



HEALTH COALITION OF ALBERTA

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Patented Medicine Prices Review Board
333 Laurier Ave. West, Suite 1400
Ottawa, Ont. K1P 1C1
Email: PMPRB.Consultations.CEPMB@pmprb-cepmb.gc.ca

RE: PMPRB Guidelines Input

To Whom it May Concern:

It is unfortunate that, once again, Canadians are forced to express disapproval of the most recent guidelines presented by the Patented Medicine Prices Review Board's (PMPRB) in October 2022. After five years of patient group submissions to PMPRB, we are still bringing forward concerns about lack of evidence, lack of transparency, lack of clarity, lack of confidence and the potential negative impact to patient care caused by these guidelines. In fact, it is growing increasingly difficult to refer to our concerns as unintended consequences when patient groups have pointed them out again and again. Sadly, Canadians are no better off than we were in 2017 and non-profit organizations and charities are wasting limited resources responding to guidelines that still do not focus on ensuring a robust health care system that achieves improved health outcomes for all.

The Health Coalition of Alberta (HCA) recommends this iteration of PMPRB's guidelines is stopped and PMPRB moves forward with implementation of the new basket of 11 countries to achieve lower medication prices in Canada. We also recommend that PMPRB monitors the process and conducts a thorough assessment to gauge both the financial savings achieved as well as determine its impact on Canadians' ability to access new medications and improved health outcomes. If any additional changes are deemed necessary, they must be created in collaboration with stakeholders, including patients and their representatives, with achieving improved health outcomes for Canadians as a core value.

Who We Are:

The Health Coalition of Alberta is an alliance of more than 100 health charities, patient groups, non-profit organizations and individuals driven by a unified purpose. Through the strength of our membership, we have voice and influence into public health decisions that impact the health of Albertans. We use a collaborative, solution-focused approach to engage with governments, health policy decision-makers and other stakeholders to achieve our goals.

The Health Coalition of Alberta advocates for the adoption of a relational model of care that is centered on patient needs to achieve their full health potential. We support shared decision-making between the health care team and educated and informed patients in order to make choices that will have the most impact on not only the health but also the emotional and social needs of each individual.

We achieve our purpose by: advocating on key health care issues; educating our members and the public so they can engage effectively with the health care system; and, by raising awareness and stimulating dialogue around health care policy and service changes that impact Albertans.

As a member of the Best Medicines Coalition (BMC), we support their submission and encourage the PMPRB to implement BMC's recommendations.

Our Feedback:

The Health Coalition of Alberta has taken the time to educate our members, staff and volunteers about PMPRB's proposals. Over the years, we have presented numerous written submissions and have yet to see any evidence that patients are being heard during this extensive reform process. Once again, we recommend that the current iteration of the guidelines is dismantled as it does not reflect the best interests of Canadian patients.

There is no evidence that the uncertainty caused by these vague guidelines will not result in delayed and reduced access to medications. Of particular concern, is the impact for patients living with cancer and rare diseases as these are areas where the value of subsequent research and expanded therapeutic indications can result in better treatment choices. Not only has any consideration of therapeutic value of new drugs been eliminated but it appears like manufacturers are dis-incentivized to continue to research expanded use of existing medications.

As an equity seeking organization, it is very clear to the HCA that these guidelines could trigger even greater gaps in care and create an environment that works against achieving health equity. If aggressive pricing approaches cause delays or prevents new medications being launched in Canada it will potentially lead to wealthy citizens leaving the country to gain access to treatments as they cannot risk that the treatment may never be available here. This inequity will create to a two-tiered health care system that penalizes vulnerable patients who are not able to access optimal care.

A core operational concept for the Health Coalition of Alberta is to take a collaborative approach to our patient advocacy efforts. Our members believe in the value of bringing together stakeholders to clearly identify issues and seek answers together. All views have value and must be considered when developing successful solutions. However, PMPRB launched these latest guidelines in isolation, without patient input and with what appears to be no recognition of concerns brought forward by patient groups in the past.

The HCA recommends that PMPRB develop a new process in partnership with stakeholders that is focused on achieving lower medication prices in Canada but will also support patients' timely access to new medications and create confidence that patient health outcomes are a priority. The only way an effective solution to providing affordable and accessible medications to Canadians can be created is when it is developed with all stakeholders as equal partners. Recognizing patients' lived experience must be an integral part of ethical considerations and assessment of the impact on care in Canada. These views must be factored into any decisions made by PMPRB.

Summary:

Sadly, the Health Coalition of Alberta is once again reiterating our past submissions to PMPRB.

It is a laudable goal to lower medication prices, and one that our members support. However, this must be balanced with the need to secure robust access to new therapies and clinical trials in Canada. The extensive process that is currently ongoing is not only unproductive but has demonstrated that patient input has no value at PMPRB. It must be dismantled.

The Health Coalition of Alberta supports the creation of an encompassing strategy, developed in partnership with stakeholders, that balances the desire for affordable prices of medications with the need to protect and grow investment in innovative research, clinical trials and timely access to new medications. This must be based on a methodology that is transparent, simple, and focused on the PMPRB mandate without over-stepping into areas already addressed by bodies like CADTH and pCPA.

The Health Coalition of Alberta also recommends the entrenchment of patient perspectives within PMPRB. Equal representation of public members must be appointed to the Board and Human Drug Advisory Panel to ensure Canadian values are reflected in PMPRB's goals. We also recommend the creation of an Expert Patient Advisory Panel to assess all projects, investigations, or decisions through a societal lens.

If you have any questions about this submission, please contact the Health Coalition of Alberta at director@healthcoalitionab.ca

Sincerely,



Beth Kidd
Executive Director