



# Submission to PMPRB Guidelines Scoping Paper

December 20, 2023

The Health Charities Coalition of Canada (HCCC) is pleased to share its views on the PMPRB's new Scoping Paper, which aims to inform the board's future Guidelines approach. HCCC represents the interests and perspectives of patients who rely on access to safe, effective, and affordable medicines in Canada. As such, we have a keen interest in the PMPRB's mandate and activities, and how they affect the availability and affordability of new medicines coming to Canada.

As the Scoping Paper does not present any specific proposals with respect to the future Guidelines, this submission provides general forward-looking considerations on some of the key issues that matter most to patients. Most of the feedback provided falls under themes five and six of the discussion paper. We hope that our input can help inform the development of a drug pricing system that reflects the needs of Canadians.

In this context, we respectfully submit the following recommendations for your consideration:

### **1. Engage in meaningful collaboration and dialogue with patients**

We would like to start by commending the PMPRB for its commitment to hold a more extensive, inclusive, and transparent consultation process. This is a welcome change in tone and approach from how the PMPRB has conducted consultations in the past. Moving forward, we believe the PMPRB can greatly benefit from incorporating the perspective of patients, who bring a unique "lived experience" to the table and are able to provide input and solutions from the perspective of the end-user, including through the collection of real-world evidence (RWE). Importantly, patient engagement is a key priority for organizations such as Health Canada and CADTH, who are continuously seeking out opportunities to expand input from those with lived experience as part of their decision-making processes.

As the PMPRB continues its commitment to a more inclusive consultation process, we encourage them to actively seek and incorporate the voices of people with lived experience, aligning with broader trends toward patient-centered healthcare decision-making. This will help lead to more effective and responsive pharmaceutical policies that not only consider the economic and regulatory aspects but also prioritize the well-being and experiences of the individuals directly affected.

It is also important to note that meaningful engagement goes beyond holding briefings and calls for submissions. It is the conscious effort to include patients every step of the way – from identifying gaps and problems to working together to find solutions. In this regard, the PMPRB should explore mechanisms to involve those with lived experience in working groups, expert panels, and decision-making forums. This ensures that patient perspectives are not merely considered as a checklist item but are integrated into the fabric of the decision-making process. The PMPRB should also strive to ensure plain language explanations for its proposals, so that patients can better understand and contribute to policy discussions.

## **2. Access to Medicines for Canadians**

Medicines play a very important role in our health system. They can help manage conditions, cure diseases, improve quality of life, and shorten or prevent time spent in hospitals, thereby reducing costs to the healthcare system in the long run. In fact, studies have shown that every dollar spent on medications results in two dollars of offsetting health and societal benefits.<sup>1</sup>

In this context, Canadians need timely, equitable, and affordable access to a wide variety of treatment options for their conditions, as what works for one person may not work for another. This includes medicines with the same chemical profile but that rely on different delivery mechanisms, as this can have a major impact on patient adherence (and therefore clinical outcomes) and quality of life. It is also important to emphasize that while some cutting-edge treatments (e.g., precision medicines) may cost more up front, they have the potential to achieve significant long-term health system savings through better health outcomes and improved disease management down the line.

Against this background, in designing its pricing Guidelines the PMPRB should carefully reflect on the impacts of its policies on timely medicine access for patients. Importantly, for some patients, waiting an additional 1-2 years for a new life-saving medication to come to Canada can literally mean the difference between life and death. We therefore need a system that supports better and more timely access to these critical tools – especially in drug categories where there are limited other therapies available. Making a medication affordable does not improve health outcomes of Canadians if the drug ultimately is not launched in the Canadian market.

Moving forward, the PMPRB should strive to create a transparent pricing system that considers unintended consequences which limit access in their decision-making, while preventing excessive medicine prices, as per its statutory mandate. It should also explore creative ways to recognize innovation and value in its price assessments, and this is an area where those with lived experience can contribute the most.

## **3. Recognize the PMPRB's place in evolving drug review landscape**

In designing its future guidelines approach, the PMPRB should reflect on its place among other key players in the health system, recognizing that things have changed and continually evolve. When the PMPRB was created in 1987, there was no pan-Canadian Pharmaceutical Alliance (pCPA), health technology assessment was in its infancy, and drug plans had limited capacity to negotiate with drug developers. However, the landscape has changed significantly since then. There are now many other actors and processes that exert downward pressure on medicine prices. Moreover, governments have emerging opportunities to leverage the National Drugs for Rare Diseases Strategy and national pharmacare policies as tools to address affordability and improve access. For these reasons, the PMPRB should focus on its mandate to ensure non-

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<sup>1</sup> Hermus G, Stonebridge C et al, Reducing the Health Care and Societal Costs of Disease: The Role of Pharmaceuticals, Conference Board of Canada, 2013.

excessive medicine prices, while allowing other actors in the system to fulfill their crucial roles in making pharmacare programs affordable and accessible for Canadians.

#### **4. Stress test future policy approaches prior to implementation**

In keeping with the PMPRB motto of “Protect, Empower, Adapt,” HCCC urges the PMPRB to take a stepwise approach to implementing its Guidelines. We recommend that the PMPRB take the time to understand the impact of its proposals by conducting extensive consultation with a diverse array of stakeholders as part of a Guidelines steering committee or working group.

Moreover, the PMPRB should conduct rigorous analysis (through case studies, impact assessments, road testing approaches one at a time, etc.) to mitigate potential unintended consequences of its new pricing policies on medicine access and the health research ecosystem. In this context, HCCC emphasizes the critical need for the PMPRB to leverage stakeholder case studies as invaluable tools for gaining insights into real-world scenarios (examples include Life Sciences Ontario / IQVIA’s analysis on new medicine launches in Canada<sup>2</sup> and the Conference Board of Canada’s research on Canada’s access to Disease Modifying-Therapies for Multiple Sclerosis<sup>3</sup>). In doing so, the PMPRB can attain a more nuanced understanding of the practical implications and potential challenges that may arise across diverse contexts.

The PMPRB should also continuously monitor and report on the outcomes and impacts of its new framework and be flexible and responsive to emerging issues and challenges. This iterative process will not only facilitate the identification of any unanticipated issues but will also provide an evidence-based foundation for necessary adjustments. This will help contribute to a system that supports both access and affordability of medicines for Canadians who need them.

#### **Conclusion**

Thank you once again for the opportunity to provide our input. HCCC remains committed to work with the PMPRB and all health system stakeholders to ensure that Canadians have access to high-quality therapies and services that are appropriate for patient needs, respect an individual’s choice and are delivered in a manner that is timely, safe and effective according to the most current evidence available. We look forward to further opportunities for engagement on this important file in the coming months and to strengthening our global position as a leader in providing access to affordable medicines for our citizens.

Sincerely,

Connie Côté

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<sup>2</sup> [https://lifesciencesontario.ca/stec\\_event/webinar-is-canada-losing-its-status-as-a-priority-medicine-launch-country-insights-from-iqvia-2/](https://lifesciencesontario.ca/stec_event/webinar-is-canada-losing-its-status-as-a-priority-medicine-launch-country-insights-from-iqvia-2/)

<sup>3</sup> <https://www.conferenceboard.ca/product/accessing-disease-modifying-therapies-for-multiple-sclerosis-a-pan-canadian-analysis/>

Chief Executive Officer  
Health Charities Coalition of Canada

## **ABOUT HCCC**

The Health Charities Coalition of Canada (HCCC) is a member-based organization comprised of national health charities which represent the voice of patients at all levels of the health continuum. The health charities that HCCC represents strengthen the voice of Canadians, patients and caregivers, and work with others to enhance health policy and increase investment in health research. HCCC strives to ensure that the federal government and policy makers look to the Coalition and its members for timely advice and leadership on major health issues of concern to Canadians; and that they recognize the expertise, commitment, and contributions of health charities in improving the health and well-being of Canadians.