

From: [Eva Villalba](#)
To: [PMPRB Consultations / Consultations CEPMB](#)
Subject: PMPRB Guidelines Reform Consultations - Quebec
Date: February 13, 2020 9:50:29 PM
Attachments: [MEMBRESACTIFS_2020.pdf](#)

To whom this may concern,

The Quebec Cancer Coalition is a patient advocacy organization founded in 2001 that seeks to improve the health care system in oncology in Quebec, on behalf of people affected by cancer (patients, survivors and caregivers). We represent almost 60 organizations from Quebec and Canada, mostly patient associations and non-profits in oncology with a very strong patient voice (see list attached).

It has recently come to our attention that PMPRB has had public consultations on the details of the proposed reforms to its guidelines, which we worry will have a significant impact on access to innovative treatments and medications for patients across Canada. We regret that we were not invited to provide input earlier. More importantly, we have heard no **consultations have been provided in French, and that no outreach has been done to include patient groups in Quebec who are primarily francophone**. As a federal body, this seems like a serious oversight. We are concerned that several key groups in Quebec have not been informed of these changes at all.

We completely agree with the revision of the basket of countries used for comparison, and that Canada should be able to negotiate the best possible prices for our treatments and medications, in order to ensure the sustainability of our public health care system. However, we are concerned with certain elements of the guidelines. We think that negotiating the best price for Canadians, while keeping that **true price confidential** to the public (while allowing key decision makers to know the true price), would be the most reasonable way to ensure access while preserving the future launch of innovative medicines in Canada. We are also concerned that cancer medications will be treated by the same standards as other types of medications, which have significantly different considerations. Just like INESSS has a specialized evaluating committee (CEPO), and CADTH has pCODR, **we would like a confirmation that a specialized panel of experts in oncology will be informing the PMPRB process**. Namely, we are concerned not only for smaller oncology patient populations (ex. Pediatric), but also for the inevitable increase in personalized treatments which are more and more precise, and thus have smaller patient numbers. We are further concerned that an ICER with no other factors considered, such as unmet need for a patient population is too limiting and dangerous, especially in these less frequent cancer or mutation cases. We expect a transparent, objective, evidence-based process which is understood by all, corresponding to all four quadrants of the CADTH deliberative framework already in use.

We would also like to **understand how exactly the PMPRB is working together with INESSS** to avoid duplication of efforts or additional delays, and how HTA and thorough evaluation process by INESSS will be used in the new reforms. Our Coalition's members find great value in the multi-faceted approach to evaluations looking at more than just the pharmaco-economic values, but also the societal impact as well as the clinical and patient need. From what little we have seen, the CADTH data will be the main reference.

Finally, even though we have taken it upon ourselves to quickly catch up on the significant policy changes that are being proposed by PMPRB which will inevitably affect the people affected by cancer which we represent, we strongly believe, and in fact request, that your consultation be opened to all French-speaking Canadian groups as well. I myself am fluently bilingual, but that is not the case for most patient associations in Quebec (or government officials). We truly appreciate the great level of transparency in listing the groups that PMPRB has met with across the country, but we can't help noticing that the Ministry of Health and Social Services of Quebec and INESSS are not on the list of organizations that were consulted.

Ultimately, **our primary concern is that the reforms proposed by the PMPRB will significantly limit or diminish access for some patients in Canada.** Can you provide any assurances that it will not?

Thank you in advance for your time and consideration.

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**Coalition
Priorité Cancer**
au Québec

Association du cancer de l'Est du Québec (ACEQ)	Fondation Virage
Association pulmonaire du Québec (APQ)	Groupe Esperance et cancer
Association québécoise des ergothérapeutes en pratique privée (AQEPP)	Groupe McPeak-Sirois
Association québécoise des registraires en oncologie (AQRO)	Huddol
Association québécoise du lymphœdème (AQL)	Innovation Exactis
BioCanRx	Institut de recherche en immunologie et en cancérologie (IRIC)
C3i	La Fondation canadienne des tumeurs cérébrales
Canadian Cancer Survivor Network (CCSN)	La Fondation Sauve ta peau
Canadian Virtual Hospice	L'espoir, c'est la vie
Cancer colorectal Canada (CCC)	Life-Saving Therapies Network (LSTN)
Cancer de la thyroïde Canada (CTC)	Lung Cancer Canada
Cancer de la Vessie Canada	Lymphome Canada
Cancer de l'ovaire Canada (COC)	Maison St-Raphaël: Maison de soins palliatifs et centre de jour
Cancer du rein Canada	Myélome Canada
Cancer Saguenay	NOVA Montréal
Cancer Testiculaire Canada	Oncopole
CellCan	Organisme gaspésien pour les personnes atteintes de cancer (OGPAC)
Clinique Regain	Pancreatic Cancer Canada Foundation
Coalition Québécoise pour le Contrôle du Tabac	PROCURE: Halte à la prostate
Conseil pour la protection des malades (CPM)	Regroupement des aidantes et aidants naturels de Montréal (RAANM)
Consortium de recherche en oncologie clinique du Québec (Q-CROC)	Regroupement des aidants naturels du Québec (RANQ)
Dense Breasts Canada	Regroupement en soins de santé personnalisés au Québec (RSSPQ)
Espoir cancer de Lévis	Réseau canadien des proches aidants
Factually Health	Réseau canadien du cancer du sein (RCCS)
Fédération des cliniques en physiothérapie du Québec	Réseau ROSE
Fondation des étoiles	Sensibilisation VPH
Fondation Rêver la vie	Société de la LMC (leucémie myéloïde chronique)
Fondation Sur la pointe des pieds	Société de leucémie et de lymphome du Canada (SLLC)
Fondation Québécoise du Cancer	Swab the World

58 MEMBRES – MISE À JOUR LE 15 JANVIER 2020