

**Written Submission for the Pre-Budget Consultations in
Advance of the 2019 Budget**

By: Crohn's and Colitis Canada

List of Recommendations

Recommendation 1: That the government recognize that Inflammatory Bowel Disease (IBD) is a national health priority by increasing resource allocation for chronic care models that reflect the episodic nature of IBD to optimize health care delivery for this patient population.

Recommendation 2: That the government improve the federal Disability Tax Credit application process to ensure fair, expert, transparent and expedited review of all IBD submissions made by patients and/or their caregivers.

Recommendation 3: That the government increase research funding to:

Prevent and treat IBD to address the physical, psychological, and social issues caused by IBD; and to improve health outcomes for special populations of people with IBD, including immigrant populations, children, seniors, and pregnant women.

Recommendation 4: That Canadian regulatory and pricing policies:

Do not jeopardize the primacy of patient/doctor choice;

Only improve affordability and accessibility outcomes for the IBD patient community;

Respect appropriate use recommendations from the scientific and medical expert consensus.

INTRODUCTION

Inflammatory Bowel Disease (IBD)

IBD is a group of diseases that causes sections of the gastrointestinal tract to become severely inflamed and ulcerated. An abnormal response of the body's immune system plays a role in each of the two main forms of IBD: Crohn's disease and ulcerative colitis. In the absence of cures, current therapies are directed at inducing and maintaining remission. Most people afflicted with IBD require ongoing medication. When this fails, surgery is often required.

These are lifelong diseases, usually starting in adolescence or early adulthood in otherwise healthy, active individuals. Crohn's disease and ulcerative colitis also occur in children, and IBD is increasingly being diagnosed in very young children (under five years of age). IBD severely impacts quality of life through ongoing and debilitating symptoms, reduction in the ability to work, social stigma, management of washroom access issues, challenges with physical intimacy, and restrictions in career choices.^v

We view Canadian competitiveness through the lens of healthy, productive populations as well as through partnerships to further clinical research and development for new prevention, diagnosis and treatment regimes. This submission addresses a number of these policy issues.

IBD in Canada

Canada has among the highest reported prevalence (total number of afflicted people) and incidence (number of new cases per year) rates of IBD in the world.^{vi} In 2018, approximately 270,000 Canadians are living with IBD. By 2030, the number of people living with IBD is expected to rise to over 400,000, or approximately 1% of the population.^{vii} Consequently, with the rising number of Canadians with IBD, health policymakers will need to prepare our healthcare system for the rising burden of IBD.^{viii}

Recommendations

1. That the government recognize that IBD is a national health priority by increasing resource allocation for chronic care models that reflect the episodic nature of IBD to optimize healthcare delivery for this patient population

In addition to the tremendous impact that IBD has on a patient's quality of life, people living with IBD face a myriad of other challenges. These include prolonged symptoms due to late or inappropriate diagnosis, social stigma of having a chronic disease that affects toileting habits, difficulty with excursions due to limited or uncertain urgent and frequent access to washroom facilities, affordability of medications, diminished employment prospects (including sustaining employment due to periods of

QUICK FACTS

CROHN'S DISEASE AND ULCERATIVE COLITIS ARE "CANADA'S DISEASES"

Today, 270,000 (0.7%) Canadians are estimated to live with IBD. By 2030, that number is expected to rise to 403,000 Canadians (1%).

IBD can be diagnosed at any age. However, the age groups that are most likely to be diagnosed are adolescents and young adults from 20 to 30 years of age.

severe flare of the disease), limited community-based supports, chronic and/or episodic pain and inequitable access to healthcare services and specialists.^{ix x xi}

The regrettable qualitative and quantitative impact of IBD on the economic productivity of patients and their caregivers could be addressed through a more integrated chronic care model focussed on more effective prevention, diagnosis and treatment of IBD. The lack of a national plan means that each province and territory is on its own leading to inequities, gaps and variation in care.

Reducing these inequities should be a priority for policymakers across the country - with the federal government playing a catalytic role - to improve quality of life and productivity of IBD patients in society.

For example, funding a national databank of prevention, diagnosis and treatment options for IBD could help to establish a base-line of clinical practice and options for health-care professionals, patients and caregivers. Prioritizing these types of initiatives under federal R&D, innovation and commercialization, as well as the science and research envelopes, could help significantly advance work in this area.

2. That the government improve the federal Disability Tax Credit (DTC) application process to ensure the fair, expedited expert review of all IBD patient submissions

It is essential that eligibility for the DTC be designed and administrated appropriately for the applicable disability and determined in a manner that is simple, fair, transparent and expedited.

The application process, specifically the T2201 form, is onerous and inappropriately designed for IBD patients.

For patients with Crohn's disease or ulcerative colitis, when the disease causes debilitating symptoms that qualify as a disability, the T2201 form's criteria are ill-designed to capture the impacts of the symptoms on the patient. The sole category on the form that captures the debilitating symptoms of IBD is the 'eliminating' (bowel or bladder function) criteria. The seemingly arbitrary, highly subjective, and non-nuanced nature of the evaluative criteria (markedly restricted for at least 90% of the time) is a simple 'yes' or 'no' option for response.

This does not allow for explanation of the fluctuating nature of symptomatic flares – some days may be less than 90% marked restriction, but more than a threshold that prevents a patient from working. Criteria should be tied to employment disruption since the DTC is an income-subsidizing tax credit meant to offset the patient's financial loss due to an unpreventable disability.

Moreover, the process is burdensome. The federal government ought to consult stakeholders and particularly its reinstated Disability Advisory Committee to reform the application review process.

Too often, IBD patients' applications are seemingly arbitrarily rejected upon review by Canada Revenue Agency (CRA) officials. Government should not be second-guessing a medical decision unless there is evidence of fraud.

- a) The federal government should begin by following the Senate's recommendations, in its June 2018 *'Breaking Down Barriers'* report, to:
 - Include representatives on the Disability Advisory Committee from episodic disability communities (such as autoimmune patient communities, like IBD) to reform T2201.

- Increase funding to non-profit disability community organizations that support people with disabilities to complete applications for the Disability Tax Credit and the Registered Disability Savings Program.

3. Increase research funding to:

- a) Prevent and treat IBD and to address the physical, psychological, and social issues caused by IBD;
- b) Improve health outcomes for special populations of people with IBD, including immigrant populations, children, seniors, pregnant women, and Indigenous populations; and
- c) Medical cannabis use for IBD patients to prevent, treat, and alleviate symptoms.

As a percentage of the total budget, federal investments in health research have flat-lined since 2008 and funding for CIHR has decreased since 2010-11. Currently, the CIHR budget represents just 2.5% of total federal spending, down from almost 4% in 2008.

While the number of research funding applications has increased from 3,625 to 5,389 between 2007-08 and 2013-14, the percentage that have been funded has declined from 22.5% to 14.8%, resulting in increased competition for fewer funds.

This gap was recognized by the 2017 Naylor Report entitled “Investing in Canada’s Future: Strengthening the Foundations of Canadian Research”. Crohn’s and Colitis Canada recommends the allotment of **\$485 million** on the current base of research funding (\$1.66 billion) for investigator-led research operating grants.

This increase will provide a pathway for researchers to pursue funding for investigator-led research through federal granting councils that promotes exploring new concepts, processes and technologies that may lead to cures or improvements in treatment or care for patients. Investment in research must be a priority for the federal government to reclaim Canada’s leadership amongst international standards.

4. That policies created through ongoing Canadian regulatory and pricing reform only improve affordability and accessibility outcomes for the IBD patient community while respecting appropriate use recommendations from the scientific and medical expert consensus

We strongly encourage all governments to ensure that patient input is included, and reflected, in these policies for a number of reasons:

- To ensure that timely access to new medications are not unnecessarily restricted and;
- To ensure that clinical research and development is not negatively impacted by policies that are not developed with a whole of government perspective – one that includes the competitiveness of Canadian clinical trials.

Pharmaceutical policies should ensure that patient/physician decisions remain autonomous and directed by the best interest and health outcomes of that individual. The primacy of patient/physician choice should not be sacrificed for near-sighted fiscal or drug budget decisions (ie reduction in drug access as an externality of pricing reform may result in an increase in more costly hospital visits) or

arbitrary interpretation of health system sustainability levels (eg the health care budget as a proportion of a total provincial budget).

It will be critical for the federal government to ensure that patient access is not limited as a result of certain regulatory and pricing policy changes. The federal consultations in respect to both the PMPRB and national pharmacare must provide formal mechanisms for, and reflect, patient input in their design and implementation.

Lastly, we ask that all savings from federal drug price negotiations are returned to be reinvested in public health budgets.

WHO WE ARE

Crohn's and Colitis Canada is the only national charity focused on finding the cures for Crohn's disease and ulcerative colitis and improving the lives of children and adults affected by these inflammatory bowel diseases (IBD).

We are one of the top two health charity funders of Crohn's and colitis research in the world, investing \$115 million in research since 1974, leading to important breakthroughs in genetics, gut microbes, inflammation and cell repair as well as laying the groundwork for new and better treatments.

We work towards improving the lives of IBD patients by also providing multiple patient programs and services, as well as advocacy initiatives and raising public awareness.

QUICK FACTS

ECONOMIC AND SOCIAL COSTS

In 2018, over 270,000 Canadians are believed to be afflicted with IBD, which is estimated to cost over \$1.2 billion to the healthcare system annually.

Outside the healthcare system, IBD is estimated to cost Canadian society nearly \$1.5 billion in 2018 from expenses known as indirect costs such as lost work productivity, disability coverage, and premature retirement or death.

Moreover, patients with IBD and their families experience a reduction in quality of life that may affect their school, work, and social interactions

Citations taken from upcoming 2018 Impact of IBD Report (to be released fall 2018).

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- ^v Becker HM, et al. Living with inflammatory bowel disease: A Crohn's and Colitis Canada survey. *Can J Gastroenterol Hepatol.* 2015 Mar;29(2):77-84.
- ^{vi} Molodecky NA, et al. Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology.* 2012;142(1):
- ^{vii} Coward S, et al. The Rising Prevalence of Inflammatory Bowel Disease in Canada: Analyzing the Past to Predict the Future. *Journal of the CAG.* 2018
- ^{viii} Kaplan GG. The global burden of IBD: from 2015 to 2025. *Nature reviews Gastroenterology & hepatology.* 2015;12(12):720-727.
- ^{ix} Vavricka SR, et al. Systematic evaluation of risk factors for diagnostic delay in inflammatory bowel disease. *Inflamm Bowel Dis.* 2012;18(3):496-505.
- ^x Schoepfer AM, et al. Diagnostic delay in Crohn's disease is associated with a complicated disease course and increased operation rate. *Am J Gastroenterol.* 2013;108(11):1744-1753;
- ^{xi} Benchimol EI, et al. Health Services Utilization, Specialist Care, and Time to Diagnosis with Inflammatory Bowel Disease in Immigrants to Ontario, Canada: A Population-Based Cohort Study. *Inflamm Bowel Dis.* 2016;22(10):2482-2490.