

January 11<sup>th</sup>, 2011

Hello,

I am writing to follow-up on my communication of December 21<sup>st</sup> where I provided a summary of the feedback we received as a result of the information sessions we hosted with patient groups in late November and early December. This communication is to let you know the results of the Steering Committee's deliberations around three specific issues raised during those sessions.

1. The first is that some patient groups suggested the opportunity to provide feedback at three points during the submission review process. Input from patient groups is important so that the pCODR Expert Review Committee (pERC) is aware of patient perspectives, values and desired outcomes as they relate to the drug under review. The pERC will consider that information directly, in tandem with the clinical and economic guidance panel reports, as they develop the funding recommendation. In addition, we want to send the information to the economic and clinical guidance panels, to be integrated into their work, and this will require having patient input due relatively early in the process (once a submission is accepted). (If you have the process diagram that was presented during the information session or the webinar, please refer to step 4.3. This will be moved to the left on the diagram so that it happens before the guidance panel processes.) In this way, pERC will receive patient input both directly and through the guidance panel reports since patient input will be integrated into the latter. Patient groups will also be able to provide input once an initial recommendation is posted. The review process will reflect these two opportunities.
2. The second request was that patient groups would like to see their feedback—and that of all other interested parties—posted publicly throughout the process. In keeping with the pCODR principle of transparency, all stakeholders—patient groups, pharmaceutical manufacturers—will have the opportunity to comment on initial recommendations at the same time. This allows us to maintain a level playing field, so to speak. In other words, pharmaceutical manufacturers provide initial input via their submission, as patient groups provide initial input to the pERC and the guidance panels. Neither the submission nor the initial patient group input will be posted. However, once the initial pERC recommendation is posted, along with the guidance panel reports, both patient groups and pharmaceutical manufacturers will be able to comment and that input will be posted publicly. This ensures that input from all stakeholders is equally posted, not giving more or less weight to one over another.
3. Many patient groups would like to see a public summary of each jurisdiction's decisions after pCODR recommendations are made. This would be helpful to all those involved in the review process and is in keeping with pCODR's transparency values. This information will be posted on the pCODR website once provincial / territorial funding decisions are made, and as quickly as pCODR staff are able.

As a reminder, we welcome your nominations for pERC Chair; these are due January 14<sup>th</sup>.

We look forward to our continued work together,

Sincerely,



Mona Sabharwal  
Executive Director