



HEALTH COALITION OF ALBERTA

403-605-2859

director@healthcoalitionab.ca

P.O. Box 81187 Lake Bonavista

Calgary, AB T2J 7C9

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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 Consultation Input

To Whom it May Concern:

Thank you for the opportunity to provide feedback on the six themes for discussion as outlined in the Scoping Document released in November. The Health Coalition of Alberta (HCA) listened to the online consultations earlier this month and will capture some learnings from that session as well as overall comments in this submission. For more than six years, we have been asking the PMPRB to adopt a process that is transparent, clear, evidence-based and engages patients. We appreciate the shift in approach signalled by the Board in this round of consultations.

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.

Overall Feedback:

In our past submissions, the HCA asked PMPRB to move forward with the implementation of the new basket of 11 countries to achieve lower medication prices in Canada. We are pleased this happened and that new Guidelines will be developed to support this amendment. We also recommended 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 and health equity for Canadians as a core value.

When listening to the stakeholder consultations in early December, it became quite evident that there still needs to be a tremendous amount of education done before the PMPRB truly understands the full scope and impact of the pharmaceutical manufacturing, marketing, distributing, funding, and patient access network in this country. We recommend that all those involved in decision-making or providing advice undergo a deeper consultation with those involved and impacted by each step of the process. This will help to ensure decisions made by PMPRB do not have unintended consequences because of ignorance and a lack of education. Hopefully, the in-person and online presentations created a more complete picture for PMPRB, but we recommend the continuation of this dialogue to develop a deeper understanding of the impact on Canadians of decisions made by PMPRB.

We recommend that PMPRB recognize its role in the Canadian access to medication process, along with the functions of the multiple other bodies that assess new medications before they are provided to patients. It is not PMPRB's role to determine societal considerations that were often questioned during the public consultations in December. For example, the questioning of the value of funding medications for limited populations living with a rare disease vs. a medication for a broader-based population. This is an assessment that is completed through the health technology assessment process conducted by CADTH, the incoming Canadian Drug Agency, and by public payers participating in the pCPA. Canadians want and deserve a system that is without duplication, that has clear delineation of areas of responsibility and that is delivered upon without separate government bodies straying into areas outside of their mandate. Taxpayers expect our dollars to be used effectively and efficiently in a modern, streamlined manner.

We also recommend that PMPRB focus on creating Guidelines to support the existing amendments before wading into expansion, scope creep, etc. These Guidelines should ensure international price comparisons are being conducted fairly, transparently, consistently, and, without any detrimental impact on the health of Canadians first.

As an advocate for health equity, it is a priority for the HCA to ensure these Guidelines do not have unintended consequences that cause even greater gaps in care and create an environment that works against achieving equity for patients in Canada. Delays in new medications being launched in Canada 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 a two-tiered health care system that penalizes vulnerable patients who are not able to access optimal care. It is essential that any moves taken by PMPRB do not drive access to medication inequities in our country.

Theme 6: Engaging with Patients, Health Practitioners, Pharmacy, and other Stakeholders:

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.

The HCA applauds the PMPRB for listening to our past advice to create a new process in partnership with stakeholders. We recommend that this is built upon the concept of patients as co-developers of policy and not as foes. An environment needs to be created for stakeholders to work together to find solutions that benefit Canadian patients. Working in partnership, we can achieve lower medication prices in Canada while also supporting patients' timely access to new medications. This will 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.

Patients and their representatives should be included as co-developers of any new work conducted by the PMPRB. To be successful, it is vital that the highest impact decisions have the highest level of engagement. The Health Coalition of Alberta 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.

Meaningful patient engagement ensures that the individual is placed at the centre of decisions that impact their health. Consultations on health policy and research must include patients, caregivers, equity seeking groups, and marginalized communities and include real-world evidence and lived experiences as data for decision-making.

Cornerstones for best-practice engagement include:

- It is equitable
- It considers patients as experts
- It builds respect, empathy and trust
- It upholds standards of ethics and confidentiality
- It includes accountability

We also recommend and encourage the PMPRB to learn more from guidance included in the many patient engagement frameworks that are used already in Canada and around the world to find methods to employ moving forward. Some examples include CADTH's patient engagement framework, as well as the guidelines and values created by the International Association of Public Participation. The Health Coalition of Alberta also has our own patient engagement guide and would value the opportunity to share this with PMPRB.

Summary:

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 Health Coalition of Alberta supports the creation of an encompassing strategy, developed in partnership with patients, 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.

We have included eight recommendations in this submission that we believe will all help achieve this goal. If you have any questions about this submission, please contact the Health Coalition of Alberta at director@healthcoalitionab.ca

Sincerely,



Beth Kidd
Executive Director