

Drug Pricing Policy Summit Working Groups Summary Report:**January - October 2018**

This report is to provide an overview of the 2018 activities and achievements of the five Drug Pricing Policy Summit Working Groups re-established at the 2017 Drug Pricing Policy Summit. Here is an opportunity coming out of the groups, which is reiterated at the end of this report:

We are looking for a **patient ambassador to share their story about accessing treatment(s) through their employer's benefits plan** to be part of a panel presentation at major Canadian conferences. Contact DPPSWorkingGroups@gmail.com for more information.

1 - Public Payers Working Group

The Public Payers Working Group met eight times since January 2018. It is composed of 10 patient and caregiver participants, including those representing six different patient groups across Canada.

Building on an environmental scan focused on real-world data (RWD) and real-world evidence (RWE) prepared in Q4 of 2017, as well as insights from public payer stakeholders at the 2017 Drug Pricing Policy Summit and the group's consensus that these areas of focus are key to shifting drug pricing policy in Canada and are not currently being led by any other patient organization or coalition, the working group arranged preliminary meetings with the Canadian Agency for Drugs and Technologies in Health (CADTH), Health Canada, and the Canadian Institute for Health Information (CIHI). These meetings were to learn about the work these national bodies are

undertaking related to RWD and RWE, while aiming to ensure patient engagement is key to shaping their RWE strategies. In addition, with CIHI, we explored their alignment with value-based health care, which will be discussed further below.

The working group is supportive of grounding Canada's health systems in delivering value for patients by ensuring optimal health outcomes are delivered for the best possible costs to achieve those outcomes. Value-Based Health Care (VBHC) is seen by the group as offering the potential to transform Canada's health systems towards a more patient-centred approach that rewards outcomes of importance to patients and overcomes the silo-ed thinking and organization currently hobbling Canada's health systems. They feel that VBHC could ultimately improve drug pricing policy and treatment access over time. In addition, RWD and RWE are vital enablers to achieving VBHC, so they see a great deal of synergy in focusing on these topics. As a result, members of the group met with the Canadian Institute for Health Information (CIHI) to discuss alignment between CIHI and VBHC. There is a great deal of alignment in terms of CIHI's mandate, strategic priorities, and leadership. However, lack of resources is the major challenge to moving ahead. An analysis was done between four health conditions/patient segments (breast cancer, hypertension, depression and anxiety, seniors) of the International Consortium for Health Outcomes Measurement (iCHOM) standard sets and CIHI's current data sets. Significant investments are needed in CIHI to address the data gaps (e.g. geographic, provider types like primary care, drug data like private payers and out-of-pocket plus other costs for different parts of Canada's health care systems, and data linkages across data sets) and enable CIHI's VBHC data leadership in Canada.

The Public Payers working group is interested in exploring the idea of a patient-led pilot in VBHC. This aligns with the interests of the Pharmaceutical Industry Working Group, which is outlined in the next section. This idea will be explored at the 2018 Drug Pricing Policy Summit. To narrow the possible areas of focus for a proposed pilot, the two working groups initiated a survey asking Canadian patient organizations about their patients' top priorities. The themes from the survey will be shared at the 2018 Summit as a starting place for the discussion about a possible VBHC pilot project.

2 - Pharmaceutical Industry Working Group

The Pharmaceutical Industry Working Group met seven times since January. It is composed of 10 patient and caregiver participants, including those representing six different patient groups across Canada plus one representing a research and knowledge mobilization organization focused on immunotherapies. In addition, they are drawing on the experience of a pharmaceutical industry representative to help answer their technical questions about the mechanics of pharmaceutical pricing as well as a Chief Information Officer at a provincial health association to answer their questions about data capability to move towards risk-sharing agreements between public payers and drug and device manufacturers.

The working group learned, through a hypothetical case study, about how pharmaceutical prices are set at the global level before they enter the Canadian ecosystem, e.g. how the "sticker prices" are set, and then how they make their way through the Canadian systems to the net prices paid by various payers. In addition, they learned about possible key players and tactics to move towards achieving the

data capability needs to enable risk-sharing, value-based contracts that tie health outcomes to drug and device costs over time.

Like the Public Payers Working Group, the Pharmaceutical Industry Working Group is interested in exploring the idea of a patient-led pilot in VBHC and look forward to this discussion at the 2018 Drug Pricing Policy Summit.

3 - Private Payers Working Group

The Private Payers Working Group met seven times since January. It is composed of six patient and caregiver participants, including those representing four different patient groups across Canada. In addition, it is drawing from the expertise of a benefits consultant working with plan sponsors (employers) to support their insurance plan decision-making with health insurance companies.

Building from a legal opinion prepared in late 2017, the group continues to seek a complainant for a possible human rights case related to new programs put into place by all the major health insurance companies in Canada that are significantly delaying their decision-making on whether or not to cover designated expensive new treatments entering the Canadian market, particularly in oncology.

In addition, the group is finalizing a panel presentation to submit to the Conference Board of Canada, Human Resources Professional Association and Benefits Canada conferences that target employers' human resources and finance executives responsible for making decisions on their organizations' benefits plans. The presentation will include patient ambassadors sharing their stories of accessing treatments through their employer's benefits plans, in order to then demonstrate the impacts and implications for employers' plan design choices.

4 - Patient Organizations Working Group

The Patient Organizations Working Group met five times since January 2018. It is composed of 12 patient and caregiver participants, including those representing 11 different patient groups across Canada.

Building on the findings of the Drug Pricing Policy Tools for Patient Organizations in Canada survey that the group developed and implemented in 2017, the working group oversaw the creation and launch of online resource and educational opportunities web pages for drug pricing policy. The two web pages (<http://survivonet.ca/act/drug-pricing-policy/resources-drug-pricing-policy-canada/> and <http://survivonet.ca/act/drug-pricing-policy/drug-pricing-policy-learning-events-patient-organizations/>) are simple and user-friendly with information about existing resources and educational opportunities to support Canadian patient groups in their drug pricing policy change efforts. They are being used by patient groups with 260 unique page views since inception, the majority of which are people using the drug pricing policy resources.

In addition, the group led the implementation of a virtual book club to build the capacity of patient groups in Canada to engage in Value-Based Health Care (VBHC). The book club focused on Elizabeth Teisberg's and Michael Porter's *Redefining Health Care*. A total of 14 patients and caregivers from 10 different patient groups across Canada and the United States were active participants. They took turns leading the facilitation of dialogue about each chapter. They also developed key questions to ask speakers at the 2018 Drug Pricing Policy Summit and developed a draft VBHC Framework for use by Summit breakout groups.

5 - Communications Working Group

The Communications Working Group met six times since January. It is composed of six patient and caregiver participants, but primarily communications staff from patient organizations, including those representing three different patient groups across Canada. This group provides external communications support to the other four working groups.

The working group supported the technical implementation, ongoing maintenance, and promotion of the web pages for drug pricing policy resources and educational opportunities. In addition, they are supporting the promotion of the 2018 Drug Pricing Policy Summit, helping achieve a sold-out event.

Opportunity for Patients/Caregivers:

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THANK YOU TO ALL MEMBERS OF THE 2018 DPPS WORKING GROUPS!

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Association of Canada
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Canadian Arthritis Patient Alliance
Canadian Cancer Society
Canadian Cancer Survivor Network
Canadian Heart Foundation of Canada
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