



**BEST
MEDICINES COALITION**

**EQUITABLE &
COMPREHENSIVE
PHARMACEUTICAL CARE
FOR ALL**

Patient Perspectives on National Pharmacare: Current Challenges, Goals and Implementation Issues

Report of the Best Medicines Coalition Survey on National Pharmacare Issues

August 2018





The Best Medicines Coalition 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. 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, and advocacy, ensuring that patient-driven positions are communicated to decision makers and stakeholders. Policy positions are informed by member organization input, under the direction of the coalition's Board of Directors. The BMC was formed in 2002 as a grassroots alliance of patient advocates. In 2012, the BMC registered under the Not-for-profit Corporations Act.

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

Kidney Cancer Canada

Lymphoma Canada

Millions Missing Canada

Ovarian Cancer Canada

Parkinson Canada

bestmedicinescoalition.org

[@bmc_patients](https://twitter.com/bmc_patients)

Table of Contents

Introduction.....	1
Executive Summary.....	2
Patient Care: What are the Strengths in the Current System?.....	4
Patient Care: What are the Challenges in the Current System?.....	5
Comprehensive Care: What Drugs Should be Covered?.....	7
Comprehensive Care: Who Should be Eligible for Drug Coverage?.....	8
Delivering Pharmacare: How Should Pharmacare be Funded?.....	9
Reform Goals: What Should Pharmacare Reform Accomplish?.....	11

Introduction

The *Survey on National Pharmacare Issues* is a core element of a process initiated in early 2018 by the Best Medicines Coalition (BMC) to gather insights on patient community perspectives on pharmaceutical care, including current challenges, reform goals and fundamental implementation considerations. The survey was completed in May 2018 by the coalition's 26 member organizations, representing a wide range of Canadian patient communities, with findings presented and explored through roundtable discussions, subsequent review and input.

Summary points, including both survey findings and key discussion themes, are compiled in this report with the goal of informing ongoing policy deliberations, including the work of the *Advisory Council on the Implementation of National Pharmacare*, announced in February 2018.

The *BMC Survey on National Pharmacare Issues* explored 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?
- How should drug coverage be managed and funded?

Overview:

Patient organizations which are part of the Best Medicines Coalition express agreement on many key issues related to national pharmacare. The following points summarize perceptions regarding the goals of reform, strengths and challenges in the current system and national pharmacare implementation issues.

Key findings: Reform goals and process

Equitable and comprehensive coverage

Everyone, without exception, must be able to obtain medicines that a qualified health care professional has deemed medically necessary.

Those in all regions of the country, regardless of income, age, or type of medical condition, must be able to consistently and equitably access the drugs they need from a comprehensive range of medicines in a timely manner.

Prioritization and collaboration

Canadian leaders must prioritize positive reform, establishing equitable and comprehensive drug coverage for all while seeking ways to gain efficiencies to improve patient care.

Key findings: Current pharmaceutical care issues

Inconsistent, inequitable and inadequate

Canada's system for managing and providing pharmaceutical care is a complicated patchwork. Many patients access medications through government-funded public plans, which vary widely across the country, or are part of diverse employer-based private plans. Other individuals are not eligible for either public or private plans and must pay for their drugs out of pocket. While some patients get the drugs they need, there are widespread inequities and shortfalls. Some of the issues identified include:

- Some patients have no drug coverage or are underinsured.
- Specific drugs are not available on government plans or are subject to restrictive limitations.
- Inconsistencies between plans are inequitable and can prompt disruptions in care as individuals move between plans.
- Patients can experience extended wait times while new drugs are reviewed.

Key findings: Implementation issues

Achieve equity, but at a high level

Everyone, without exception, must be able to obtain medicines that a qualified health care professional has deemed medically necessary. Reforms must fix inequities and deliver comprehensive care for all, regardless of where they live and work. The needs of those who are falling through the cracks must be addressed, including the uninsured and the underinsured.

No one gets left behind

Comprehensive care means that formularies of drug plans must encompass a full range of drugs to meet the needs of all patients, regardless of condition. Both primary and speciality drugs, including curative or breakthrough treatments and drugs for rare disorders, must be available to all individuals that medically require them. Most public drug programs do not provide an adequate level of care, and a limited Essential Medicines List should not be considered.

Delivery models must ensure equitable, comprehensive care

Delivering comprehensive drug coverage equitably in a timely and efficient manner must be the goal of pharmacare reform. The question of whether this is possible through government funding, private insurers, or a mixture of both, warrants careful consideration regarding feasibility and sustainability. The status quo, a convoluted, mixed funding model where both governments and private payers provide highly variable coverage to some while others have no, or not enough, coverage leaving them unable to get the drugs they need, is unacceptable.

Collaboration to improve the lives of all

Positive, progressive reform must be a priority and the process of change must be transparent and based on cooperative and meaningful stakeholder consultations. Patients and patient organizations must be fully integrated in the review, development and implementation of all reform options.

Patient Care: What are the Strengths in the Current System?

Overview:

In some cases, the current pharmaceutical care system adequately meets patient needs, particularly for those with uncomplicated conditions. Those within employer-based, private plans generally have timely coverage without restrictions. Within the public system, qualifying patients sometimes get access to the drugs they need, depending on condition and other factors. Within hospital settings, drugs are dispensed at no cost to patients.

Additional points:

- When core public plans (standard formularies) do not meet needs, there are sometimes other options, often in response to exceptional needs. Compassionate care programs from drug companies also fill in some gaps in specific situations
- For specific conditions, there are examples within the many government-funded public programs where patients have satisfactory access to a range of medications, allowing for some choice.
- There are positive aspects of some public programs which are cited as strengths in the current system:
 - Alberta offers publicly funded drug programs to ensure that some basic coverage is available for all, including low-income earners, people with disabilities and seniors, along with a non-group plan available regardless of pre-existing conditions.
 - British Columbia offers coverage of prescription medications without deductibles for low income individuals/families.
 - Quebec mandates everyone be covered either through an employer plan or, failing that, a group plan at a reasonable cost ensuring no one is without coverage.
 - New Brunswick offers a catastrophic drug program that covers all drugs included in the standard provincial formulary.
 - In Ontario, cases outside the Exceptional Access Program may occasionally be handled through specialized programs, such as for life-threatening situations. OHIP+ has filled the need for uninsured or underinsured children/youth until they turn 25.

Patient Care: What are the Challenges in the Current System?

Overview:

Pharmaceutical care across Canada is a disconnected patchwork of drug programs, including private and government-funded public insurance plans. Each plan comes with significant variances, and individuals who are not part of any plan must pay out of pocket. There are widespread inequities and inconsistencies, leaving some patients uninsured or underinsured. Issues include drugs that are not available, in shortage, or subject to limitations, lack of portability between jurisdictions, and extended wait times for reimbursement decisions.

The following are considerations:

Inadequate coverage:

- Some patients have no drug coverage as they are not part of an employer-based plan and do not qualify for a public plan, perhaps because of age or income thresholds. They pay out of pocket and costs can be prohibitive in the context of other living expenses. In some cases, patients forgo treatment.
- Some patients who are part of private plans can be described as underinsured, facing prohibitive co-pays and caps on coverage, among other issues.

Limitations/restrictions:

- Within public programs, criteria to qualify for specific drugs can unreasonably restrict a patient's ability to receive a drug considered medically necessary. This can also be the case within private drug plans, but to a far lesser extent.
- Some drugs, such as newer, specialty drugs, are rarely or never included in public programs for various reasons, including cost. In addition, there are some drugs available in other countries that are never introduced in Canada.
- Within some programs, special authority processes which require specialists to complete forms can provide an administrative and access burden which creates a barrier to optimal care.

Timeliness:

- Patients often experience unreasonably long wait times while a drug moves through the process of approvals, assessments and negotiations (from Health Canada through to reimbursement bodies) until a necessary drug is available to them.

Inequity/disrupted care:

- The current system is inequitable with discrepancies between various public programs regarding what drugs are covered, and under what circumstances. Differences between public programs and employer-based private plans are even more marked, creating significant inequity.
- Decisions on treatment that are based on financial considerations rather than what has been deemed to be appropriate and effective for an individual patient can sometimes act as a barrier to optimal care.
- Lack of portability between government programs within Canada, along with varying consistency in what is covered in each program, means that patients can temporarily or permanently lose access to coverage if they move between provinces. Coverage can also be lost when changing employers, or when changes are made to a plan.
- Lack of collaboration between government and private plans means that patients in transition between plans must try other options (e.g. step therapy) or apply for exceptional access to be eligible for a recommended drug already shown to be effective for them.
- There is a lack of integration between hospital prescribing and ongoing care, with limited planning prior to discharge or during outpatient treatment to ensure drug coverage continues in the community. This can sometimes result in disruptions in care.

Health system challenges:

Several health system challenges which contribute to inefficiencies, delays, and optimal prescribing are identified, including the following:

- Lack of access to specialists and diagnostic tests can delay treatment plans, including appropriate prescriptions. Wait times to see some specialists can be up to two years.
- Canada lacks data infrastructure to track patient outcomes and value. Systems for integrating and evaluating real world data are necessary to measure how drugs perform and inform ongoing decision-making.
- While maximum prices for drugs are regulated and then negotiated by payers, in some cases the high cost of certain therapies results in refusal to list by some governments.
- Canada lacks a system to link credible, up-to-date evidence-based treatment guidelines to drug funding, resulting in clinicians sometimes offering sub-optimal care based upon reimbursement, not on evidence.
- Additional health care costs associated with patients not being able to access drugs, including but not limited to workplace productivity, disability, frequent hospitalizations and long-term care, need to be considered.

Comprehensive Care: What Drugs Should be Covered?

Types of drugs:

For a national pharmacare program 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, regardless of type or incidence of condition. In addition, there must be the capacity and flexibility to incorporate new developments and provide coverage for drugs to meet unmet patient needs. Comprehensive coverage must encompass both widely-prescribed, primary drugs, as well as specialty drugs, including:

- Drugs which are considered curative or breakthrough because they offer extremely significant improvements for life threatening or debilitating conditions.
- Drugs for a full range of conditions, regardless of incidence, including chronic and rare disorders.
- Future, next generation treatments such as gene and cell therapy.

Formulary scope:

Comprehensive means a range of drugs address the individual needs of each patient. Through the lens of equity, the range of drugs currently provided through the formularies of many private plans are considered comprehensive and suitable for all Canadians. Regarding other options, the following considerations are offered:

- The current Quebec formulary, the largest government drug program in Canada, is usually regarded as including a sufficient scope of drugs to be considered comprehensive. National implementation of this scope of formulary is seen as feasible.
- While a formulary of all drugs approved by Health Canada would provide a high level of options for care, this is not generally seen as feasible.
- Other public drug programs, which have more narrow formularies than Quebec, are not seen as being comprehensive enough to provide an adequate level of care.
- Proposals presenting an Essential Medicines List, whereby a limited list of about 125 widely-prescribed, mostly generic medicines for non-specialized care would be available to all at no cost or modest cost, do not offer value or contribute to comprehensive care. The limited nature of an Essential Medicines List does not recognize the complexities and variability of patients and their needs. Implementation would bring coverage below current levels, in many cases.

Comprehensive Care: Who Should be Eligible for Drug Coverage?

Drug coverage must be universally available, providing comprehensive care which equitably meets the needs of each individual. As such, if a single-payer model were adopted, everyone regardless of age, disease-type, income or employment status should be eligible.

If a mixed system, with a role for both public and private programs, is continued those who do not have access to private coverage should be part of public drug program, with the following considerations:

- Coverage should be based on medical or financial need, where those with low incomes or high drug costs relative to their income are not faced with catastrophic drug costs. Subsidies could be available for low income Canadians.
- Situations where employed individuals are considered underinsured and facing high costs must be addressed to ensure equity.
- Coverage should not always be based on age, as it is not appropriate to prioritize wealthy individuals ahead of working age Canadians or others who do not have any or sufficient drug coverage.

Delivering Pharmacare: How Should Pharmacare be Funded?

Overview:

Ensuring that comprehensive drug coverage is available equitably to all must be the primary goal of pharmacare reform. Whether this is made possible through government-funded public plans, private insurers, or a combination of both, warrants careful consideration regarding the feasibility of providing comprehensive care which equitably meets the needs of all Canadians.

Importantly, the status quo, which is a mixed funding model where both governments and private payers provide variable coverage to most Canadians leaving some with no coverage or not enough coverage, is unacceptable.

The following are considerations:

Public funding:

- There is support for a model whereby the provinces and territories secure sufficient additional funding from the federal government, to be able to ensure universal coverage which is delivered consistently and equitably to all Canadians.
- There is also support for a more limited role for the federal government in providing additional funding to the provinces and territories to provide all residents with consistent financial protection for catastrophic drug costs.

Mixed public and private funding:

- There is support for a role for private insurance in delivering pharmacare, along with governments, within a mixed system. In addition, there is support for the notion that in any type of model the ability to buy additional private drug insurance should be retained.

Funding considerations:

- The challenge of inequity in coverage based on income and employment status, which are an aspect of a mixed public and private system, must be reconciled and addressed. The need to purchase additional insurance because of shortfalls in the public system inherently discriminates against individuals who are unable to afford extra insurance. In addition, several patient populations are unable to work and do not have access to employer-based insurance programs or buy additional insurance. They should not be discriminated against by being restricted in terms of access to some drugs.
- Various models for private insurance within a mixed system have both merit and challenges, and each should be examined and evaluated in the context of the public system. International experiences should be reviewed regarding impact on patient care and other implications, along with made-in-Canada approaches.

- Models which mandate employers to provide coverage should be approached cautiously, and must be fully understood in terms of feasibility and implications, specifically including impact on small businesses.
- Frameworks for regulating the insurance industry also need to be considered, focused both on protecting patients and sustainability of delivering comprehensive coverage affordably.
- Integration and coordination between public and private systems is important to ensure optimal patient care. Processes must be well planned and efficient to ensure that patients are not left without coverage while coverage decisions are reviewed.
- There are concerns about the stability and long-term role of private plans, specifically the ability of governments to control or regulate them.
- In a mixed system, available public funding must be directed at ensuring comprehensive care with a full range of treatment options for patients, and in this context, government as a first payer for those with private coverage is likely not feasible.
- Alternate funding models for specific drugs need to be explored, regardless of if they are within a single payer or mixed system. An example is risk-sharing agreements (pay for performance models), which would involve more engagement in negotiation processes.
- A national pharmacare program cannot be comprehensive and equitable if it is underfunded, even if offered within a mixed system. Therefore, funding must be made available to ensure public program budgets are sufficient.
- While there are concerns about an additional tax burden, taxes are also sometimes considered to be an equitable source of funds. Further understanding is needed on whether Canadians are willing to pay for national pharmacare through increased taxation, such as a supplemental tax like the Health Tax in Ontario, premiums in BC or co-pays and premiums in Quebec.

Reform Goals: What Should Pharmacare Reform Accomplish?

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 without sinking to the lowest common denominator. Reform should build upon the best of what is in place now and ensure 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.

Address the uninsured and underinsured:

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 public plans. It 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.

Improve 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, with streamlining and standardizing approvals and formularies.

Focus on the right drugs:

Reform should move away from a sole focus on cost-saving to improving care – improving access to the drugs that people need including drugs for chronic or rare diseases, new drugs and specialty drugs. The ability to meet unmet needs and prevent complications must be valued. In addition, patients should not be switched from drugs that work well just to save money.

BEST MEDICINES COALITION

Alliance for Access to
Psychiatric Medications

Arthritis Consumer Experts™

Asthma.ca
Asthma Canada

BPC Better Pharmacare Coalition

braintumour
foundation
OF CANADA

CAPA Canadian Arthritis Patient Alliance
experience · perspective · voice

CBCN
RCCS

CANADIAN COUNCIL
OF THE BLIND LE CONSEIL CANADIEN
DES AVEUGLES

Canadian
epilepsy
Alliance Alliance
canadienne de
l'épilepsie

Canadian Hemophilia Society
Help Stop the Bleeding
Société canadienne de l'hémophilie
Arrêtez le hémorragie

The
CANADIAN
PKU AND ALLIED DISORDERS

Canadian Mental
Health Association
Mental health for all

Canadian
Psoriasis
Network Réseau
canadien
du psoriasis

CSPA Canadian Skin
Problems Alliance

Canadian Society of
Intestinal Research

Canadian
Spondylitis
Association

C T A C

Crohn's and Colitis
Foundation of Canada

The FOUNDATION
FIGHTING BLINDNESS

badgut.org
Gastrointestinal Society
Société gastro-intestinale

HEALTH COALITION
OF ALBERTA

Cancer
du rein CANADA Kidney
Cancer
CANADA

LYMPHOMA
CANADA

MILLIONS MISSING CANADA

Ovarian Cancer Canada
Cancer de l'ovaire Canada

Parkinson Canada