



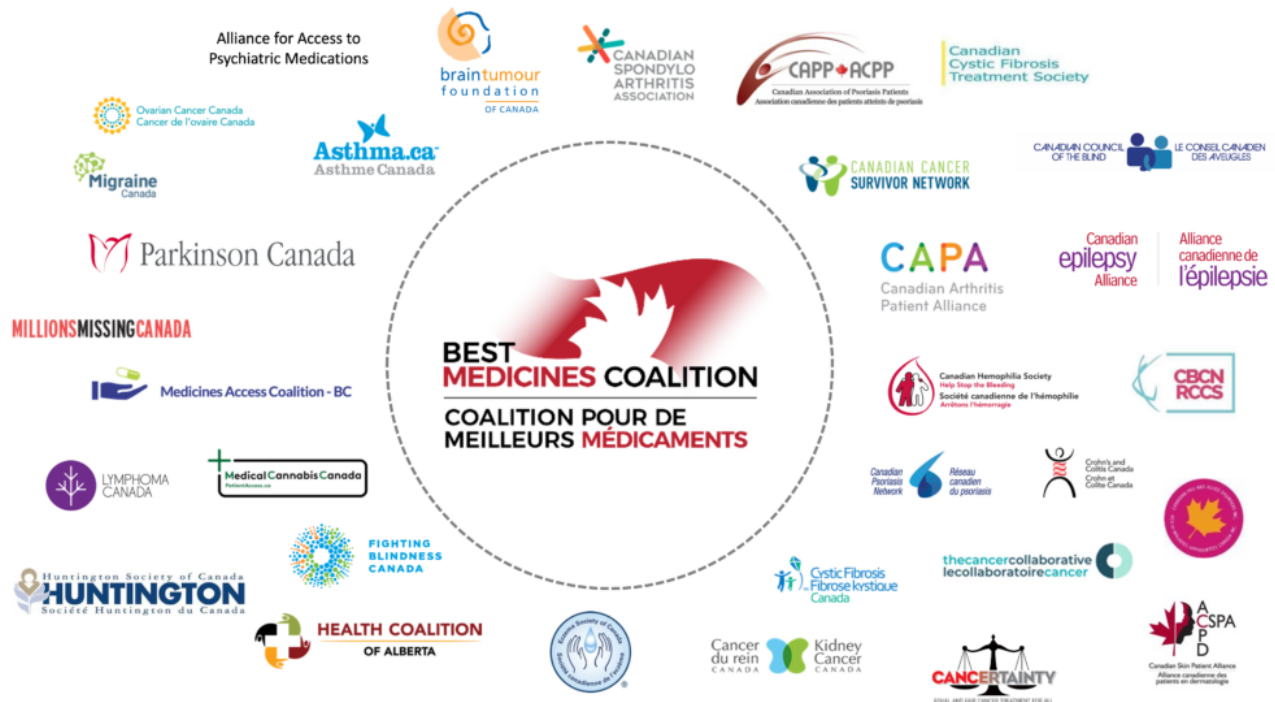
# BEST MEDICINES COALITION

## COALITION POUR DE MEILLEURS MÉDICAMENTS

Submission to the Standing Senate Committee on  
Social Affairs, Science and Technology

*Bill C-64, An Act Respecting Pharmacare*

### Best Medicines Coalition



September 4, 2024

## **Recommended Amendments**

1. In addition to the requirements contained in Bill C-64, *An Act Respecting Pharmacare*, for the Minister of Health to request strategies on bulk purchasing and a national formulary, that the Minister is required to review and propose specific whole-of-government strategies that Health Canada can undertake to address delays, inequities, shortages and inadequacies in regulatory, health technology and formulary listing reviews and related processes and their outcomes. The Minister should be required to *request* participation in the development and implementation of these strategies from the Canadian Drug Agency/Canadian Agency for Drugs and Technologies in Health, l'Institut national d'excellence en santé et en services sociaux (INESSS), the Patented Medicine Prices Review Board and the pan-Canadian Pharmaceutical Alliance.
2. That the Minister of Health is required to table an annual report to Parliament that details how patients' access, equity and comprehensive timely care has been impacted for both contraceptive and diabetes medications, as well as all other categories added later, and on the implementation of the National Strategy for Drugs for Rare Diseases.
3. That the Minister of Health, in addition to appointing an advisory council: must (1) detail the rationale for how the advisory council is selected, (2) publicly release the council's terms of reference and (3) be required to produce in annual reports any recommendations made by the advisory council, the Government's response to each recommendation and the rationale for not moving forward with any recommendations the advisory council made to the Minister.
4. That the Minister of Health is required to appoint a Chief Patient Officer established within a framework that empowers the Chief Patient Officer to fully exercise authority to ensure that patient expertise, values, voices and outcomes are recognized and drive reform, decision making and ongoing work. As an individual with lived experience with the healthcare system and fully vetted to ensure credibility, including regarding possible biases and conflicts of interests, this officer would be required to work with relevant agencies with which Health Canada is directly engaged regarding regulatory review, health technology assessment and formulary listings of drugs including review, approval, evaluation and negotiation. To ensure effectiveness, the Chief Patient Officer would be fully resourced and supported, with access to an advisory committee with broad and diverse patient representation.
5. That the Minister of Health is required to ensure that any pharmacare strategy or any new national formulary must be fully funded, comprehensive and flexible to ensure that there are no longer any out-of-pocket payments for pharmaceuticals by individual patients.
6. That the Minister of Health is required to establish an exceptional patient pathway which is clearly understood and transparent in terms of process and decision-making criteria. Such an exceptional patient pathway would provide a prescribing health care professional the ability, without undue administrative burden, to access an independent, scientific committee for approval for a specific patient to have access to a drug or related treatment which is not on a formulary or for an indication not yet approved by Health Canada. In addition, the Minister of Health shall report to Parliament annually on the work and outcomes of the exceptional patient pathway.

7. That the legislation includes a provision for the creation of a Patient Ombudsman that reports to the Parliament of Canada to advise Parliament on any issues in contravention of this Act or the Canada Health Act, and any failure for the Government to uphold the Canada Health Act, with defined intervention and enforcement powers. The Patient Ombudsman would also assess barriers and concerns as expressed by patients in relation to access to medications approved by Health Canada as well as through an exceptional patient pathway.
8. The Canadian Drug Agency must be established in legislation rather than at the direction of the Minister of Health, subject to Parliamentary oversight, the Access to Information Act, Auditor General scrutiny and interventions by a Patient Ombudsman.

## **Introduction**

The Best Medicines Coalition (BMC) is pleased to make a submission on the government's Bill C-64, *An Act Respecting Pharmacare*. The BMC offers perspectives from its community of 31 patient organizations, together representing the interests of millions of Canadian patients, each of which are informed and motivated by patient experiences and the need to improve care for all.

This submission was informed by position documents developed in consultation with BMC's member organizations as well as specific consideration and review regarding Bill C-64, *An Act Respecting Pharmacare*, and its implications. Positions and recommendations expressed here reflect areas of consensus among the organizations listed at the end of this document.

## **Overview: Considerations**

The status quo for how drug and related treatments and products are managed and provided is insufficient to meet the needs of all patients in Canada. Significant reforms are needed to address extended delays, inequities, recurring shortages and inadequacies that lead to compromised outcomes at great cost and suffering to individuals and families.

The current patchwork of patient access and postal code lottery, as identified by then Minister of Health Jean-Yves Duclos in March 2023, must be addressed and eliminated to provide consistency and equity. As a core principle, all patients, without exception, must be able to obtain medically necessary medications in a timely manner and at no cost to the patient. Approximately 20 per cent of drug expenditures in Canada are currently paid out-of-pocket by individual patients.

Further, the BMC supports the transition to a universal system as a worthy long-term goal *if it achieves equity and provides comprehensive timely care for all patients*. A phased approach is acceptable if it encompasses levelling up public programs to address inequities within and between public drug programs and prioritizes reforms which address the most critical disparities in the system.

No patient in Canada should lose existing coverage of drugs provided through private health insurance because of reforms or programs related to this Bill and to Pharmacare. In other words, any changes must not leave any patient worse off with respect to access to medications than prior to the implementation of reforms or programs related to National Pharmacare.

The work of delivering National Pharmacare to all patients in Canada equitably is critically important. Importantly, patients in Canada must be able to access the medicines they need in a timely manner. Current estimates show it takes two years on average from Health Canada approval for medications to be available on public drug plans, and approximately eight months for private plans.

All governments - federal, provincial, territorial, and Indigenous - must work together in consultation with stakeholders, including patients and the organizations that represent them. The focus must be on building an efficient and streamlined infrastructure aimed at improving patient care by delivering equity at a high level with a comprehensive range of medicines available to all based on medical need and provided in a timely manner.

The establishment of the Canadian Drug Agency is an opportunity to address complex, wasteful, and duplicative policy and program delivery. The Canadian Drug Agency must not be an additional layer, but rather a lean instrument for modernization and effectiveness. As such, which duplicative organizations and/or functions that will be replaced must be clearly identified and addressed. Further, to ensure transparency and accountability, the Canadian Drug Agency must be established by statutory law, subject to Parliamentary oversight, the Access to Information Act, Auditor General scrutiny, and interventions by an Ombudsman-type office.

A national formulary must be fully funded, comprehensive and flexible given the rapidly evolving landscape – supported by tax revenues, not patient cost-sharing approaches such as premiums, deductibles, coinsurance, or annual or lifetime limits. In addition to commonly prescribed, long-standing medications, comprehensive care includes drugs for complex, difficult to treat and/or rare conditions.

For a formulary or other type of list to be considered comprehensive, it must include specialized drugs, and medications considered curative or breakthrough in that they represent a significant improvement in effectiveness over standard of care. In addition, genetic and genomic testing must be scaled to match demand and provided equitably. Any formulary must align with the intent of the Canada Health Act. While an “Essential Medicines List” may have merit as a stop gap measure, reform towards a comprehensive solution must be prioritized and expedited. An Essential Medicines List would isolate many patients in Canada, leaving them without adequate coverage. Medicare in Canada did not start with a list of only essential hospital care, surgeries or physician services, but rather it is based on the fundamental principle of what is medically necessary, and this same premise must apply for pharmacare.

The legislation must also establish a clear and transparent exceptional patient pathway which provides any prescribing health care professional the ability, without undue administrative burden, to seek approval for a specific patient to access a medication which might not be possible through routine channels. Such an exceptional patient pathway would enable a prescribing health care professional the ability to apply to an independent, scientific committee for approval for use and payment of a drug or related treatment not on a formulary and/or for an indication not yet approved by Health Canada. Such a process recognizes patient exceptionality and ensures that no patient is unable to benefit from a medication deemed to be necessary in their case. An exceptional patient provision recognizes patient variability and the growing role of precision medicine. In addition, there should be a dedicated Ombudsman, as an Officer of Parliament, to address drug access barriers and concerns as expressed by patients.



### About the Best Medicines Coalition

The Best Medicines Coalition is a national alliance of 31 patient organizations. The BMC seeks timely access to a comprehensive range of medically necessary, safe, and effective drugs and related treatments, informed by patient-driven evidence and values, and delivered equitably and affordably to all patients in Canada. The BMC's areas of interest include drug approval, assessment, and reimbursement, as well as patient safety and supply issues. As an important aspect of its work, the BMC strives to ensure that Canadian patients have a voice and are meaningful participants in health policy development, specifically regarding pharmaceutical care. The BMC's core activities include issue education, consensus-based position development, and advocacy, making certain that patient-driven positions are communicated to decision makers and other stakeholders. The BMC was formed in 2002 as a grassroots alliance of patient advocates. In 2012, the BMC was registered under the federal Not-for-profit Corporations Act and operates under the direction of a Board of Directors comprised of representatives of member organizations and elected annually.



Alliance for Access to Psychiatric Medications  
 Asthma Canada  
 Brain Tumour Foundation of Canada  
 Canadian Arthritis Patient Alliance  
 Canadian Breast Cancer Network  
 Canadian Cancer Survivor Network  
 Canadian Council of the Blind  
 Canadian Cystic Fibrosis Treatment Society  
 Canadian Epilepsy Alliance  
 Canadian Hemophilia Society  
 Canadian PKU & Allied Disorders  
 Canadian Skin Patient Alliance  
 Canadian Spondyloarthritis Association  
 CanCertainty  
 Crohn's and Colitis Canada

Cystic Fibrosis Canada  
 Eczema Society of Canada  
 Fighting Blindness Canada  
 Health Coalition of Alberta  
 Huntington Society of Canada  
 Kidney Cancer Canada  
 Lymphoma Canada  
 Medical Cannabis Canada  
 Medicines Access Coalition – BC  
 Migraine Canada  
 Millions Missing Canada  
 Ovarian Cancer Canada  
 Parkinson Canada  
 Psoriasis Canada  
 the cancer collaborative