Canadian Organization for Rare Disorders

ROADMAP TO OPTIMAL ACCESS

Amendments to Patented Medicines Regulations & OHIP+ Kids' Pharmacare

Toronto, June 14, 2017

CONFERENCE REPORT

CORD hosted a one day forum for patients and other stakeholders on two recently-announced policies impacting patient access to optimal treatment:

- Federal proposals to reform the Patented Medicine Prices Review Board (PMPRB) through amendments to the Patented Medicines Regulations; and
- The Ontario announcement of a new OHIP+ drug plan to provide universal first dollar drug coverage for young people under 25 years of age.

About 65 people were in attendance, including patient group members of CORD, Best Medicines Coalition, Health Charities Coalition of Canada, government officials, private insurers and the pharmaceutical industry. Delegates took part in plenary discussions, workshops and heard presentations and panel discussions with leading experts and officials.

Federal Proposals to Reform the PMPRB

- Patients are in favour of programs and policies that support access to optimal treatment on a timely basis. It is important that Canada continue to be one of the first countries of launch for first-in-class therapies and the site of clinical trials on breakthrough medicines.
- Drug prices in Canada are currently regulated by the federal PMPRB (patented drugs only); provincial cost containment measures include: mandatory generic substitution, maximum allowable cost (MAC) and reference pricing; application of health technology assessment by Canadian Agency for Drugs and Technologies in Health (CADTH) and Institut national d'excellence en santé et en services sociaux (INESSS); joint price negotiations on conditions of coverage and confidential rebates through the panCanadian Pharmaceutical Alliance (pCPA) and policies of private payers.
- The federal PMPRB proposals are intended to lower the prices of patented medicines; patients support proposals to lower drug prices if they do not result in a reduction or delays in the availability of important new medicines in Canada. Patients (along with others) stipulated that savings garnered from lowered prices should be re-invested in the drug budgets and/or in other healthcare services.
- Expenditures on pharmaceuticals are incorrectly viewed as a cost to the system; they should be viewed as an investment in health - an investment that improves quality of life for patients, improves productivity, and often reduces the cost burden on other components of health and social expenditures.
- Avoid silo thinking. PMPRB is part of broad system of pharmaceutical system management and it should be assessed and modernized in the context of how it should fit in the broad system and relationship to other programs, especially CADTH/INESSS and pCPA.

- Similarly, in the context of the Three A's, policymakers should not look at prices in isolation of the impact on other aspects of Affordability, Accessibility and Appropriate use. Participants recommended a fourth "A": Accountability. Governments and agencies should be accountable, that is, open and transparent in terms of operations and outcomes with patients, public, and other stakeholders.
- Inefficiency in program delivery adds to costs and introduces delays in patient access to necessary treatment. It is essential to reduce or eliminate overlap and duplication in the various review and approval mechanisms for the pricing and reimbursement of drugs. The rationale for separate HTA and budget impact assessments for pCPA and PMPRB purposes is not clear; there is a risk of delays in decision-making. If these processes are meant to be parallel (simultaneous) between PMPRB and CADTH/pCPA, it ix not clear how and by whom the information (HTA and BIA) will be analyzed by PMPRB toward price setting
- Savings received by governments in the form of product listing agreement (PLA) rebates (approximately $1 billion annually) and payments to PMPRB as a result of Board Orders and Voluntary Compliance Undertakings (over $32 million to date in 2017) are put into general government revenues rather than returned to the prescription drug budget or even the larger health budget; this situation needs to change.
- Question: Will patients be better off with these reforms? Answer: We don't know. More broad consultation and sharing of data and analysis are required.
- More consultation is required, preferably in multi-stakeholder fora.

OHIP+

- Patients support government programs that facilitate timely access by patients to optimal therapy.
- Most of the patients diagnosed with rare disorders are children; CORD supports programs to improve and ensure access to optimal treatment by young people.
- Questions were raised about the pros and cons of first payer/last payer models; in the case of OHIP+, the government of Ontario has selected the first payer model.
- Today, patients relying only on public coverage typically must wait 8 to 12 months longer than those with private coverage due to the HTA and pCPA processes. Private insurance representatives stated that private plans could/will continue to provide coverage as they do now until OHIP+ coverage kicks in.
- Transition at age 25: Measures will be needed to help patients navigate the system and determine their options to switch coverage to another public or private plan.
- Measures will be required to ensure that patients losing coverage at age 25 will not be penalized under "pre-existing conditions" provisions of a plan.
- Drugs available under the Exceptional Access Program (EAP) will be covered under OHIP+, but information on which drugs are eligible is not readily available. OPDP should make that information more readily available to patients and HCPs.
- Ideally, programs should be available to ensure access by all patients with rare diseases, regardless of age, to optimal therapies; OHIP+ is an important step in the right direction.

Click here to view the presentations from the forum.