Health Charities Coalition of Canada Coalition canadienne des organismes de bienfaisance en santé

September 11, 2024

Patented Medicine Prices Review Board
Box L40, 333 Laurier Avenue West, Suite 1400
Ottawa, Ontario K1P 1C1

Submitted via email

Dear Members of the Patented Medicine Prices Review Board,

The Health Charities Coalition of Canada is pleased to provide input into the Patented Medicine Prices Review Board (PMPRB) Consultation on Shaping the Future: A Discussion Guide for PMPRB Phase 2 Consultations on New Guidelines. Our submission addresses topic areas outlined in the consultation guide that are most relevant to our membership and the patients/ individuals with lived experience and populations that we serve.

The Health Charities Coalition of Canada (HCCC) is a member-based organization comprised of national health charities who represent the voice of patients at all levels of the health continuum. Our mission is to lead national collective action on health policy and health research to benefit patients living in Canada. Our members are co-funders with the governments on some of the most important leading health research in Canada and together we translate knowledge gathered through research to advocate for better public policy and better health outcomes for Canadians.

Over the last eight years, our members have provided input to the PMPRB consultations for the simple reason that we believe that access to affordable medicines is an important issue for our membership. Prescription drugs can manage conditions, cure disease(s), improve quality of life, shorten or prevent time spent in hospitals and reduce the demand for health care services, potentially leading to positive health outcomes and decreased costs to the healthcare system. An effective and sustainable drug approval process is key in being able to provide timely access to medicines for Canadians.

While the focus for these consultations has been on the modernization of the guidelines, it is important to acknowledge and reiterate the key function that PMPRB plays in protecting consumers from excessive patent drug costs and in listening to the voices and views of Canadians. As your website so aptly states, "*The PMPRB has made a commitment to "listening to the voices and views of Canadians and to including them in decision making. Effective and meaningful stakeholder involvement is essential to enable the PMPRB to fulfill its mandate, deliver programs, launch new initiatives and build public trust."* [1] It is unclear how the PMPRB intends to uphold the aforementioned commitment of including Canadians in their decision making process.

Meaningful engagement of patients/the lived experience is foundational to creating health system improvements and we propose the following opportunities for meaningful engagement at the PMPRB:

[1] Retrieved from PMPRB website https://www.canada.ca/en/patented-medicine-prices-review.html on August 30, 2024.

- Create a designated board position for a patient/person with lived experience on the PMPRB Board of Directors,
- Include individuals with lived experience as one of the designated groups within the Human Drug Advisory Panel that PMPRB staff may access, and
- Continue providing opportunities for patient representatives to meet with the Board Chair to share and discuss information and issues surrounding decisions that are before the Board.

We would be pleased to meet with the Board to discuss opportunities for extending engagement with patient partners in the PMPRB.

Topic 4 of this consultation asked, "Who should be permitted to submit a complaint?"

Currently the PMPRB will investigate complaints from Canadians who are concerned that they are being charged too much for their medications. Any individual or group who feels as though they have been affected by the price of a patented medicine can submit a complaint directly to the PMPRB. Based on the important role that the PMPRB has to "protect and inform Canadians by ensuring that the prices of patented medicines sold in Canada are not excessive and by reporting on pharmaceutical trends", there is an ongoing expectation that any Canadian may file a complaint regarding an excessive drug price and have the PMPRB respond.

It is essential that Canadians have an opportunity to have their voices heard on these issues and that there is a well-documented and simple process for doing so. We strongly recommend that the opportunity for patients/citizens to submit a complaint regarding excessive patented drug pricing directly to the PMPRB not be impeded in any way.

We understand that as part of the modernization of the guidelines the Board is seeking guidance on who can submit a complaint that will lead to an automatic in-depth review. A clear articulation of how complaints will be processed and what criteria must be met in order to trigger the in-depth review is needed.

Topic 7: Future role of HDAP (Human Drug Advisory Panel)

At a minimum, staff should have available to them an advisory panel available to assist them with scientific evaluations in view of their broad general knowledge of drug therapy, drug evaluation, drug utilization and clinical research methodology. As some of the comparators that may be considered include factors such as patient convenience and outcomes of head to head clinical trials, it is highly recommended that a patient partner be recommended as an integral part of the Human Drug Advisory Panel.

We thank you for the opportunity to provide comment and look forward to participating in the next phases of the consultation.

Sincerely,

Connie Côté
Chief Executive Officer
Health Charities Coalition of Canada