

BEST MEDICINES COALITION

COALITION POUR DE MEILLEURS MÉDICAMENTS

Priorities for the 2024-25 Federal Budget

Best Medicines Coalition



February 8, 2023

Key Recommendations:

1. **National Pharmacare and Related Reforms:** The federal government must allocate long-term and permanent federal dollars to support meaningful change which will tangibly improve access to medicines for all patients, including any initiatives related to National Pharmacare. Likewise, the role and contribution of the Canadian Drug Agency must be clearly articulated and focused on improving patient care and outcomes and funded accordingly. Improving timeliness and addressing the postal code lottery of patient access to drugs across the country must be shared goals.
2. **Drugs for Rare Diseases:** The federal government must move expeditiously to flow planned funding for the National Strategy for Drugs for Rare Diseases, moving forward on the national strategy including the funding commitments. Funding must ensure the effective implementation of the government's vision to improve access to effective drugs and better health outcomes. The shared goal of reducing the postal code lottery of variable patient access to medicines must be addressed, even if that means allocating additional federal money.
3. **Drug Supply and Shortages:** The federal government must adopt and implement effective and proactive approaches to address drug and vaccine supply challenges, such as intermittent and ongoing shortages of drugs, vaccines, and other therapeutic products. This includes investments to build domestic manufacturing capacity and other measures to address existing and anticipated supply pressures. Specifically, the federal government must continue to be vigilant regarding developments in the United States which enable the bulk importation of drugs from Canada from domestic supplies, ensuring that sufficient resources are allocated and targeted enforcement, regulatory and legislative tools are pursued.

Introduction:

The Best Medicines Coalition (BMC), a national alliance of 30 patient organizations, welcomes the opportunity to provide input to the 2024 Federal Pre-Budget Consultation. This submission was informed by position documents developed in consultation with BMC's member organizations. Statements and recommendations expressed here reflect areas of consensus among the organizations listed at the end of this document.

As its mission, 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. In its advocacy on related national issues, the BMC seeks policies and frameworks which recognize and embody patient-driven principles while valuing and investing in both incremental and breakthrough advancements in care. Related to this, the BMC seeks improved pathways to timely access to all medically necessary drugs and related treatments, and systems which are efficient, streamlined, transparent, and accountable.

In its ongoing work, the BMC provides recommendations on selected issues within the context of regulation and programs related to pharmaceutical care for patients in Canada, including strategies to support patients with rare diseases, drug supply initiatives, and broad pharmaceutical care reform.

1. National Pharmacare and Related Reforms

- Policy reform and the establishment of effective frameworks for how pharmaceuticals are managed and delivered must address the most critical disparities and inequities and ensure a comprehensive range of medicines are available to all, no matter where they live.
- As the government considers legislative options for National Pharmacare, it must clearly articulate objectives, specifically how the patient experience and health outcomes will improve and allocate long-term and permanent federal dollars in this upcoming budget to support these objectives. One metric must be to reduce the postal code lottery of highly variable levels of access to medicines depending on where a Canadian lives. In addition, extended timelines for assessment, negotiation and decisions on drugs and related treatments before patients can access necessary medicines must be addressed and improved.
- Every patient, without exception, needs a path to access medicines and reform in this area must address out of pocket costs, reported to be more than 20 per cent of total drug expenditures.
- The government must move to streamline infrastructure and processes, potentially through the new Canadian Drug Agency (CDA). The role and contribution of the CDA must be clearly articulated and focused on improving patient care and outcomes and funded accordingly.
- The current drug approval and listing process in most cases takes too long to deliver new drugs to patients, a critical issue especially for those with unmet needs. The CDA must not be an additional layer. Rather it must deliver effectiveness and modernization, with appropriate governance including patient representation, established by statutory law and subject to accountability, transparency, and Parliamentary oversight.

2. National Strategy for Drugs for Rare Diseases

- A comprehensive and effective National Strategy for Drugs for Rare Diseases must first and foremost focus on saving and transforming patients' lives. A better vision would be for an overall strategy for rare disease patients, not just for drugs. The national strategy must have at its heart a mandate of helping patients and seek to address health system sustainability from this starting point of sustaining and improving patient lives and outcomes. Gaining access to medically necessary treatments is critical and the strategy and enabling funding allocations must reflect this reality.
- Since the initial federal commitment, the process for developing and implementing the strategy appears to have stalled and this must be addressed. The Federal Budget 2019 committed \$1 billion over two years with up to \$500 million per year ongoing for Canadians to access treatment for rare conditions, starting in 2022-2023. Limited funding has flowed with no clarity on plans for 2024. Efforts must be made to expedite and flow funding immediately to positively impact patients.
- For the government to achieve its vision to improve access to effective drugs and better health outcomes, the strategy must ensure effective treatments are delivered to patients in a timely manner across Canada. This includes ensuring early diagnosis of rare diseases, data and real-world evidence driven decisions, and incorporation of patient and clinician voices. In addition, drug access and reimbursement systems must be improved to better encourage developers to bring new drugs to Canada which treat unmet needs, including therapies for rare disorders.

- Importantly, the federal government must dedicate sufficient financial support to ensure meaningful and sustained gains to improving patient care, even if this means additional money beyond previous commitments. An effective rare disease strategy must be sufficiently resourced, and all efforts must be focused on understanding the scope of patients' and caregivers' needs, the full extent of necessary financial support and then allocating funds as appropriate, in partnership and consultation with patients and other stakeholders.

3. Drug and Vaccine Supply and Shortages

- Disruptions to drug supply, including intermittent and ongoing drug shortages and drug discontinuations, are critical and long-standing with critical implications for patient care and outcomes. Tangible actions to support Canada's biomanufacturing capacity and other measures to mitigate shortages must be funded, initiatives pursued, and regulations modernized.
- We recognize and commend that the federal efforts on drug shortages was expanded to include shortages of infant formulas plus medical foods, formulas, and supplements necessary to treat patients on medically supervised diet therapy. We acknowledge and support the current consultation to modernize regulations on medical foods and formulas which will better align with the 2022 amendments to the Income Tax Act regarding medical foods and formulas. This seems a good example of a whole-of-government approach.
- Canada must be prepared to address global supply pressures and able to effectively execute appropriate measures to protect Canadian patients. Specifically, given developments in the United States in early 2024 which would enable bulk importation of drugs from Canada, the Government of Canada must continue to be vigilant, ensuring that sufficient resources are allocated to ensure the implementation of sufficient issue advocacy, regulatory, and legislative tools.



About the Best Medicines Coalition

The Best Medicines Coalition is a national alliance of 30 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 involve 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 Association of Psoriasis Patients
 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 Psoriasis Network
 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