

February 14, 2020

Re: PMPRB Guidelines

To whom it may concern,

We are writing to you to provide our feedback on the draft PMPRB pricing guidelines. We appreciate efforts made to communicate the proposals through the non-industry session and follow-up call. It helps all stakeholders better understand the proposed legislative changes related to drug pricing in Canada.

Healthcare and human costs

We know all too well that that medicines used for various forms of inflammatory arthritis are expensive. In Ontario, the annual cost of biologics for rheumatic conditions and inflammatory bowel disease (infliximab, etanercept, and adalimumab) reached \$269.7 million annually in 2018 (source: [Ontario Drug Policy Network](#)). However, as patients who have lived with long-standing disease, we also remember when treatment options were limited for people living with arthritis before the early 2000's. In that time, patient outcomes were worse, and patients were often unable to work, relied on government provided income supports and were unable to participate in all aspects of life. The healthcare system also spent more on patients living with inflammatory arthritis. For example, there were rheumatology beds in hospital and long-term care facilities and higher numbers of surgeries to keep people functioning.

Today, there are different challenges, including substantial personal costs, with managing high drug costs. This may mean the person living with arthritis or partner may

The Canadian Arthritis Patient Alliance is a grass-roots, patient driven, independent, national organization with members across Canada and supporters in Canada and beyond. We believe the first expert on arthritis is the individual who lives with. We provide a strong voice and concerted effort to promote the well-being of people living with arthritis and we assist our members to become advocates not only for themselves but for all people with arthritis. The organization is a small virtual organization and powered by volunteers who all live with various forms of arthritis.

stay in a job which has the required insurance for medicine reimbursement. There is also increased stress from managing high co-pays or navigating public or private insurance programs. All this while also living with a painful and complicated illness and trying to live one's life to the best of their ability.

Determining value

Given the human costs to patients and the healthcare system, we need to look at costs more broadly and consider the impact on patients' lives and the overall healthcare system. Within the draft guidelines, the notion of pharmacoeconomic value is introduced. We strongly recommend that additional criteria be added in determining pharmacoeconomic value including the human costs to patients and their families and healthcare costs and savings. Patients and patient groups should have the ability to provide input into this assessment based on their lived experiences with the disease. To date, we are unaware of any studies that have demonstrated the pharmacoeconomic and societal value of new treatments for people living with inflammatory arthritis. This would be an opportune time to set up the right methodology and approaches to track patient outcomes prospectively.

Managing the costs of medicines

There are also ways to better manage the costs of medicines when looking at the broad range of therapeutics now available for arthritis. In our current healthcare system, there is little support available to patients who are taking the older, and very inexpensive, medicines such as Methotrexate, Plaquenil, and Sulfasalazine. These medicines are often the first line treatments that patients use as per the [Canadian Rheumatology Association RA Guidelines](#). These medicines still play an important role in managing the disease yet are often difficult to tolerate, resulting in patients often moving onto other, more expensive medicines due to poorly managed side effects. Patients on these medications do not receive the type of supports that may be helpful to keep them on these medications, which may prevent or delay them needing to move on to more expensive medications.

Supporting the under or uninsured

As noted in your presentation at the non-industry stakeholder meeting, about 1 in 5 Canadians report having no prescription drug coverage while many more are underinsured or face high deductibles or co-pays. The proposed regulatory changes do not directly support this vulnerable group and they would only benefit from the new price ceiling established. In addition, uninsured Canadians do not have the bulk purchasing power of large employers, public drug programs, or insurance companies so they are at risk of paying the most for medically necessary prescription drugs. As part of the implementation of the new drug pricing framework, consideration must be given to supporting this vulnerable group more directly. We can appreciate that a national pharmacare program is currently being discussed but no final decisions have been made on the design or implementation. Under or uninsured Canadians need support today in managing their significant prescription drug costs.

Greater transparency

Today, there is little public transparency in how the government reviews drug pricing, the negotiations underway, and the operations of the Pan-Canadian Pharmaceutical Alliance (PCPA). Often these negotiations delay the listing of medicines in public drug formularies, restricting access to necessary prescription medicines. It is important to communicate how the PMPRB and related organizations operate and what they do to protect Canadians from excessive drug pricing. To that end, we would be happy to work with you to develop a short video on the role of the PMPRB to our community of people living with arthritis.

Monitoring and evaluation

It is important to monitor the implementation of the drug pricing changes on key outcomes of importance to patients. A key area to evaluate is how the proposed changes affects market access and whether patients are losing access to medicines needed to manage their health.

Patients are often affected by the unintended consequences of policy changes. For example, moving to a single source supplier for generic drugs to get the best price has

led to significant drug shortages. The impact on patients was significant where patients lost access to these older and less expensive prescription medications. This highlights the need to anticipate and monitor the unintended consequences of any policy changes on patients and their health. Another key area to monitor is how health policy is coordinated and integrated. With different mandates belonging to different federal departments or to the provinces / territories, we see how health policy issues are not addressed holistically, with a negative impact on patients. The implementation of these proposed drug pricing changes is an opportunity to change this for the benefit of patients across Canada.

In closing, it is important that the proposed regulations ensure accessibility from a cost perspective and ensure access to the appropriate medicines to manage the health of Canadians. We hope that the broader patient community will be engaged in policy decisions and implementation of the proposed regulatory changes.

We thank you for the opportunity to provide our perspective on behalf of people living with arthritis.

Sincerely,



Laurie Proulx
2nd Vice-President
Canadian Arthritis Patient Alliance