



**EQUITABLE &
COMPREHENSIVE
PHARMACEUTICAL CARE
FOR ALL**

National Pharmacare Implementation: Patient Perspectives and Considerations

Submission to the Advisory Council on the Implementation of National Pharmacare

September 2018

Background and current context

Patient-driven perspectives and positions

The Best Medicines Coalition (BMC) is a national alliance of 26 patient organizations with a shared goal of equitable and timely access for all Canadians to a comprehensive array of safe and effective medicines that improve patient outcomes. 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.

Since its inception, the BMC has articulated insights and positions from the broad patient community regarding challenges in how pharmaceutical care is managed and delivered in Canada. Early in its work, the BMC offered patient insights as part of the National Pharmaceutical Strategy initiative in 2004. More recently, the BMC participated in policy discussions and developed materials regarding pharmacare perspectives, as follows:

- [*Equitable Pharmaceutical Care: Principles and Considerations Regarding Pharmacare for All Canadians*](#), which outlined consensus principles such as universality, inclusivity, timely access and collaboration. In turn, these principles informed a submission to the Parliamentary Standing Committee on Health regarding pharmacare.
- Working with the Canadian Pharmacists Association and the Health Charities Coalition of Canada, the BMC developed [*Better Pharmacare for Patients: Evaluating Policy Options*](#), a discussion paper which evaluated key policy options against patient-driven principles.

Working together to inform current National Pharmacare discussions

In early 2018, the BMC initiated a process to gather updated perspectives on pharmaceutical challenges, reform goals and implementation considerations with the goal of informing current pharmacare discussions and specifically the work of the *Advisory Council on the Implementation of National Pharmacare (ACINP)*, announced in February 2018. The BMC Survey on National Pharmacare asked coalition patient group representatives the following fundamental questions:

- What are the strengths and weaknesses in how pharmaceutical care is provided?
- Who should be covered?
- What drugs should be covered?

Completed in June 2018, findings were presented to the coalition and explored through roundtable discussions, subsequent review and written input. Summary points, including both survey findings and key discussion themes, are compiled in a document entitled [*Patient Perspectives on National Pharmacare: Current Challenges, Goals and Implementation Issues*](#) with the goal of informing ongoing policy deliberations, including the work of the Advisory Council on the Implementation of National Pharmacare. This summary report is provided to the ACINP as reference, along with this submission.

This submission to the ACINP is a distillation of the deliberations and policy output of the BMC with respect to pharmacare reform and establishes key policy considerations to guide its work on advancing National Pharmacare. Statements and positions expressed within this report are informed by the BMC pharmacare survey report and subsequent summary consensus statements.

Establishing comprehensive and equitable care for all

Through a process of consultation and review by its member organizations, the BMC has established patient-centric core positions regarding any proposed implementation model for National Pharmacare.

National Pharmacare Core Positions

- All patients, without exception, must be able to obtain medicines that a health care professional has deemed medically necessary. Pharmacare reforms must address existing inequities and deliver timely, comprehensive care which is appropriate for each individual, regardless of disability, condition or where they live or work.
- Advancements need to address critical deficiencies in how pharmaceutical care is provided in Canada. Any changes contemplated for the implementation of a National Pharmacare program must leave all patients no worse off with respect to access to medications.
- Canadian leaders must prioritize addressing the most critical disparities and inequities in patient care and consider possible transition to a single payer, public system to be a longer-term proposition.
- Pharmacare reforms need to be considered in light of other suggested changes to drug price regulation, Health Canada practices and the need for drug discoveries to meet unmet patient needs.
- Patients and the organizations that represent them must continue to play an integral role during the development and integration of pharmacare strategies and programs.

Establishing priorities

Understanding shortfalls and strengths

Design of drug insurance programs across Canada is highly variable with notable differences in how access to drugs is determined, including by age, province/territory of residence, employment status, income, disability or disease type. These inadequacies and inequities lead to compromised care and poor outcomes for patients and impose great costs on individuals, families, health care systems and society.

There are aspects of prescription drug plans that function well, including those for defined age groups and specific conditions. However, significant deficiencies are seen by patient representatives in the following areas:

- Some individuals are without any prescription drug coverage, or have inadequate coverage, requiring them to make difficult choices to pay for necessary medications or to go without medications. In addition to prohibitive out of pocket costs related to prescription medicines, some patients may require over-the-counter medications, special equipment and have other related expenses.
- Specific drugs approved by Health Canada as safe and effective are not available on public drug plans or are subject to restrictive limitations.
- In addition to contributing to inequity, inconsistencies among plans may result in disruptions in care as individuals move from one plan to another.
- Patients can experience extended wait times while new drugs are reviewed. Medicines delayed are medicines denied.

Advancing National Pharmacare to meet patient needs

In charting a path forward, maintaining and achieving high quality pharmaceutical care with no disruptions or diminishment is fundamental and critical to success. A phased approach is a pragmatic and appropriate way forward with early efforts focused on resolving critical inequities and disparities, while acknowledging that more substantive reform, possibly involving transition to a single-payer system to deliver universal drug coverage, may be a worthy, long-term consideration. An approach to phased reform is outlined below:

Early focus on levelling up to improve care

Inaugural reform should harmonize, or level up, all federal, provincial and territorial drug programs to the best standard of access established across the dimensions of age, jurisdiction, employment status, income, disability or disease type. Reform should build upon the best of what is in place now along with a further focus on addressing the most glaring shortfalls and inequities that exist in the current mix of public and private drug coverage.

Within this approach, private drug insurance plans would remain, with efforts focused on addressing the needs of currently uninsured and underinsured populations. This could include standardization of programs focused on reimbursement for catastrophic prescription drug costs that surpass certain thresholds of household income.

Consideration of longer-term transition, substantive reform

Establishing a single-payer public system which provides high quality, comprehensive care to all, efficiently and effectively, may be an appropriate long-term reform goal. This should be carefully considered and pursued once the most critical drug access and management issues have been addressed and resolved.

Establishing high standards of care

Defining comprehensive coverage

While cost reduction is often discussed in the context of National Pharmacare, improvement of health outcomes and patient experiences should be the focus of reform. As such, implementation models must deliver a high level of comprehensive care. Various considerations on the concept of comprehensive coverage are offered below:

Breadth versus depth of coverage

For coverage to be considered comprehensive, it must be broad in scope and encompass a range of drugs necessary to meet the individual needs of all patients. It is not appropriate, or ethical, to limit coverage by choosing between depth of options within a treatment and breadth of coverage for drugs for a wider range of conditions. Forcing choice between depth and breadth does not support the advancement of pharmaceutical care that is in the best interests of patients. The range of medications covered must meet the individual needs of all patients, regardless of type of condition, whether acute and chronic, or incidence/rareness of disease. Likewise, the range of medications must include those not supported by a full body of clinical evidence, such as for rare diseases. To be comprehensive, coverage must encompass both widely-prescribed drugs used in primary care, and specialty drugs used in specialized care.

Breakthrough and future medications for unmet needs

Importantly, programs must have the capacity and flexibility to incorporate yet to be discovered and introduced medications, with a focus on those drugs that address unmet patient needs. This is vital as we enter a new era of medicine where innovations are transforming our ability to attack the cause of disease, not just the symptoms. For a drug program to be comprehensive, it must include drugs which are considered curative or breakthrough because they offer significant improvements to life threatening or debilitating conditions. There must also be the capacity to provide for future, next generation treatments such as gene and cell therapy. New models of paying for long-term benefits from a single course of treatment are urgently needed.

Defining formulary scope

Drug formularies must have capacity to address individual patient needs. Through the lens of equity, the range of drugs currently provided through formularies of many private, employer-based plans have capacity to meet individual needs. In addition, the current Quebec formulary, the largest public formulary in Canada, is arguably the most comprehensive public drug plan. Levelling up all existing public programs to this standard of coverage would be a reasonable early step in achieving national equity. Recognizing that unique patient needs will arise, a National Pharmacare model must also provide for a type of “safety valve” for consideration of those exceptional cases where a treatment is medically necessary but not provided for otherwise.

Comprehensive scope for all

Those within the public or private systems require access to a comprehensive range of medications. The challenge of inequity regarding the differences in the scope of drugs offered, which is an aspect of a mixed public and private system, must be reconciled and addressed.

Ensuring reforms deliver value to patients

A limited Essential Medicines List would not offer value or contribute to comprehensive care if offered in isolation. Limited lists do not recognize the complexities and variability of patients and their needs. Unless offered in combination with wide-ranging enhancement programs, implementation would bring coverage below current levels.

Comprehensive care through appropriate funding

Whether reform is made possible through a solely public system, or a mixed combination of private and public coverage, appropriate funding options must be carefully considered. Whatever its form, National Pharmacare cannot be comprehensive and equitable if it is underfunded. Enhanced funding must be provided to ensure budgets are sufficient even if some level of cost reduction is realized through improved efficiencies and other measures.

Funding of National Pharmacare needs to consider the following:

Assessing taxation options

While there are concerns about an additional tax burden, taxes in various forms are also sometimes considered to be an equitable source of funds. Further understanding is needed to understand whether Canadians are willing to pay for National Pharmacare through increased taxation, such as a supplemental tax like the Health Tax in Ontario and elsewhere.

Cost-sharing if affordable and equitable

Recognizing that a key aspect of current discussions regarding National Pharmacare is directed at resolving the issue of prohibitive out-of-pocket drug costs borne by patients, any funding construct for National Pharmacare must ensure that cost-sharing measures do not place undue financial burden on patients and perpetuate the problem of cost-based barriers to drug access. Careful consideration must also be given to fairness and equity. Patients who need medications, or certain types of medications, must not be asked to carry a financial burden or be penalized in ways that those who require other medical services are not. In addition, cost sharing should not be used as a tool to encourage appropriate use in the absence of evidence that this is effective. That said, cost-sharing fees at levels which are affordable, equitable and proven to not impede access could be acceptable and warrants thoughtful consideration of all evidence.

Funding models for specific drugs

Alternative funding models for specific drugs need to be explored, regardless of whether within a mixed or single payer system. Risk sharing agreements could enable certain types of drugs to be made available. Models to pay for unique single course treatments would allow patients to realize the long-term benefits of these medications.

Need to fully understand implications

The potential financial impact of any pharmacare model must be carefully assessed and federal pharmacare funding for any selected model must be long-term, flexible (to account for new drug discoveries and future cost pressures) and sustainable. Models must be fully reviewed to understand all implications. For example, in Ontario, actual program cost data for OHIP+ (in its early months) may soon be available and provide an opportunity for pharmacare policy-makers to assess the projected costs of pharmacare expansion (for a specific population) against these established costs.

Integration, coordination and evidence

In considering reform, it is important that the broader framework for pharmaceutical care in Canada be reviewed to ensure that all aspects support better patient care and that a National Pharmacare initiative not be viewed in isolation. Furthermore, National Pharmacare should not occur at the detriment of broader health programs but be realized in a complementary approach.

The following aspects of pharmaceutical review, assessment and access warrant careful consideration:

Coordination with current drug policy reform initiatives

Ensuring timely, sustainable access to medicines is a critical focus of pharmaceutical policy development, and the advancement of a National Pharmacare program must be in concordance with these objectives. Specific National Pharmacare proposals must be coordinated with other reform efforts including with the Patented Medicine Prices Review Board (PMPRB), Health Canada's regulatory review of drugs and devices (R2D2) initiative, and other initiatives.

Rapid access to necessary medicines

Any advancements in pharmacare must provide for rapid access to necessary medicines with minimal administrative burdens. Integration and coordination between public and private drug insurance systems is important to ensure optimal patient care. Efficiency, accountability, transparency and timeliness must be embedded within any pharmacare framework including the review, assessment and reimbursement processes.

Tracking outcomes and value

Making better choices about drugs requires the best possible evidence. Real world data (RWD) and real world evidence (RWE) are playing an increasing role in health care decisions. However, Canada lacks much of the data infrastructure required to track patient outcomes and value. Development of a National Pharmacare program or strategy will require a parallel effort to build the infrastructure necessary to determine what drugs are providing value in our health care system to inform ongoing inclusion on drug formularies.

What should National Pharmacare achieve?

Equity, but at high level

Pharmacare reform must address current inequities, but it must do so within the context of providing comprehensive care for all and improving the current healthcare system. Importantly, equity must be achieved by levelling up, with reforms building upon the best of what is in place now and ensuring that all Canadians have comprehensive coverage regardless of where they live and work. This includes addressing standards on eligibility, with equity across all age groups and conditions, and costs to patients. Regarding the scope of formularies, there must be equity across all plans with the same drugs made available under the same conditions for all Canadians.

Fully insured population

The needs of Canadians who are falling through the cracks must be addressed, including those who have no coverage because they are not part of a private plan and are not eligible for or enrolled in public plans. This also includes the underinsured whose coverage is insufficient, thus preventing them from benefiting from drugs which have been deemed necessary for them. The uninsured and underinsured must have access to a comprehensive range of drugs, like all other Canadians.

Timeliness and efficiency

Drugs should be accessible to all within reasonable time frames. Likewise, for drugs with a high potential for improved outcomes where there are unmet needs, there should be an accelerated review process. Related to this, reform should address the current, overly-complicated system of reviews and decision-making. Bureaucratic and administrative burdens should be addressed by streamlining and standardizing approvals and formularies.

Focus on improving patient care

Reform should move away from a sole focus on cost-saving. Improving patient care and outcomes should be the priority, including improving access to the drugs that people need, such as drugs for chronic, rare diseases and specialty medications. The ability to meet unmet needs and prevent complications must be valued, and patient health and the potential to achieve optimal outcomes must not be compromised.

Continued collaborative consultation

The effort made by the ACINP to engage patients to aid in understanding current challenges and assessing implementation options are acknowledged and valued. The ACINP is encouraged to continue this collaborative discussion throughout its mandate particularly as implementation models are developed and evaluated. Indeed, ongoing meaningful participation of patients and their representative organizations needs to be an integral part of any implementation model. The ACINP is urged to ensure that the patient voice is formally included in all future policy development and program design phases.

Appendix: About the Best Medicines Coalition

The Best Medicines Coalition (BMC) is a national alliance of 26 patient organizations with a shared goal of equitable and consistent access for all Canadians to safe and effective medicines that improve patient outcomes. 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 building, planning 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 Not-for-profit Corporations Act.

Mission

The BMC is committed to ensuring that all Canadians have safe and timely access to medications which have been shown, based on best available evidence, to improve outcomes for patients.

Goals

- Drug programs which deliver high standards of equitable and consistent access to medications for all Canadians.
- Drug review and post-marketing surveillance systems to address patient safety; knowledge of risks and benefits throughout drug lifecycle.
- Effective models for meaningful and equitable patient participation in drug reviews and policy development.

Integrity

To ensure ongoing independence and to make certain that all activities and interactions are pursued within a framework of integrity, the coalition adheres to a [Code of Conduct](#) to meet the following goals:

- Ensure that funding arrangements or relationships with funders do not influence or jeopardize the mission, goals, and advocacy activities of the BMC and/or its members.
- Ensure that arrangements and relationships between the BMC, its members, and funders are ethical, transparent, and reflect positively on all parties.
- Provide BMC and its members with a solid operating framework and appropriate guidelines to enable ethical, effective, and confident interaction with funding organizations.

BEST MEDICINES COALITION



Alliance for Access to Psychiatric Medications
 Arthritis Consumer Experts
 Asthma Canada
 Better Pharmacare Coalition
 Brain Tumour Foundation of Canada
 Canadian Arthritis Patient Alliance
 Canadian Breast Cancer Network
 Canadian Council of the Blind
 Canadian Epilepsy Alliance
 Canadian Hemophilia Society
 Canadian PKU & Allied Disorders
 Canadian Mental Health Association
 Canadian Psoriasis Network

Canadian Skin Patient Alliance
 Canadian Society of Intestinal Research
 Canadian Spondylitis Association
 Canadian Treatment Action Council
 Crohn's and Colitis Canada
 Foundation Fighting Blindness
 Gastrointestinal Society
 Health Coalition of Alberta
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