solutions. Virtual medicine has shown promise in a number of previous studies, and these studies highlight the potential to address delays and complications that can be avoided (35–37). Virtual medicine may be particularly well suited for IBD disease monitoring, virtual visits for issues that may be triaged as ‘non-complex’, and for the reporting of test results and conduct of follow-up visits.

While historically there have been barriers to the adoption of virtual care modalities such as privacy concerns, reimbursement challenges, tech-literacy and technology (hardware, software) issues for both patients and providers, this method of health care delivery may help meet growing demands and help to improve access by reducing travel-related barriers for rural patients. One positive advance that has occurred during the COVID-19 pandemic is the rapid uptake and support of virtual health care technology in clinical practice. This technology has allowed for rapid implementation and, in some cases, evaluation of innovative models of care. IBD patients in rural and remote settings currently face inequity with respect to accessing care. The consideration of rurality as a determinant of health may help tailor the IBD care needs of this population. As one Summit participant remarked, care options were sometimes limited in rural locales due to the lack of access to specialized medical health care providers (38). As a result of disparities tied to health care access for rural and remote IBD patients, access to care for this population should be prioritized as part of any new model of care. eHealth modalities may hold promise to address access issues, potentially even creating a ‘virtual medical home’ structured as a ‘hub and spoke’ model for IBD patients leading to improvements in outcomes for IBD patients in rural and remote settings.

Another barrier to optimized IBD care and access is practice legacy and innovation resistance. For IBD care, practice legacy is based on the principle of continuing ‘status quo’, and a sense of pushback from clinicians when presented with new models of care (i.e., medical home) or approaches to care (technology). While previous studies report that the perceived utility and ease with which an innovation can be adopted by clinicians plays a role, more recent data also reveal issues around remuneration and general ‘resistance to change’ as influencing adoption (39). What is clear from Summit participants is that IBD patients view the adoption of technology and innovative models of care favourably and that unmet information sharing and communication needs could also be addressed through these platforms going forward.

The findings from this Summit have a number of implications for improving access to care for IBD patients and identifying a challenge area for future work on how to better integrate IBD favourable policy into existing health services (Supplementary Table 3). To this end, the importance of community engagement and pre-implementation work cannot be overstated. The results from this Summit should inform future practice and highlight key areas of focus to ensure practitioners are well positioned to respond to patient and system challenges. The delivery of health services must readily adopt practical guidelines and a streamlined response to the growing number of IBD patients. Improved training of clinicians in IBD care, not simply specialists, but those who would be responsible for the care for this population in emergency and primary care settings was identified as being of great importance. Summit participants suggested that formal training could be supplemented by training of primary health

care providers through collaborative work and exposure to specialist care providers.

The policy implications of this work highlight the importance of resource allocation. Resources are currently spent on what was described by participants as ‘archaic’ means of paper-based communication and information sharing, and that electronic data and health management solutions may not only improve access, but also efficiency. The efficiencies that the health care system would derive from a move to electronic data and health record management, could allow resources to be reallocated to serve the needs of rural and remote patients. Finally, Summit patients made contributions and provided important perspectives from their lived experiences. This Summit was an example of the importance of engaging IBD patients, such that decisions can be made with IBD patients and not for them. In this way, patients can be key decision makers and stakeholders in their own care. As the system evolves towards more patient-centred approaches, it is important to understand how they can be better supported and equipped to participate in their care.

Enhancing communication between patients and providers, information sharing, and implementing a more comprehensive integrated multidisciplinary care approach that embraces integrated and patient-centred care can all be facilitated by eHealth technology (e-consults, e-referrals and EHRs). These technologies can support patients, primary health care providers, specialists and other members of the health care team to maximize patient monitoring and improve communication within the broader health care team. eHealth will facilitate more streamlined triage and referral processes which could be developed and shared at a provincial and national level, thus incorporating best practices and guidelines into clinical care. Future policy design for IBD care should be informed by implementation and evaluation of health system innovation and care delivery programs to ensure limited resources are being allocated appropriately.

Strengths and Limitations

The work stemming from the IBD Access Summit has a number of strengths and limitations that need to be acknowledged. The findings, while based on a small convenience sample, allowed for rich thematic understanding regarding access to care and for a number of stakeholder voices to be included. The results, while not generalizable, do provide insights from individuals who often do not have opportunities to share perspectives and knowledge in the same setting or context. A notable exception was the absence of the primary care practitioner’s voice as well as a more representative sample of IBD nurses, both of whom are critical players in the provision of collaborative IBD care. Community engagement with this group is being pursued as a direct result of this Summit meeting. Finally, while the views shared cannot account for full regional variation, regional variation is represented in the sample.

CONCLUSION

Future directions relating to access to IBD specialty care should give strong consideration not only to the changing complexity of patient needs, but also to the evolving dynamics of patient–provider interactions and system-level

practices and policies that are ripe for innovation. Through this initiative, an understanding of the experiences of IBD patients and clinicians, the system-level barriers and facilitators, and the roles of clinicians can help move innovation forward toward the development of new integrated models of IBD care.

Supplementary Data

Supplementary data are available at *Journal of the Canadian Association of Gastroenterology* online.

Author Contributions

S.M.: Study design, audio transcription, report writing. C.H.: Study design, Summit facilitation, data collection, report writing. H.M.: Study design, report writing. R.M.: Study design, data analyses, report writing. N.R.: Report writing. J.J.: Grant support, Study design, Summit facilitation, data collection, report writing, project oversight.

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Conflict of Interest

None declared.

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