

# Advisory Council on the Implementation of National Pharmacare Best Medicines Coalition Position Points on Key Recommendations

July 2019

### **Core Positions:**

- The Best Medicines Coalition (BMC) is in full agreement with the Advisory Council's conclusion that the status quo is insufficient to meet the needs of all Canadians. In our submission to the Advisory Council, we called for significant reforms to address inequities and inadequacies that lead to compromised care outcomes at great cost and suffering to individuals and families. As a core principle, we believe that all patients, without exception, must be able to obtain medically necessary medications.
- While a transition to universal drug coverage through a single payer system, perhaps, is a
  worthy goal, we suggest a phased approach to reform, levelling up the public programs to
  address inequities and prioritize addressing the most critical disparities in the system. Another
  principle we support is that no Canadian should lose existing coverage of drugs provided
  through private health insurance. In other words, any changes must not leave any patient
  worse off with respect to access to mediations than prior to the implementation of National
  Pharmacare.

## Positions Regarding Key Recommendations of the Advisory Council:

As next steps regarding National Pharmacare are considered, the BMC offers perspectives from our community of patient organizations, each of which are informed by front-line contact with Canadian patients and motivated by the urgent need to improve care for all:

Efficient and effective infrastructure. The proposed Canada Drug Agency has great potential to drive positive reform and deliver system infrastructure which is integrated and efficient while facilitating timely access to the medications that Canadians need including new breakthrough therapies. Establishment of the agency is an excellent opportunity to address the current complex and duplicative policy and program delivery labyrinth by eliminating duplication, waste and redundancy. The new agency must not be an add on or additional layer, but rather a lean instrument for modernization and effectiveness. It should be a requirement of good policy to identify clearly which duplicative organizations and/or functions will be replaced by the CDA. In addition, substantial investment in information technology infrastructure to enable sophisticated data collection and analysis, as recommended, is necessary, but safeguards must be in place to ensure efficient and effective execution. We strongly recommend, to ensure transparency and accountability, that the CDA be established by statutory law, subject to Parliamentary oversight, the Access to Information Act, Auditor General scrutiny, and interventions by an Ombudsman-type office.

**Patient-driven governance.** The enshrinement of the patient voice within governance bodies, as recommended, has our full support as it will be, if enacted, an important and powerful tool to ensure that patient expertise, values and outcomes are recognized and drive reform, decision-making and ongoing work. We note that the patient role in governance is not reflected in the status quo. Indeed, an enhanced role for patients throughout policy development and decision-making processes should be entrenched at all relevant agencies engaged in drug review, approval, evaluation and negotiation.

Ensuring comprehensive care. As the Advisory Council recommends, reform should transition to a full and comprehensive national formulary, which the status quo lacks profoundly. From our perspective, comprehensive means that all patients, without exception, must be able to get the medications each requires. This includes those with chronic, complex, difficult to treat, and/or rare conditions. Comprehensive must include specialized drugs, and medications considered curative or breakthrough. We note that the Advisory Council's recommendation regarding the "comprehensive" scope of National Pharmacare speaks to an eventual "broad" formulary of covered drugs but it is not consistent with the definition of "medically necessary" in the Canada Health Act. We urge the federal government, and its provincial and territorial counterparts, to take an approach which is consistent with meeting the medical needs of patients.

Furthermore, we are disappointed in the Advisory Council's recommendation that National Pharmacare start with a less than comprehensive formulary of so-called "essential" medicines. While an essential medicines list designed for Canadians may have merit as a stop gap measure, reform towards a comprehensive solution must be prioritized and expedited. This approach, if adopted, will leave too many Canadians without adequate coverage. Further understanding is needed regarding options for patients during the transition period between a limited list in 2022 and adoption of a more comprehensive list in 2027, as proposed. Canadians will be disappointed, to say the least, if our elected representatives and civil servants continue to have access to a broad range of insured drugs which other Canadians do not have coverage for. It is a matter of fairness in public policy.

**Out-of-pockets costs to patients:** In our submission to the Advisory Council, we recommended that the current practice of patient cost-sharing of pharmaceuticals must be addressed, with recognition that drugs are a legitimate and important element of medical care and should be made available to all like other essential medical services. Therefore, we fully support the Advisory Council recommendations that a universal, comprehensive National Pharmacare strategy must address and overwhelmingly reduce the 22 percent of drug spending which is paid out-of-pocket by individual Canadians.

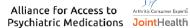
**Addressing rare diseases.** The Advisory Council report and the 2019 federal Budget have both rightly highlighted rare diseases as warranting a specialized approach and the Federal Government has committed in the Budget to creation of a national strategy for high-cost drugs for rare diseases and allocated funding. This approach must be championed and advanced by all leaders, including federal Health and Finance Ministers and provincial and territorial counterparts.

## Moving forward with focus on improving patient care:

The important work of delivering universal and truly comprehensive National Pharmacare to all Canadians has begun and we urge all governments - federal, provincial and territorial - to 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 but at a high level – not the lowest common denominator approach - with a comprehensive range of medicines available to all based on medical need.

#### **About the Best Medicines Coalition**

The Best Medicines Coalition (BMC) is a national alliance of 28 patient organizations with a shared goal of equitable and consistent access to safe and effective medicines for all Canadians. With interests in drug approval, assessment, reimbursement, and safety and supply issues, As a coalition, the BMC strives to ensure that patients, and the organizations that represent them, have a strong, meaningful voice in health policy development, specifically regarding pharmaceutical care. Formed in 2002 as a grassroots alliance, the BMC registered under the Not-for-profit Corporations Act in 2012.











nadienne de

















































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 Cancer Survivor Network Canadian Council of the Blind Canadian Epilepsy Alliance Canadian Hemophilia Society Canadian Mental Health Association Canadian PKU & Allied Disorders Canadian Psoriasis Network

Canadian Skin Patient Alliance Canadian Spondylitis Association Canadian Treatment Action Council Crohn's and Colitis Canada Cystic Fibrosis Canada **Foundation Fighting Blindness** Health Coalition of Alberta **Huntington Society of Canada** Hypertension Canada Kidney Cancer Canada Lymphoma Canada Millions Missing Canada Ovarian Cancer Canada Parkinson Canada