

Summit Report

Drug Pricing Policy in Canada: Measuring Progress and Making Our Mark



November 15-16, 2017

Toronto, Ontario



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Introduction

November 15 and 16, 2017, marked the dates of the second annual summit, *Drug Pricing Policy in Canada: Measuring Progress and Making our Mark* (the Summit). Held in Toronto, the event stemmed from the joint efforts of the Save Your Skin Foundation, the Schizophrenia Society of Ontario and the Canadian Cancer Survivor Network, with the contributions of several volunteers, panelists, facilitators and other collaborators.

The Summit offered a space for patients, patient advocates, caregivers and their groups from all disease and disability areas to come together and examine how we can meaningfully participate in regulatory, public and private drug pricing policy processes in Canada. In addition to hearing recommendations and ideas from key stakeholders to inform and guide our discussions on these issues, participants were also invited to review the work that had been carried out by the five working groups formed after the first Summit, held in 2016. Participants worked together to revise and develop strategies and action items in the short, medium and long term, to help shape drug pricing policy in Canada, and to make related processes more transparent, accessible and inclusive.

Ultimately, the Summit allowed patients, patient advocates, caregivers and their groups:

- To learn more about the current drug pricing policy landscape in Canada, its key players, and opportunities for change within the system;
- To engage in dialogue with diverse stakeholders to identify shared issues and opportunities for collaboration;
- To review the work carried out since the 2016 Summit and identify actionable items and next steps in the short, medium and long term, through the creation of a revised Work Plan for 2017-18;
- To revise the constitution of the working groups and renew participation and commitments;
- To explore new paradigms in how health and drugs are measured, understood and covered in the Canadian context;
- To continue strengthening the individual and collective voices of patients, patient advocates, caregivers and their groups to be more meaningfully involved in and change the future of drug pricing processes and policies in Canada.

This report offers an overview of the 2017 Summit, including the event program, participants and key themes to have emerged.

The Summit Program

Like the foundational event in 2016, the 2017 Summit was organized collaboratively by three patient-centered organizations, the Save Your Skin Foundation, the Schizophrenia Society of Ontario and the Canadian Cancer Survivor Network. These three partner organizations all work towards patient education and empowerment in their activities. Following the success of the first Summit in 2016, the decision was made to host a second Summit to bring together patients, patient advocates, caregivers and their groups, in order to continue learning about the stakeholders and processes that affect drug pricing, policies and access in Canada, and to explore commonalities and areas for collaboration and change.

The program for the 2017 Summit was developed by building upon the teachings and strengths of the foundational event, while incorporating new elements. Once again, an impressive roster of experts representing diverse stakeholder groups were invited to offer 15-20 minute presentations (see Appendix 1 – Event Program, to see the full list of panels and speakers). Panelists were invited to provide updates and insights on the policy and regulatory environments for drug pricing in Canada, and to explore what value-based healthcare would look like in this context, a point that will be discussed more extensively in the Key Themes section of this report.

After each panel, a group of three representatives from patient organizations were invited to respond to what had been presented, by offering their insights through a patient-centered lens, and by asking the panelists to respond to questions. This approach was selected as a strategy to ensure the prominence of patient voices as a formal element throughout the event program. The accounts of the patient respondents were followed by an opportunity for all participants to ask questions as a large group, or to address speakers individually when not enough time remained for all questions to be posed publicly.

Though patients, patient advocates, caregivers and their groups constituted the primary audience for the 2017 Summit, as they had in 2016, a number of other stakeholders were also invited to attend. They included representatives from the pharmaceutical industry, private and public payers, government bodies, and health-care providers. Once again, these stakeholders were invited to participate as observers.

During the afternoon of the first day, participants were asked to break out into smaller groups and to take part in a facilitated discussion aimed at distilling the information presented into key themes and associated action items. Participants were provided with a note-taking template to assist them in this process. In order to create a space where patients, patient advocates, caregivers and their groups could be open in sharing their feedback and ideas, and in developing action items, observers were invited to step out during periods of collaborative work.

The observers took part in their own facilitated discussions, which focused on identifying recommendations that patients may want to consider as a way to become more actively involved in the work of the stakeholder groups they represent. The observer facilitators were also invited to provide a brief overview of the key themes and ideas identified during the observer discussions, another new addition to the 2017 program.

Though the 2017 Summit offered an interesting opportunity for education and dialogue in and of itself, it was conceived as another step in a longer process of coalition-building, education and strategizing amongst patients, patient advocates, caregivers and their groups, started in 2016 and extending in 2018 and beyond. The program, questions and activities were structured with a particular focus on identifying actionable items and ongoing opportunities for collaboration after the event.

On the first day of the event, representatives of the working groups formed after the 2016 Summit were invited to present the activities carried out over the year. During a large facilitated discussion on the second day of the event, patients, patient advocates, caregivers and their groups were invited to revise the working group constitution and activities to be carried out subsequently. The organizers look forward to continuing to facilitate the activities of the working groups and the implementation of the Work Plan identified at the Summit throughout and beyond 2017 and 2018.

As a way to maximize our time spent together at the Summit, all participants were invited to abide to a set of ground rules, as follows:

- There are many different perspectives and stakeholders gathered together at the event. While it is important to be critical in order to move things forward, let us try to respect each other's opinions, and to understand where everyone is coming from when they are speaking. Let us also share the space, so that everyone has a chance to contribute and voice their perspective.
- When you are making a statement, please identify whether you are doing so as an individual, or as a representative of an organization (i.e., are you speaking from your personal perspective, or from the organization's perspective?)
- While stories of our personal journeys are of fundamental importance, we have limited time together. Please abstain from going into the details of your personal story, and focus your interventions on broader policy issues (i.e., what can your personal story, or that of those who are living with a similar disease/disability, teach us about the broader systemic and policy issues that need to be addressed?)

- If you have questions or comments that are specific to your disease or disability group, but that may not contribute to our broader policy discussion, feel free to write them down, along with your contact information. We will be happy to provide you with additional information or to connect you to a panelist or other individual who can be of further assistance.

Fig. 1 Organizations Represented at the Summit

aHUS Canada	CLL Patient Advocacy Group
Best Medicines Coalition	Colorectal Cancer Canada
Better Pharmacare Coalition	Crohn's and Colitis Canada
Health Coalition of Alberta Society	Epilepsy Ontario
Brain Tumour Foundation of Canada	Gastrointestinal Society
Canadian Arthritis Patient Alliance	Heart and Stroke
Canadian Cancer Survivor Network	Heart and Stroke Foundation of New Brunswick
Canadian Council of the Blind	HepCBC
Canadian Obesity Network	Hypertension Canada
Canadian Organization for Rare Disorders	Lymphoma Canada
Canadian Pituitary Patient Network	Manitoba Schizophrenia Society and Schizophrenia Society of Canada
Canadian Pituitary Patient Network & Alberta Pituitary Patient Society	Myeloma Canada
Canadian PKU and Allied Disorders	Ontario Caregiver Coalition
Canadian Organization for Rare Disorder	Ovarian Cancer Canada
Canadian Pulmonary Fibrosis Foundation	Patient Partners In Arthritis (PPIA)
Canadian Spondylitis Association	Prostate Cancer Canada

CTAC	Rethink Breast Cancer
Cardiac Health Foundation of Canada	The Arthritis Society
Save Your Skin Foundation	The Canadian Arthritis Patient Alliance
Schizophrenia Society of Ontario	The CML Society of Canada
Sickle Cell Awareness Group of Ontario	Vancouver Acromegaly Support Group

The Summit Participants

Patients, patient advocates, caregivers and their groups

Fifty-six individuals representing patients, patient advocates, caregivers and their groups attended the Summit. They represented a range of disease and disability areas, and came from six provinces and territories (see Figure 1).

Through the distribution of a note-taking template and facilitated discussions as a large group and in smaller subsets, patients, patient advocates, caregivers and their groups were invited to reflect upon the themes and issues raised by the panelists, and to establish opportunities for action, by answering these questions:

- A. What are the top 3 issues that emerge and/or messages that you will take away from this panel?
- B. From the perspective of a patient, patient representative and/or caregiver, how do these issues or messages affect treatment access or other related areas?
- C. Using a health outcomes lens, what are practical measures or changes that need to be put in place to address these issues?

Observers

Thirty-nine observers from stakeholder groups including pharmaceutical industry, private and public payers, provincial/territorial and federal government bodies and health-care providers attended the Summit. In addition to sitting in on the panel sessions and participating in subsequent question periods, observers took part in facilitated discussions amongst themselves. During the small group discussions, the observers identified a number of important themes and action items, which have been included in the thematic section of this report.

Towards greater and greater representativeness - a portrait of yearly participation rates				
Summit	# patient or caregiver participants	# provinces or territories represented	# patient and caregiver groups represented	# observer participants
2017	56	6	42	39
2016	50	5	28	36

Key Themes

Harmonizing systems and increasing patient engagement

The processes that shape drug pricing policies, coverage, access and reimbursement in Canada are multi-layered and complex. They draw from the participation of varied stakeholders, who all have their own priorities, mandates and processes. Throughout the 2017 Summit, it was stressed that the system as a whole lacks transparency and harmonization. Although encouraging examples of new collaborations between stakeholder groups were highlighted during the panel presentations, overall, it seems that many systems are duplicating and unnecessarily complicating processes. In turn, this impacts patients' ability to meaningfully understand and participate in related activities, and to access the drugs and other therapies that we require.

Overall, it was stressed that current processes are not inclusive enough of patients, patient advocates, caregivers and their groups. The consultative mechanisms that do exist to engage patient voices do not always seem to fully account for these important perspectives. Moreover, they often lack feedback loops, such that those consulted are not always made aware of how their comments and suggestions have been considered and integrated. All stakeholders should therefore consider increasing their efforts and adapting their processes to engage patients, patient advocates, caregivers and their groups more meaningfully, in a way that moves beyond tokenism and is accountable to those involved in the consultative processes.

Patient education and empowerment

As patients, patient advocates, caregivers and related groups, we also have an active role to play when it comes to involving ourselves in the drug pricing policy landscape in Canada. Learning about the systems, stakeholders and policies is an important first step. Working with allies, such as treatment access navigators, researchers and health-care providers can also help us to advocate for our individual disease and disability group needs, and patients more generally.

Patients need – and want – to be involved in drug pricing policy processes, as demonstrated by the eagerness and engagement of participants at the 2016 and 2017 Summits, and related activities. However, in order to be able to participate meaningfully, patients, patient advocates, caregivers and their groups require resources that can allow us to do so. Such resources include educational opportunities, as well as financial support, time and human resources.

Working within and across patient groups, while recognizing differences

The Summit and associated activities offer an important opportunity for patients, patient advocates, caregivers from diverse disease and disability groups to come together and collaborate. Though all can benefit from identifying shared issues and action items to address them, participants at the 2017 Summit stressed the importance of doing so in a manner that actively recognizes the factors that create differences in experience within and between patients, their groups and their experiences.

In the Canadian context, geography is a notable factor. Given a healthcare system that is divided between the federal and provincial/territorial governments, there are great discrepancies when it comes to what is publicly accessible, and under which conditions, from one province or territory to another. In addition to discrepancies between provinces and territories, individuals in rural or remote areas, or in smaller municipalities, may face significant barriers when it comes to accessing healthcare services, or the opportunity to participate in decision-making processes.

Social determinants of health must also be actively considered – for example, people who are street-involved or without a fixed address face significant barriers when it comes to accessing the medications they need. Similarly, individuals who are stigmatized on account of their health condition (as in the case of HIV infection), their gender identity, their race, or the presence of one or more disabilities, can face significant barriers to access and meaningful inclusion.

FRAMEWORK 6 — WIDER DETERMINANTS OF HEALTH MODEL
(DAHLGREN & WHITEHEAD, 1991)



(A visual representation of the social determinants of health, taken from A Review of Frameworks on the Determinants of Health by the Canadian Council on Social Determinants of Health, 2015)

A health equity lens, which seeks to create a space for everyone at the table, while recognizing the impact of social determinants of health and strategies to mitigate them, can therefore serve as a useful frame of reference to inform both the activities of the working groups and planning of subsequent Summits, as well as the work of all the stakeholders involved in shaping the drug pricing policy landscape in Canada.

Health at all stages of the spectrum

Just as social, economic, geographical and other factors must be accounted for when thinking about the experiences of patients and caregivers, so too can we benefit from understanding health in a more comprehensive and holistic manner. Our healthcare and drug pricing systems are premised on addressing problems when they have already happened, when a situation has reached a critical point. Similarly, we often view, categorize and expense the drugs, therapies and processes required to respond to a patient's medical needs in a disjointed manner; for

example, physicians are most often paid based on individual interventions, as opposed to a more global approach to managing their patients' health.

By putting in place mechanisms that focus on wellness more comprehensively, we may end up saving considerable costs further down the line. In fact, this strategy was raised as one that a growing number of employers are utilizing in their provision of health supports and insurance plans to employees. By creating opportunities and incentives for individuals to stay and remain well, not only will we save on costs, but we can also prevent patients and their caregivers from having to face unnecessary suffering and hardship.

While it is fundamentally important to ensure that patients have access to the individual interventions and therapies that they require when they are unwell, participants at the Summit also raised the importance of understanding health at all stages of the spectrum. This includes recognizing the importance of prevention, including testing and early detection for asymptomatic patients. If and when they do become sick, shifting away from a focus on individual drugs and therapies, to a time-based understanding of the patient's care path, can also provide valuable ideas to address patients' experience more comprehensively, while finding ways to maximize the value related to spending.

Shifting to a new paradigm

Throughout the 2017 Summit, it was stressed that the healthcare system in Canada is not sustainable in its present siloed construct, given many factors that include the growth in precision and personalized medicine and associated companion diagnostics, and the increasing amount of research related to rare diseases. This situation will only worsen as the population continues to age and as new and high priced therapies become available. Moving forward, governments and other stakeholders will have to make increasingly difficult decisions as to what is covered, or not, when it comes to health-related services, treatments and technologies.

During the Summit, panelists and participants were encouraged to consider a new paradigm for the provision and coverage of healthcare and drugs in Canada. In fact, the opening plenary on the first day of the Summit brought together key experts from the developing field of Health Outcomes Measurement. This approach is gaining ground internationally, and it has been endorsed by the 27 OECD countries and by the World Economic Forum.

The Health Outcomes Measurement approach is a transformative approach of healthcare delivery, one that is premised on a different definition of what constitutes value. Within this lens, value is not only based on a monetary formula of quality of adjusted life years, known as

QALYs, but a formula that measures health outcomes that matter to the patient, with the costs of delivering these outcomes over the care cycle.

Health outcomes that matter to patients differ depending on patient groups or segments (e.g., healthy adults, low income seniors, complex acute conditions, at risk adults, multiple chronic conditions and frail or disabled seniors). Expectations for health outcomes cannot be the same for each of these groups. Mental health issues must also be factored into care.

Similarly, it is important to distinguish between health outcomes and health goals. Whereas health outcomes are categories that can apply to patients within and across disease or disability groups, health goals are more precise individual desires and ambitions. For example, for a younger patient having undergone hip joint replacement surgery, the goal might be to get back to the same level of physical activity as before, including participation in high impact sports. For an older patient, the goal might be to reclaim mobility to be able to go for walks with their grandchildren. In both cases, however, it is possible to develop an overarching outcome within which to position these individual goals.

Once the patient-reported outcome is determined, a cost is attached to achieving that outcome. There is no siloing at that point between different parts of the health budget to achieve that goal.

By way of implementation, a Health Outcomes Measurement approach benefits from being broken down into steps, whereby:

- One begins by integrating primary care into units based on patient conditions and the different patient segments identified above. These units are managed separately.
- Outcomes and cost per segment are then measured.
- Payments are bundled to the care team, not individual service providers, and based on overall health outcomes value, as opposed to volume.
- This model is then applied to multi-site health systems, such as hospitals, primary care facilities, long term care facilities and prevention-based care.
- Affiliations of diverse health care facilities are set in place across geography to enhance the value to the patients in each segment.
- IT platforms are an indispensable part of the entire structure, to facilitate the capture and sharing of data and measures.

Patient engagement in data collection

An essential element in the implementation of a Health Outcomes Measurement approach is the systematic and harmonized collection and integration of data and evidence. As had been stressed at the Summit in 2016, where the subject of real-world evidence surfaced as a key theme and area for patient involvement, so too can patients play a key role when it comes to collecting evidence on health outcomes.

For example, the creation of patient registries, many of which exist already, can provide some key insights to help develop measures for health outcomes. Patients are uniquely positioned to collect quantitative and qualitative information about their health, as well as their experiences as they navigate healthcare and drug access systems.

Though there are of course some key ethical questions to keep into consideration when it comes to data collection, including issues around privacy and the sharing of information, participants at the 2017 Summit seemed to express a keen interest in exploring further how patients may be involved in the collection of data. Key is the willingness of all stakeholders collecting and retaining data to determine a common set of criteria for the collection of data; the sharing and consolidation of the data (through a central repository, for example); and ensuring anonymized access to patients and patient groups. This area has been flagged as a priority for the 2018 Work Plan.

Moving forward

Ultimately, *Drug Pricing Policy in Canada: Measuring Progress and Making our Mark* offered another important opportunity for patients, patient advocates, caregivers and their groups to come together to learn about the drug pricing policy landscape in Canada, and to explore new opportunities for action, collaboration and change. Though the 2017 Summit constituted a key deliverable in and of itself, it also created a space to look back upon the work carried out over the last year, and to revise a Work Plan and working groups to implement action items in 2018 and beyond.

Moving forward, it is helpful to remember that change can be slow and progressive, and that as individuals and groups with limited resources, we can only accomplish so much. Several panelists at the Summit reminded us to take a bite-sized approach in our work, to focus on small interventions and tangible action items. Through the identification and pooling of pre-existing resources and tools, and through the sharing of best practices and lessons learned, we can avoid duplication and benefit from activities that have already been carried out.

Finally, and most importantly, we must continue to work together as patients, patient advocates and caregivers, and to implicate ourselves and advocate for our meaningful inclusion in the work of other stakeholders. Slowly but surely, we can all move towards a system that is more responsive to individual and communal needs, one that cuts across silos in systems and experiences to address health, and drug pricing policy, more ethically and holistically.



Appendix 1
Drug Pricing Policy Summit: Measuring Progress and Making Our Mark Program

November 15-16, 2017
Japanese Canadian Cultural Centre, 6 Garamond Court, Toronto, Ontario

DAY 1 - WEDNESDAY NOVEMBER 15, 2017

- 8.30-9.00 Breakfast and registration
- 9.00-9.10 Welcome Address **Kathy Barnard**, President & CEO, Save Your Skin Foundation
- 9.10-9.20 Overview of Summit Agenda **Sophie Wertheiner**, Summit Facilitator
- 9.20-10.30 **Keynote Panel: Light at the end of the Tunnel: Value Based Health Outcomes Measurement**
- **Louise Binder**, Health Policy Consultant, Save Your Skin Foundation – Introductory remarks
 - **Andre Dias**, Head of Regulatory and Commercial, Myia Labs
 - **Fred Horne**, Principal, Horne and Associates, and Senior Advisor, 3 Sixty Public Affairs, and Former Minister of Health, Alberta (2011-2014)
 - **Terri Lohnes**, Vice President and Practice Lead, Public Sector, Healthcare and Not-For-Profit Group, Optimus ISBR
- 10.30-10.50 **Patient Perspectives: So what does this really mean to patients?**
- **Martine Elias**, Director Access, Advocacy and Community Relations, Myeloma Canada
 - **Phil Upshall**, Senior Policy Advisor, Mood Disorders Society of Canada
 - **Linda Wilhelm**, President, Canadian Arthritis Patient Alliance
- 10.50-11.00 Q&A
- 11.00-11.15 BREAK
- 11.15-12.00 **Working Committees: What have we been up to since last year?**
- 12.00-13.00 LUNCH

- 13.00-14.00 **PANEL 2: What’s Hot and What’s Not Under “Sunny Ways”?**
- **Michèle Chadwick**, Lead, Regulatory Review of Drugs and Devices, Health Canada
 - **Wayne Critchley**, Senior Associate, Global Public Affairs Health & Life Sciences
 - **Sarah Berglas**, Patient Engagement Officer, Canadian Agency for Drugs and Technologies in Health (CADTH)
- 14.00-14.10 **Patient Perspectives: What does this mean for patient access?**
- 14.10-14.20 Q&A
- 14.20-14.45 **Patient Roundtable Discussion**
- 14.45-15.00 BREAK
- 15.00-16.00 **PANEL 3: Not such “Sunny Ways” for Those Who Write the Cheques?**
- **Imran Ali**, Senior Manager, pan-Canadian Pharmaceutical Alliance Office
 - **Sylvie Bouchard**, Director of Medication, Institut national d’excellence en santé et en services sociaux
 - **Dr. Kim Critchley**, Deputy Minister, Health and Wellness, Province of Prince Edward Island
 - **Chad Mitchell**, Executive Director, Pharmaceutical and Health Benefits, Alberta Health
- 16.00-16.10 **Patient Perspectives: Sunny or rainy days for patient access?**
- 16.10-16.20 Q&A
- 16.20-16.45 **Patient Roundtable Discussion**
- 16.45-17.00 Wrap-up of Day 1



DAY 2 - THURSDAY NOVEMBER 16, 2017

8.30-9.00 Breakfast and registration

9.00-9.10 Welcome Address – Day 2

9.10-10.10 **PANEL 4: Creative Ideas to Manage Cost and Sustainability**

- **John Law**, Global Director of Benefits & Director, Total Rewards (Americas), Pitney Bowes Inc.
- **Noel MacKay**, Principal Consultant, National Benefits, The Williamson Group
- **Joan Weir**, Director, Health and Disability Policy, Canadian Life and Health Insurance Association

10.10-10.20 **Patient Perspectives: What does this mean to patients?**

10.20-10.30 Q&A

10.30-10.45 BREAK

10.45-11.45 **PANEL 5: Implications for the Pharmaceutical Industry in Canada**

- **Kim Furlong**, Director, Federal Government Affairs and Policy, Amgen Canada
- **Ilias Iliopoulos**, Associate Director, Patient Access Ontario and Federal, Merck Canada Inc.
- **Mark Legault**, Director, Market Access & Strategic Pricing, Pfizer Canada

11.45-11.55 **Patient Perspectives: What do these changes mean for access?**

11.55-12.05 Q&A

12.05-13.00 LUNCH

13.00-14.00 **PANEL 6: How do We Get There from Here? Words to the Wise**

- **Alan Birch**, Drug Access Facilitator, North York General Hospital
- **Jamie Keller**, Assistant Professor – Teaching Stream Leslie Dan, Faculty of Pharmacy, University of Toronto
- **Dr. Sandy Sehdev**, Medical Oncologist

- 14.00-14.10 Q&A
- 14.10-14.25 **Observer High Level Perspectives and Observations**
- 14.25-14.40 BREAK
- 14.40-15.40 Group Work
- 15.40-16.35 **Priority Setting and Next Steps (Draft 2017-2018 action plan review and committee sign-up)**
- 16.35-16.45 Summit Wrap Up and Evaluation

Appendix 2 Drug Pricing Policy in Canada Summit – Note-taking Template

Panel : _____

A. What are the top 3 issues that emerge and/or messages that you will take away from this panel?

- 1.
- 2.
- 3.

B. From the perspective of a patient, patient representative and/or caregiver, how do these issues or messages affect treatment access or other related areas?

C. Using a health outcomes lens, what are practical measures or changes that need to be put in place to address these issues?

Appendix 3 Summary of the Summit Evaluation Results

Following the 2017 Summit, an electronic evaluation form was sent to all individuals who attended the event. A total of 19 evaluation forms were completed. 68% of respondents identified that they were affiliated with a patient or caregiver organization, and 32% identified as being affiliated to another type of group or institution, a ratio that reflects the patient/observer participation rates at the event.

One respondent provided feedback on the evaluation process itself, recommending that we “Have evaluations after every session. I had a lot to say during the summit but now, as the days have passed, I don't remember everything.” For future summits, it has been decided that participants would be provided with both a paper evaluation form during the event, and a follow-up electronic form after the event.

Usefulness of event participation

Overall, all evaluation respondents found their participation at the summit to be worthwhile, with 69% of respondents indicating that they found the event to be “very useful,” 18.75% of respondents noting the event to be “useful,” and 12% of respondents noting the summit to be “somewhat useful.” Qualitative feedback provided includes:

- This is an amazing event that really elevates skills and capabilities to engage on complex, important issues. Kudos to the organizers.
- It was very well organized - congratulations. Good mix of Qs from audience, breaks, topics, presentations, 2 days the right length, and venue was perfect for me (though I know others would have liked downtown or near airport)
- Thank you for such a great event that not only brought patient groups together, but also generated so much meaningful conversation regarding drug pricing advocacy!
- Thank you so much for having this event! I learned so much and met some great people!
- Thank you for providing patient travel awards and bringing together such a diverse group of stakeholders. It was definitely patient- oriented!
- Great job. I look forward to the summary and joining the working groups to tackle the issues!

Quality and variety of speakers

While overall, respondents indicated that they found their participation at the 2017 Summit to be pleasant and productive, the quality of the panel presentations and speakers resonated as a particularly valuable element of the Summit. When asked to name one of the “best things” about the Summit, respondents note:

- Variety of speakers
- Knowledge / Expertise of speakers
- Great presentations and varied speakers
- High quality speaker list

Another respondent elaborates on this point and provides feedback for future work and events by stating:

- Thanks for putting together the private payer panel - it's clear that private plans are trending towards not providing interim coverage, prior to provincial coverage. It would be useful to pursue this to understand the value proposition of private plans if they take as long as provinces, provide less \$ coverage than provinces, and will not provide catastrophic coverage eventually available through the public. Great job!

Feedback on previous/for future events

The completed evaluation forms also provide valuable feedback to assess the impact and quality of the Summit in comparison to the inaugural event in 2016, as well as points to take into consideration as we plan future summits. Related feedback includes:

- You've made tremendous progress in minimizing air time for personal complaints and/or causes, and elevating the discussion. I'd like to see this maintained and continually improve.
- Last year, we had a few more small groups discussion. While there were more panels and more information this year, the group discussion does help different organizations get a better understanding of the information from each of the panels. one idea is separate the groups into the working groups and discuss issues from different stakeholder perspectives.
- Shorten the summit. It could have been 1.5 days...or even one day. I would also like to lump the sessions so that everyone doesnt need to stay for the whole 2 days in order to be at the sessions they need to be at.

- More focused end goal for summit/what we'd like to accomplish in the short- and long-term.

Lessons learned at the Summit

As a way to assess the quality of new knowledge acquired at the Summit, participants were asked to identify “One thing that I learned at the Summit.” Responses include:

- More grasp of health outcome measurement and what value can potentially mean.
- The need for patients to take charge of showing the value of medicines
- There is no way for patients to have more say in drug pricing policy until the system changes to recognize the value of patient consultation and our governments make change to the existing policy to allow this (but they have no incentive to do this without pressure).
- The importance of health outcome measurements in sustainability of our health system.
- Collaborative advocacy is important!
- The great information of what is truly happening in our medical field and what it going on with our medications, and how we need to change things in Canada for better care and lower cost of medications.
- Delisting of medicines and more limitations to Access (ie criteria) are high priority solutions for government. While biosimilars offer opportunity to create headroom, taking a policy position on biosimilars is more difficult than delisting, more restrictions, more aggressive negotiations, etc.
- The importance of health outcome measurements in sustainability of our health system.

Opportunities for future learning

Participants were also asked to identify themes or issues that would like to learn more about in the future. Feedback provided by respondents includes:

- I'd like to see us come up with a concrete plan for change that makes our system better.
- You mentioned patient registries - and patient organizations owning the data. Would be good to have more discussion around this - opportunities for patient organizations to build their capacity and own the dialogue.
- How to actually engage government and what kind of process is involved.
- Role of various governing bodies such as pCPA
- How do pharma companies set their prices and can we influence these prices?
- Drug bundling

- I am very interested in the role that health outcomes measurements can play in creating a sustainable health system.

These suggestions have been flagged as areas and themes that may be taken on by the working groups over the course of the year. This feedback, and comments provided on other aspects of the Summit, will also be accounted for in the development of the 2018 event. We thank all respondents for sharing their valuable comments and insights.

Appendix 4 Event Sponsors

THANK YOU TO OUR SPONSORS

