



Canadian
Cancer
Society

Submission to the Standing Committee on Health
Study on the Patented Medicines Prices Review Board's Final Guidelines
By the Canadian Cancer Society
November 2020

To date, the Canadian Cancer Society (CCS) has provided input to every formal consultation that was issued by the Patented Medicines Prices Review Board (PMPRB) regarding the modernization of the Patent Act and changes to the guidelines. In all CCS submissions, CCS has recognized the complexity of balancing competing interests in the development of the new guidelines. CCS is disappointed by the release of the new guidelines because our concerns and recommendations have been largely overlooked, and requests for data that informed the decisions made by the PMPRB has not been made publicly available. CCS would like to use this opportunity to re-iterate our recommendations. CCS puts forward the following recommendations to the Standing Committee on Health regarding their study on the PMPRB guidelines:

1. Ensure that continued investments in research in Canada take place, including a robust clinical trial ecosystem.
2. Ensure that Canadians with cancer receive access to treatments without financial hardship, regardless of where they live.
3. Implement a phased approach of the PMPRB guidelines.
4. Ensure the PMPRB releases the data publicly that was used to inform the development of the revised PMPRB guidelines.

Research in cancer treatment

CCS believes it is important to foster a research environment in which cutting edge cancer research is sustainable. In 2019, we invested \$40.66 million in the best cancer research in Canada. These funds supported 248 innovative and influential research projects to help people with cancer live more fully. The new guidelines do not address our concerns about the need to support continued investments in research and we believe, they may represent a threat to those patients who rely on a robust clinical trials infrastructure to support their cancer journey. There are potential long-term ramifications to the health research ecosystem as a result of COVID-19. The Canadian research ecosystem is facing devastating consequences due to limited funding abilities from charities including CCS. Access to clinical trials are being impacted. Challenges for patients participating in a trial may arise from; social distancing requirements, cancer centre restrictions, travel limitations, interruptions to the supply of investigational products, or because of the strain on hospital resources.

Oncology is experiencing a significant wave of innovation that is changing the way cancer is diagnosed, treated and monitored. Advancements in cancer treatment includes gene therapy, immunotherapy, hormone replacement therapy and targeted drug delivery systems. CCS believes in establishing a health system that supports and facilitates the implementation of novel interventions in health practice.

Access to cancer treatment

CCS believes that all Canadians should have access to needed cancer treatments without financial hardship, regardless of where they live. CCS recognizes that the Canadian oncology market has been characterized by significant sales growth and increasing treatment costs in recent years, resulting in issues of affordability and access for people living with cancer. For that reason, CCS strongly supports the PMPRB in its efforts to secure lower prices for medicines, particularly, through comparisons of prices charged in similarly developed countries. However, in light of a lack of data addressing the effects of the PMPRB's proposed reforms, it is critical to take a phased approach to the implementation of the revised guidelines in order to fully understand the impact of these changes. CCS among other key stakeholders have consistently requested this information, however, we have not received the relevant data used by the PMPRB to inform the new guidelines. Otherwise, the proposed guidelines could substantially undermine access to medications and the availability of new treatments in Canada.

Among the 37 new medicines launched globally in 2018, over half of them were not launched in Canada, with a majority of those being in oncology or rare disease medications. It can be extremely difficult for a person living with cancer and their family members to know that a cancer medication may be accessible in the global market, but not available in Canada. More often than not, people living with cancer have a limited amount of time to manage their disease before the disease progresses and are unable to wait for prolonged periods of time for a new treatment to emerge. As such, timely access to treatment is extremely critical to people with cancer.

Need for increased transparency

Considering a lack of data on the full impact of the guidelines on patient access to new medicines, CCS has consistently called on the PMPRB to publicly address these concerns through releasing data that has been used by the PMPRB to inform their decisions on the development of the new Guidelines. However, the PMPRB has not released information or data to support the decisions that have been made in the new guidelines.

CCS is keen to engage on this matter to ensure access to drugs for people with cancer remains a continued priority for the Government of Canada, including the PMPRB. However, to date, our recommendations have not been incorporated by the PMPRB. CCS is open to further discussion on this matter.

Conclusion

Unfortunately, there are still many questions that remain unanswered in the new PMPRB guidelines. CCS's concerns have not been addressed. In conclusion, CCS acknowledges the complexity of this matter and recognizes the importance of collaboration in order to ensure that the end result would improve health outcomes for all patients. CCS welcomes the prospect of continuing to engage with the PMPRB in an effort to ensure that the reforms support, not hinder, people with cancer.

About us

The Canadian Cancer Society is a national, community-based organization whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. We are the country's largest national charitable funder of research into all types of cancer and are a trusted source of information about all types of cancer.