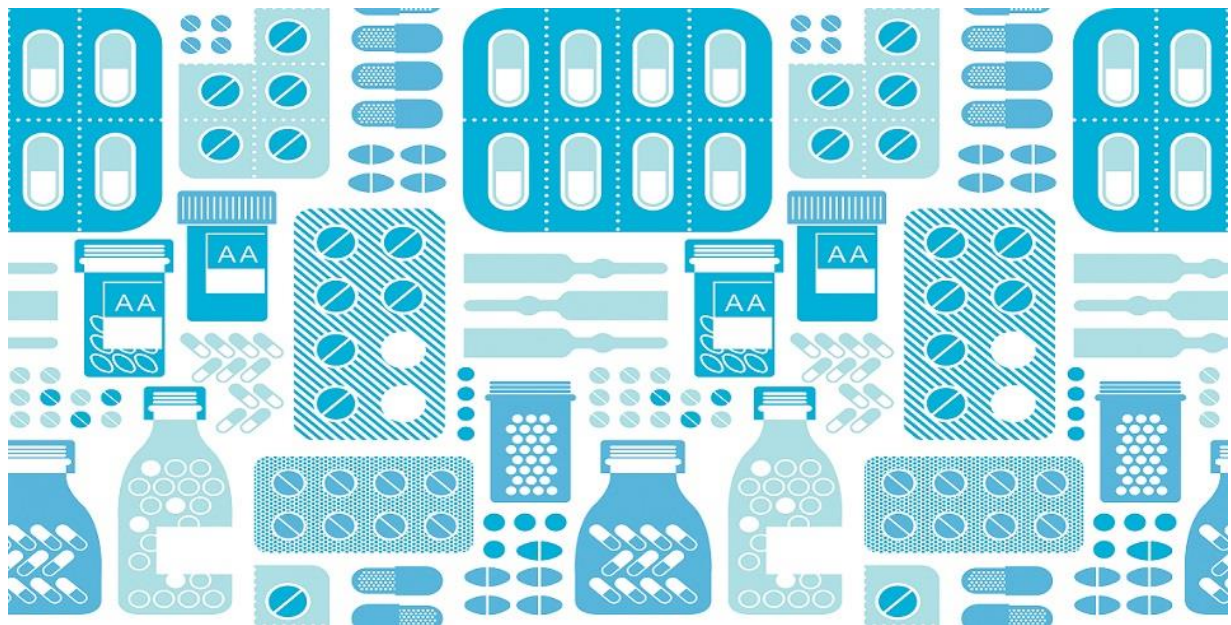


# **Drug Pricing Policy in Canada: Mobilizing Patients to Action**

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**November 15-16, 2016  
Toronto, Ontario**



## **Event Report**

# Drug Pricing Policy in Canada: Mobilizing Patients to Action

## The Summit

On November 15 and 16 of 2016, *Drug Pricing Policy in Canada: Mobilizing Patients to Action*<sup>1</sup> (the Summit) was held in Toronto. The event stemmed from the collaborative efforts of the Canadian Cancer Survivor Network, the Save Your Skin Foundation and the Schizophrenia Society of Ontario, with the contributions of several volunteers, panellists 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 they can meaningfully participate in and influence regulatory, public and private drug pricing policy processes in Canada. In addition to hearing recommendations and ideas from key stakeholders to inform and guide their discussions on these issues, participants worked to identify tangible strategies and action items in the short, medium and long term to 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 this system;
- To engage in dialogue with varied stakeholders to identify shared issues and opportunities for collaboration;
- To begin developing a *Blueprint for Action* by identifying actionable items and next steps in the short, medium and long term, and by forming working groups to carry this work forward;
- 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 the drug pricing processes and policies in Canada.

This report offers an overview of the Summit, including what took place over the two days (the Process), who participated and what their roles were (the People), and some of the key issues to have been raised and discussed at the event (the Themes).

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<sup>1</sup> A note about the title: The observant reader might notice that the word “policy” was missing from the original title of the event, as published on the program and earlier correspondence. The organizers feel that “Drug Pricing Policy in Canada” more effectively captures the scope and ambitions of this project. The name of the event and the project have been modified accordingly in the report, and in all written materials moving forward.

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### **The Process**

The Summit was organized collaboratively by three patient-centered organizations, the Canadian Cancer Survivor Network, the Save Your Skin Foundation and the Schizophrenia Society of Ontario. These three organizations are keenly aware of the importance of educating and providing tools for patients to advocate for their own health, and for their inclusion in the decision-making processes and systems that impact their lives. While the organizations had offered individual trainings and webinars in the past, the idea of coming together to organize a broader event that would reach across disease and disability groups presented itself as an interesting opportunity for collaboration.

Though each disease or disability group faces its own struggles when it comes to accessing treatments and other health technologies, there are some underlying processes and issues that affect drug pricing and access across Canada. As such, it was determined that patients, patient advocates, caregivers and their groups might well benefit from coming together to explore opportunities for collective work. These issues are particularly timely as a number of government agencies and departments are holding consultations that propose potentially significant changes to their respective mandates, and discussions on federal/provincial/territorial Health Accords are also taking place.

The Summit was thus organized with the aim of bringing together patients, patient advocates, caregivers and their groups to learn about the various stakeholders and processes that affect drug pricing, policies and access in Canada, and to explore commonalities and areas for collaboration. This underlying objective shaped the development of all aspects of the program, including the elaboration of expert panels. Experts representing diverse stakeholder groups were invited to offer 10-15 minute presentations, with a particular focus on their own involvement in shaping the drug pricing environment in Canada, and on offering recommendations to increase patient involvement in these processes. Each panel was followed by an opportunity for participants to ask questions as a large group. After each panel, participants were invited to break out into smaller groups and to take part in a facilitated discussion aimed at examining how, given the information presented in the panel, patients might become more involved and affect change.

Though patients, patient advocates, caregivers and their groups were the primary audience for the Summit, a number of other stakeholders were interested in attending, including representatives from the pharmaceutical industry, private and public payers, government bodies, unions and health-care providers. The organizers felt it would be relevant and beneficial to include the participation of these stakeholders as observers, as they too have an active role to play in shaping the drug pricing policy environment in Canada, and in helping to increase the involvement of patients at all levels. Moreover, it was felt that bringing these varied stakeholders together might offer some important opportunities for dialogue and networking, both as a large group and at the individual level.

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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 privately, observers were invited to attend the panels and subsequent question periods, but to step out during periods of collaborative work. The observers took part in their own facilitated discussions, which focused on addressing barriers and facilitators to patient involvement in their work.

Though the Summit offered an interesting opportunity for education and dialogue in and of itself, it was conceived as the beginning of a longer process of coalition building, education and strategizing amongst patients, patient advocates, caregivers and their groups. The program, questions and activities were structured with a particular focus on identifying actionable items and opportunities for collaboration after the event, in the form of a *Blueprint for Action* for 2017 and beyond. In small group discussions and a larger facilitated discussion on Day 2, patients, patient advocates, caregivers and their groups were invited to identify working groups and activities to be carried out subsequently, with the aim of increasing overall involvement and affecting change in the Canadian drug pricing policy landscape.

The organizers look forward to facilitating the activities of these working groups and the implementation of the action items identified at the Summit throughout and beyond 2017.

### **The People**

#### **Patients, patient advocates, caregivers and their groups**

Fifty individuals representing patients, patient advocates, caregivers and their groups registered for the Summit. They represented a range of disease and disability areas, and came from five different provinces (see Figures 1 and 2). A number of organizations and groups who were not able to attend the Summit indicated their desire to become involved in next steps. The organizers will reach out to them, as well as a number of additional patient and caregiver groups, to invite them to participate in working groups and next steps, and to attend the follow-up Summit to be held in the Fall of 2017.

Through 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 panellists and to establish priorities and opportunities for action, by answering these questions:

- What are some of the main themes and issues around drug pricing policy and access that were raised by the speakers?
- Do we agree or disagree with the themes and issues that were raised and why? Do we think certain themes and issues were missing from the presentations?
- What are some tangible actions that we as patients and caregiver groups can do to address these issues? What resources do we require to implement these actions? Which stakeholders would we have to partner with to implement these actions?
- How can we work together amongst ourselves and with other stakeholders to address these issues and make change in 2017 and beyond?

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<b>Fig. 1 Organizations at the Summit</b>
aHUS Canada
Asthma Society of Canada
Brain Tumour Foundation of Canada
Breast Cancer Support Group
Canadian Cancer Society
Canadian Cancer Survivor Network
Canadian Digestive Health Foundation
Canadian PKU & Allied Disorders Inc.
Canadian Psoriasis Network
Canadian Spondylitis Association
Cardiac Health Foundation of Canada
CCAN
CNETS Canada
Crohn's and Colitis Canada
Cystic Fibrosis Canada
GIST Sarcoma Life Raft Group Canada
HepCBC
Muscular Dystrophy Canada
Myeloma Canada
National Asthma Patient Alliance
Ontario Caregiver Coalition
Ontario Rheumatology Association
Ovarian Cancer Canada
Patient Alliance in Nova Scotia, Asthma Society of Canada
Prostate Cancer Canada
Save Your Skin Foundation
Schizophrenia Society of Ontario
The Arthritis Society

<b>Fig. 2 Provinces at the Summit</b>
British Columbia
Manitoba
Nova Scotia
Ontario
Quebec

### Observers

Thirty-six observers from stakeholder groups including pharmaceutical industry, private and public payers, government bodies, unions 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 throughout the event, where they were invited to reflect upon the following questions:

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- What do you think needs to change in the future to create a more accessible drug pricing system and to increase overall access to drugs?
- How do you see your own role within the system? What can you do you individually and in collaboration with other stakeholders to impact meaningful change?
- How can you engage patients more meaningfully in your work, and how can you play a role in building a more patient-centered system?

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.

### **Expert Panelists**

The Summit featured a series of expert panels structured around the following key stakeholder groups:

- Public drug pricing stakeholders at the federal and provincial levels;
- Private payer stakeholders;
- The pharmaceutical industry; and
- Researchers, prescribers and patient navigators.

Additional speakers were invited to share their expertise on key themes. Adam Cook, who represents the Canadian Treatment Action Council (CTAC) opened the Summit by presenting an overview of the history and impact of drug pricing as it relates to hepatitis C. This is a particularly timely case study given the significant developments that have occurred around HCV treatment in the last decade, including the development of a cure. Matthew Brougham, Senior Consultant at Brougham Consulting and Laser Analytica and Amir Tahami, Director of Market Access and Health Economics at Bristol-Myers Squibb Canada and Adjunct Professor of Medicine, Epidemiology and Biostatistics at McGill University offered insights into some of the economic factors and concepts that underline drug pricing processes and decisions in Canada.

(For a complete list of presenters, please see Addendum 1 – Program at the end of this report).

In their short presentations, the panelists were invited to answer the following questions, to help inform the discussions of the patients, patient advocates, caregivers and their groups:

- What are your thoughts on the current state of drug pricing policy in Canada?
- What do you see happening in the future if nothing changes?
- What are your ideas and recommendations to patients and other stakeholders to make meaningful change in 2017 and beyond?

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## **The Themes**

A number of key themes emerged during the Summit, from the panel presentations, the subsequent question periods and the facilitated group discussions amongst patients, patient advocates, caregivers and their groups and observers, as follows:

### **Challenges and opportunities with drug pricing policy in Canada**

Throughout the event, it was stressed by many speakers that the health care system in Canada is no longer sustainable and that costs far exceed available drug budgets. 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, in order to keep the system sustainable within drug budgets that are not likely to increase.

Overall, many government stakeholders calculate that Canada has some of the highest prices for drugs, including generic drugs, relative to economically equivalent countries. Other stakeholders dispute these analyses, claiming that the pricing of drugs is a complex process that balances cost recovery, market maximization and profit, currency fluctuations and competitive advantage, sometimes referred to as “what the market will bear.” Decisions about what is an excessive price for a drug to be sold in Canada are based on comparisons with seven OECD countries. Given the very different populations, demographics, economic, political and health value systems within these countries, it may be worthwhile examining other models upon which to base our decisions, and that match our own environment more closely.

As it stands, public plan decisions on drug pricing policies in Canada are made around very specific and economically-based notions of value, and what is worth paying for, both within and across disease groups. Throughout the Summit, it was stressed that we may also benefit from re-examining our processes and the definitions that underline these choices (for example, what constitutes “value”) to move beyond a narrow economic focus. Patients have a key role to play when it comes to enhancing definitions of what is valuable to our lives, and to society more broadly.

### **Lack of transparency and collaboration**

The processes behind drug pricing policies, coverage and reimbursement in Canada are multi-layered and complex, and they draw from the participation of varied stakeholders, who all have their own priorities, mandates and processes at play. Throughout the Summit, it was stressed that the system as a whole lacks transparency and collaboration. From the development of drugs through innovation, research and clinical trials, to the review and evaluation of these drugs to determine their cost and effectiveness in comparison to equivalent treatments, to the decision to cover these drugs (or not) on the part of public and private payers, to the paucity of data to be found about drugs once they have



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been approved, there are numerous issues, steps and players involved in shaping what drugs patients can ultimately access.

In addition to a dearth of transparency and collaboration amongst the decision-making stakeholders involved in these various steps, it was noted that opportunities for patient involvement at all levels are drastically lacking. Everyone seemed to agree that all stakeholders would greatly benefit from collaborating together more, and from creating opportunities for patients to provide meaningful input. While patients have a role to play when it comes to educating themselves and claiming their seat at the table, present systems limit their ability to do so. Ultimately, all stakeholders will benefit from (re)examining how they do their work and the underlying assumptions that shape their processes, while exploring avenues for greater transparency and collaboration amongst themselves, and with patients, patient advocates, caregivers and their groups.

### **Placing value on the patient perspective**

Most, if not all of the processes involved in affecting drug access and pricing in Canada are not designed to be accessible to patients, nor do they encourage active or meaningful patient engagement. In fact, it appears that CADTH's Health Technology Assessment (HTA) process is one of the only areas where patient feedback is actively sought and incorporated. This is an area where patients can continue to impact change, and one that plays a key role in influencing which drugs are covered, or not, across the country. As such, it may be beneficial for patients to examine how they can ensure their continued and meaningful involvement in this process, where further improvements can be made, and to use this example to advocate for greater patient involvement in other processes.

Beyond the HTA, patients need to be meaningfully involved in all drug pricing processes in Canada. After all, we are the ones who are directly impacted by these decisions. Throughout the Summit, it was stressed that the system needs to value patient input and perspectives more, and that new avenues need to be explored and created to facilitate this.

The notion of real-world evidence, of data related to drugs once they move out of the clinical trial context, surfaced frequently throughout the Summit as an area where patients could play a key role. Again, because they are the ones who directly experience issues related to treatment in the real world, patients are the primary keepers of real-world evidence. The system would benefit from working with patients, caregivers and their health-care providers, to gather input on which therapies are working well, and on their value to the lives of patients beyond economics.

### **Educating and empowering patients**

Overall, it was stressed throughout the Summit that patient involvement, directly and through patient organizations, needs to increase at all stages of the drug pricing policy process in Canada. Patients and caregivers have valuable insights to offer, and stakeholders involved in shaping the drug pricing policy



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landscape in Canada would benefit from re-examining how they do their work and how they can involve patients' knowledge and experiences meaningfully throughout.

Patients also have an active role to play when it comes to involving themselves in the drug pricing policy landscape in Canada. Learning about the system, stakeholders, policies and processes is an important first step. Working with allies, such as treatment access navigators, researchers and health-care providers can help patients learn to advocate for themselves, their disease and disability group needs, and patients more generally. Finding ways of becoming involved in drug trials and being active in their own care is another means by which patients can contribute to affecting what is available and covered in Canada. Finally, patients must also recognize that in an era of static drug budgets and increased utilization of drugs, but also greater longevity for people and exciting new research on drugs that are often high in price but more effective, concerns about sustainability mean that we must also make choices as to what we consider to be “reasonable access” in the public drug system.

Patients need – and want – to be involved in drug pricing policy processes, as demonstrated by the eagerness and engagement of participants at the Summit. However, to be able to participate meaningfully, patients, patient advocates, caregivers and their groups require resources including knowledge, tools, guidance and mentorship. While this Summit offered an opportunity to develop some of these elements, it is hoped that activities will continue beyond the Summit to facilitate the exchange of knowledge and skills to increase the participation of patients in all stages of the drug pricing policy process in Canada.

### **Looking at the bigger picture**

Beyond the processes that affect what drugs are available to Canadians, including their price and their cost, a number of other factors impact the experiences of patients and their caregivers when it comes to accessing the treatments and technologies that they need. Key among these is the fact that Canada is a health care system divided between the federal and provincial/territorial governments, with funding from both levels, and where drug coverage is the jurisdiction of each province/territory. Ultimately, decisions about which drugs are covered fall upon provinces and territories, creating great discrepancies when it comes to what is publicly accessible and under which conditions from one province or territory to another. During the Summit, it was highlighted that to address some of these discrepancies, we need to break down silos between federal and provincial/territorial governments and bring increased focus on the need for affordable access to drugs across Canada.

In addition to discrepancies between provinces and territories, all patients within the same province or territory are not created equal when it comes to accessing the treatments they require. For example, individuals in rural or remote areas may face significant barriers when it comes to accessing health-care services and related information, or the opportunity to participate in clinical trials and decision-making processes. Other social determinants of health can also play a decisive factor – for example, people who

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are street-involved or without a fixed address face significant barriers when it comes to accessing the medications that they need, and meaningfully participating in these processes.

Additionally, patients and their caregivers do not experience their lives, or their health, in silos. Though the drug pricing policy landscape in Canada is quite segmented, we would benefit from stepping back and looking at healthcare more comprehensively and holistically. For example, even if a drug is particularly expensive and may represent an important expense for a payer, there may well be some potentially significant gains to be accrued from covering it (by avoiding costs related to hospitalization, further treatment, and in the case of mental health, contact with the criminal justice system).

The tendency of the system to wait until things are very bad before taking action (treating acute situations as opposed to preventing, treating and effectively managing chronic and/or preventable diseases) may end up costing more than these alternative approaches. Patients, patient advocates, caregivers and their groups are uniquely positioned to help identify and deconstruct some of the silos that limit our understandings of what is valuable, and how monies should be spent – efficiently avoiding duplication while achieving the most effective results.

### **Conclusion**

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Ultimately, *Drug Pricing Policy in Canada: Mobilizing Patients to Action* offered an 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 avenues for increased and more meaningful participation. Though the Summit constituted an important opportunity in and of itself, the organizers look forward to collaborating with those who were present at the event, and to reaching out to other groups, to continue moving this important work ahead.

Through increased collaboration with patients, patient advocates, caregivers and their groups, and the various other stakeholders who generously volunteered their time and their expertise around the Summit, it is our hope that we can continue moving towards drug pricing policy processes that are more transparent, collaborative, inclusive, effective and efficient, with patient values at their core.

# Drug Pricing Policy in Canada: Mobilizing Patients to Action

## Addendum 1: Event Program

### DRUG PRICING IN CANADA: MOBILIZING PATIENTS TO ACTION

#### AGENDA DAY 1

Tuesday November 15, 2016

8.30-9.00am	BREAKFAST	
9.00-9.10am	Welcome	Jackie Manthorne, CCSN
9.10-9.20am	Setting the Stage for the Summit	Louise Binder, CCSN
9.20-9.30am	Summit Overview and Housekeeping	Sophie Wertheimer
9.30-10.00am	Panel 1: The Case for Hepatitis C	
	<i>Adam Cook</i> , Health Policy Researcher, Canadian Treatment Action Council	
10.00-10.15am	BREAK	
10.15-11.30am	Panel 2: Public Drug Pricing Stakeholders	
	<i>David K. Lee</i> , Executive Advisor to the Assistant Deputy Minister / Health Products and Food Branch Health Canada, Government of Canada, <i>Doug Clark</i> Executive Director, Patented Medicine Prices Review Board (PMPRB), <i>Brent Fraser</i> , Vice President, Pharmaceutical Reviews, Canadian Agency for Drugs and Technologies in Health (CADTH), <i>Reiner Banken</i> , M.D. M.Sc., Consultant	
11.30-11.45am	Q&A	
11.45-12.15pm	Breakout Session	
12.15-1.15pm	LUNCH	
1.15-2.15pm	Panel 3: Public Drug Pricing Stakeholders	
	<i>Imran Ali</i> , Senior Manager of the pan-Canadian Pharmaceutical Alliance (pCPA) Office, <i>Kevin Wilson</i> , Executive Director, Drug Plan and Extended Benefits Branch, Saskatchewan Ministry of Health, <i>Scott Gavura</i> , Director, Provincial Drug Reimbursement Programs, Cancer Care Ontario	
2.15-2.30pm	Q&A	
2.30-3.00pm	Breakout Session	
3.00-3.15pm	BREAK	
3.15-4.00pm	Panel 4: Private Payer Stakeholder	
	<i>Karen Voin</i> , Assistant Vice President of Group Benefits and Anti-Fraud at the Canadian Life and Health Insurance Association (CLHIA), <i>Ned Pojskic</i> , Pharmacy Strategy Leader, Green Shield Canada	
4:00-4:15pm	Q&A	
4:15-4:45pm	Breakout Session	
4.45-5.30	Developing a Blueprint for Action – Day 1	Sophie Wertheimer

# Drug Pricing Policy in Canada: Mobilizing Patients to Action

## DRUG PRICING IN CANADA: MOBILIZING PATIENTS TO ACTION

### AGENDA DAY 2

Wednesday November 16, 2016

8.30-9.00am BREAKFAST

9.00-9.15am Welcome Day 2

Sophie Wertheimer

9.15-9.45am Panel 1: Future Trends in HTA

*Matthew Brougham*, Senior Consultant, Brougham Consulting and Laser Analytica, *Amir Tahami*, Director of Market Access and Health Economics, Bristol-Myers Squibb Canada and Adjunct Professor of Medicine, Epidemiology and Biostatistics at McGill University

9.45-10.00am Q&A

10.00-10.30am Breakout Session

10.30-10.45am BREAK

10:45-11.45am Panel 2: Pharmaceutical Industry Challenges

*Glenn Monteith*, Vice President, Innovation & Health Sustainability, Innovative Medicines Canada, *Allan Miranda*, Therapeutic Director, Janssen, *Jennifer Chan*, Vice President, Policy & External Affairs, Merck Canada, *Christian Ouellet*, Director, Government Affairs, Sandoz Canada, *Katherine Bonter*, Founder, Alliance for Innovation in Molecular Diagnostics; PhD Candidate, McGill University

11.45-12.00pm Q&A

12.00-1.00pm LUNCH

1.00-1.30pm Breakout Session

1.30-2.30pm Panel 3: Impact on Researchers and Physician Prescribing

*Dr. Sandy Sehdev*, Medical Oncologist, *Jamie Kellar*, Assistant Professor, Teaching Stream Leslie Dan Faculty of Pharmacy, University of Toronto, *Dr. Natasha Kekre*, Associate Scientist, Clinical Epidemiology Program, Ottawa Hospital Research Institute, *Alan Birch*, Drug Access Facilitator at North York General Hospital

2.30-2.45pm Q&A

2.45-3.00pm BREAK

3.00-3.30pm Breakout Session

3.30-4.50pm Developing a Blueprint for Action – Day 2

Sophie Wertheimer

4.50-5.00pm Closing Remarks

Jackie Manthorne, CCSN

