



August 31, 2021

Patented Medicine Prices Review Board  
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Email: [PMPRB.Consultations.CEPMB@pmprb-cepmb.gc.ca](mailto:PMPRB.Consultations.CEPMB@pmprb-cepmb.gc.ca)

**RE: PMPRB Revised Draft Guidelines**

To Whom it May Concern:

Despite providing patient feedback on the Patented Medicine Prices Review Board's (PMPRB) Guidelines for the past several years, there remains too many outstanding questions for Canadians to have confidence in the final Guidelines let alone the latest proposed changes. Patients and their representatives have repeatedly expressed concerns about the uncertainty, complexity, lack of clarity and unintended consequences caused by these Guidelines.

Most recently, the PMPRB's culture of bias towards patients and their representatives was made public through the release of an Access to Information and Privacy (ATIP) request made by Alberta MP Tom Kmiec<sup>1</sup>. This highlighted the lack of respect and even simple acknowledgement many patient advocates have experienced in attempts to engage with PMPRB.

The PMPRB has clearly demonstrated an inability to develop unbiased guidelines that take into account stakeholder views and, as a result, the current iteration of the Guidelines should be dismantled, ongoing tinkering with no rationale for changes must end, and, the systemic culture of bias towards patients and their representatives must be eliminated.

A new process needs to be developed in partnership with stakeholders that will not only achieve lower medication prices in Canada but will support patients' timely access to new medications and create confidence that patient health outcomes are a priority.

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<sup>1</sup> <https://twitter.com/tomkmiec/status/1395851080441999364>

## **Who We Are:**

The Health Coalition of Alberta (HCA) is a group of 100 voluntary health sector organizations, consumer groups and individuals committed to working together and advocating with a united voice for better access to optimal healthcare for all Albertans. Primary initiatives of the Health Coalition include advocacy on key healthcare access issues, education of members and the public, and awareness regarding healthcare reform decisions and service changes which could impact Albertans, and particularly patients in their care pathways and health outcomes.

As a member of the Best Medicines Coalition (BMC), we support their submission and encourage the PMPRB to implement BMC's recommendations aimed at achieving effective, fair and balanced pharmaceutical pricing regulations.

## **Our Feedback on the Latest Revisions:**

Unfortunately, Canadians have once again been asked to provide feedback on revisions to the PMPRB Guidelines without any data, evidence or rationale to demonstrate the impact of these changes. We have not been given any analysis that these modifications will be effective, will help to improve Canadians' access to medications and will not jeopardize patient health outcomes. The lack of clarity about the objectives and goals behind these changes only add to the apprehension this will trigger unintended consequences and drives fear that such sweeping reforms will cause disruption to Canadians' ability to access new medications in an equitable and timely manner.

The 2021 federal budget<sup>2</sup> included a commitment of billions of dollars related to the health and life sciences sector. For example, more than \$2 billion was committed towards growing a vibrant domestic life sciences sector and another \$1 billion was designated to develop a Strategic Innovation Fund to target "promising domestic life sciences and biomanufacturing firms". Here in Alberta, the provincial Minister of Health, Tyler Shandro, has expressed his government's interest in attracting biopharmaceutical investment, research and development to Alberta.

This support for building medication development and innovation capacity in Canada is exciting for patients. However, the HCA cannot see how this can be achieved without evidence that the proposed PMPRB Guidelines will support governments' investments in the life sciences sector and not prove to be a dis-incentive for pharmaceutical research, development and manufacturing across Canada.

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<sup>2</sup> <https://www.budget.gc.ca/2021/report-rapport/toc-tdm-en.html>

As such, the Health Coalition of Alberta cannot support the proposed changes without evidence to demonstrate this will not result in a negative impact for Canada's patients and our healthcare system.

**Our Recommendation:**

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.

In an effort to end the PMPRB's evident culture of bias towards patients and their representatives, 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 through a societal lens.

If you have any questions about this submission, please contact the Health Coalition of Alberta at [director@healthcoalitionab.ca](mailto:director@healthcoalitionab.ca)

Sincerely,

A handwritten signature in black ink that reads "B. Kidd."

Beth Kidd  
Executive Director