

Key Recommendations:

1. **Patient Ombudsman:** The Parliament of Canada establish a Patient Ombudsman to report independently to Parliament on any issues in contravention of the Pharmacare Act or the Canada Health Act, with defined intervention and enforcement powers.
2. **National Pharmacare Funding:** The federal government 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.
3. **Canada's Drug Agency:** Canada's Drug Agency (CDA) establish improving timeliness and addressing the postal code lottery of patient access to drugs as a primary objective and report to Parliament on progress.
4. **Drugs for Rare Diseases:** The federal government moves expeditiously to flow planned funding for the National Strategy for Drugs for Rare Diseases. Funding must ensure the effective implementation of the government's vision to improve access to effective drugs and better outcomes for patients and the health system.
5. **Chief Patient Officer:** Budget 2025-26 direct the Minister of Health to appoint a Chief Patient Officer to ensure that patient expertise, values, voices and outcomes are recognized and drive reform, policies and practices, decision making and ongoing work.
6. **Drug Supply and Shortages:** The federal government strengthen measures to ensure a secure, consistent and comprehensive supply of drugs and related treatments, including moving forward new regulations to address shortages as quickly as possible and ensuring that a full range of COVID-19 vaccines are available, including protein-based options.

Introduction:

The Best Medicines Coalition (BMC), a national alliance of 30 patient organizations, welcomes the opportunity to provide input to the Standing Committee on Finance's 2024 pre-budget consultation. This submission was informed by current BMC position documents developed in consultation with BMC's member organizations. Statements and recommendations expressed here reflect areas of consensus among the member 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 policies, programs, legislation and regulations related to pharmaceutical care for patients in Canada, including regarding broad pharmaceutical care reform, pharmaceutical review, assessment and pricing, strategies to support patients with rare diseases and drug supply initiatives.

1. Patient Ombudsman

Bill C-64, the Pharmacare Act, lays out groundwork for the first phase of a national universal pharmacare program, initiating a process to ensure Canadians have universal access to medicines, not just services of doctors, hospitals and labs, with the potential for an improved framework. We note that Canada is the only country with a publicly funded healthcare system that does not have a universal program for coverage of prescription drugs.

We need patients to be included from the start and at each step of this process to ensure that the groundwork is solid. Without a solid foundation, Canadians will continue to lack timely access to the drugs they need.

A patient ombudsman would work outside the government reporting directly to Parliament. Besides reporting any failures to uphold the Pharmacare Act and the Canada Health Act, and any of their regulations, this ombudsman would also assess barriers and concerns as expressed by patients when it comes to accessing medications and recommend changes.

2. National Pharmacare Funding

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 legislation advances through Parliament, 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 by the Canadian Institute for Health Information to be approximately 20 per cent of total drug expenditures.

3. Canada's Drug Agency

The government must move to streamline infrastructure and processes through Canada's 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 health technology assessment, price negotiation 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. We consider recent changes to add a patient to the CDA board of directors to be a step in the right direction, with more steps needed.

4. 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, and ideally there would be an overall strategy for rare disease patient care, not just for drugs. The national strategy must have at its heart a mandate of sustaining and improving patient lives and outcomes and seek to address health system sustainability from this starting point. 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 needs to be expedited. The Federal Budget in 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 to pan-Canadian health organizations. We welcome the July 23, 2024 announcement of the first bilateral agreement, in this case between Health Canada and British Columbia. Efforts must continue to reach similar agreements with all provinces, territories and indigenous partners. We are still counting the days until the first patient receives the first drug from this 2019 commitment.

The strategy must ensure effective treatments are delivered to patients in a timely manner across Canada. This includes ensuring early screening for and 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.

We welcome the news of July 23, 2024 that the federal Government has committed to continue to provide up to \$500 million a year, beyond the initial three-year period. We ask that this base funding be augmented including being adjusted for inflation, population growth and economic growth.

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.

5. Chief Patient Officer

Budget 2025-26 should direct the Minister of Health to appoint a Chief Patient Officer to ensure that patient expertise, values, voices and outcomes are recognized and drive reform, decision making and ongoing work. This officer would be required to interact with relevant agencies with which Health Canada is directly engaged regarding regulatory review, health technology assessment and formulary listings of drugs including review, approval and evaluation. 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.

The BMC recommends having patient interests represented through a formal Chief Patient Officer imbedded in Health Canada, working from within the organization. It should be someone with lived experience whose role includes authority to ensure that patient expertise is recognized and used to drive reform and ongoing work. The Chief Patient Officer should be supported by an advisory committee with diverse patient representation.

6. Drug supply and shortages

Supply disruptions to drugs and related treatments as well as vaccines, including intermittent and ongoing shortages and discontinuations, have 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 welcome recent initiatives to develop new regulatory amendments to enable improved management and shortage mitigation. We urge the federal government to move expeditiously to bring these reforms to fruition.

As reforms proceed, we ask that the scope be broadened to include non-Drug Information Numbered (DIN) products. For many patients, treatment goes well beyond what are considered drugs, as defined by those that have a DIN, including medical foods, medical formulas and medical supplements. Patients experience negative outcomes from shortages of these treatments just as they do from drug shortages.

In addition, the goal of improved communication is extremely important to patients, including broad understanding of the nature of shortages as well as notification on specific shortages. As regulatory reforms are pursued, improved communication at all levels including at community pharmacies so that shortage situations can be proactively addressed and effectively managed must be incorporated.

Secure and consistent availability and access to a broad range of vaccines is critical, particularly regarding diverse COVID-19 vaccine options, including those beyond mRNA vaccines. Specifically, many patients in Canada require protein-based COVID-19 vaccines, such as Novavax, which currently has extremely limited availability or, in many areas, is completely unavailable to patients. The federal government must ensure that adequate doses are acquired and distributed across the country such that barriers to access are eliminated.



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 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