



SUMMARY REPORT

DRUG PRICING POLICY SUMMIT 2018: PATIENTS REDEFINING HEALTH CARE

November 13-14th, 2018
Toronto, Ontario



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INTRODUCTION

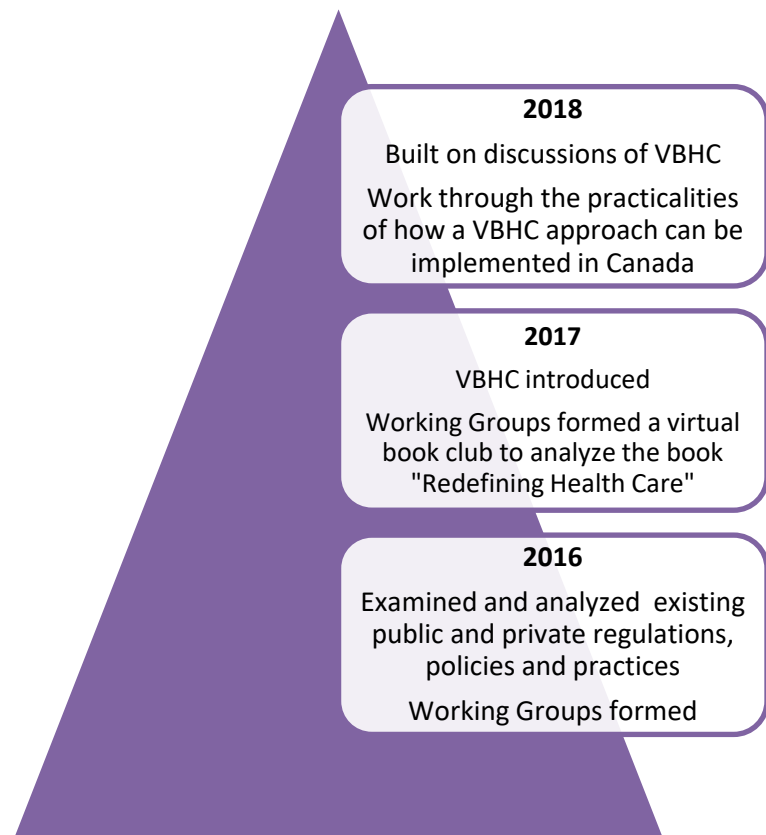
November 13-14th, 2018 marked the third annual Drug Pricing Policy Summit: Patients Redefining Health Care (the Summit) held in Toronto, Ontario. The Summit is a joint effort led by the Save Your Skin Foundation in collaboration with the Schizophrenia Society of Ontario and the Canadian Cancer Survivor Network with contributions from the Canadian Psoriasis Network and several generous volunteers, panellists, facilitators and other collaborators.

This event builds on the [2016](#) and [2017](#) Summits which provided an unprecedented opportunity for patients, patient representatives and advocates, caregivers and their groups from diverse disease and disability groups to come together to discuss a shared vision for health care in Canada. The objectives of each Summit have evolved over time.

The 2016 Summit examined and constructively critiqued existing public and private regulations, policies and practices at a national and provincial/territorial level that have had either a direct, or an indirect, impact on drug pricing, drug costs and ultimately drug access in Canada. From this Summit, five Working Groups were created to develop action plans coming out of the themes, in both the public and private spheres.

The 2017 Summit built on the inaugural Summit and Working Group activities. It also introduced the concept of Value-Based Health Care (VBHC) as defined by Drs. Porter and Teisberg in their book "Redefining Health Care, Creating Value-Based Competition on Results". VBHC was seen as a possible approach to transform health care to address some of the larger, systemic concerns raised during the two Summits. Working Groups continued and a virtual book club was organized to read, discuss and analyze the principles and strategies in this book in the Canadian context.

The 2018 Summit was a forum for patient groups and health care stakeholders from across the



country to explore a new vision for health care in Canada based on a VBHC approach. It explored ideas developed by Working Groups about what would be an appropriate approach to VBHC in the Canadian context including a proposed vision and principles, strategic considerations for its implementation and ideas about patient groups' role in moving this approach forward and with whom they should partner and collaborate to move closer to that objective. It also followed the approach of previous Summits to support coalition-building, education and strategizing amongst patients, patient representatives and advocates, caregivers and their groups, with the opportunity to connect with other stakeholders and key allies.

THE PROGRAM

To help set the stage for this year's Summit, a pre-Summit [webinar](#) was presented by experts in the policy and regulatory environments impacting access to treatments including drug pricing in Canada. They provided updates and insights since last year on Health Canada, the pan-Canadian Pharmaceutical Alliance, the Canadian Agency for Drugs and Technologies in Health and the Patented Medicine Prices Review Board. This webinar provided a review of key concepts and systems discussed in previous Summits and formed a foundation for exploring how VBHC can fit into the current health care systems, structures, processes and policies in Canada.

The 2018 Summit program was developed by building upon the concepts first presented at the 2017 Summit about health outcome measures and specifically the framework of VBHC. As in previous years, an impressive roster of experts representing diverse stakeholder groups was invited to offer 15-20 minute presentations (see Appendix 1 – Summit Program, to see the full list of panels and speakers). Speakers explained fundamental concepts of VBHC and introduced international and Canadian examples of VBHC initiatives. They also provided considerations for the implementation of VBHC in Canada, including shifting the focus of health care to patient-defined outcomes and using data to move VBHC forward.

As with previous Summits, although patients, patient representatives and advocates, caregivers and their groups were the primary audience for the 2018 Summit, a number of key stakeholders were invited to attend as observers. These observer participants consisted of representatives from various groups including government bodies and public payers, the pharmaceutical industry, academia and the private health industry.

The 2018 Summit followed a similar structure as that of previous years. Following a series of panel presentations that were attended by all and included question and answer

Value-Based Health Care is a patient-centered approach to health care with a goal of improved value for patients, measured by health outcomes per dollar spent to achieve those outcomes.

periods, participants formed breakout groups to engage in facilitated discussions aimed at distilling the information presented into key themes and developing associated action items for patient engagement in 2019. In order to create a space where patients, patient representatives and advocates, caregivers and their groups could share their feedback and ideas, and develop action items, independently, observers were invited to attend a parallel facilitated session to engage in their own discussions on the topics presented by the panellists.

This year, as part of the Summit's commitment to enabling collaboration during and after the event, the Summit partnered with Huddol to build a collaborative community around key Summit themes. Huddol is a social collaboration application that supports co-operative learning and sharing among various stakeholders. Three Summit communities were created in Huddol – a common community for all participants, a closed group for patient and caregiver participants, and an open community for observers. Throughout the two days, participants were invited to sign-up and share contributions through the platform and to participate in survey questions that gauged participant opinions and ideas about VBHC concepts in real-time. Moreover, breakout groups were encouraged to share their group notes through the platform so that they were accessible to all patient and caregiver community members.

To help guide the breakout group discussions, participants were provided a draft Vision and Principles, Strategies and Tactics for VBHC document. This draft was developed by book club members based on their discussions and analysis of the aforementioned book, "Redefining Health Care".

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

- Consider, discuss and refine the vision and principles of VBHC
- Consider strategies for VBHC in Canada, including identifying enablers and barriers to implementing a VBHC approach
- Think about implications for the idea of undertaking a patient-led, multi-stakeholder VBHC catalyst project in Canada
- Have international and Canadian VBHC leaders and early adopters provide insights, key learnings and inspiration for pursuing a VBHC approach

SUMMIT OVERVIEW

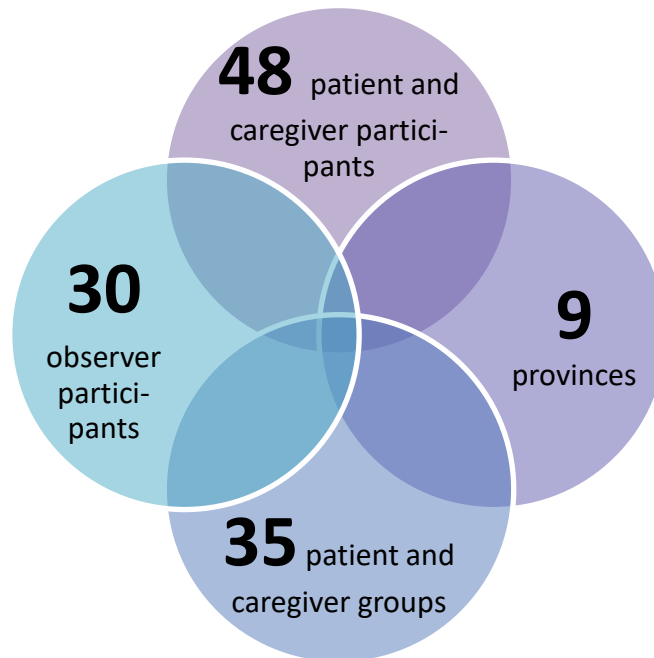
This Report offers an overview of the 2018 Summit, including the event program, participants and key themes that emerged from patient group and observer group discussions.

PARTICIPANTS

Forty-eight individuals representing patients, patient representatives and advocates, caregivers and their groups attended the Summit. They represented a range of disease and disability areas and nine out of 10 provinces were represented (see Figure 1) with one U.S. representative. All 24 patients and patient representatives that applied for scholarships received them.

Thirty observers from stakeholder groups including government and public payers, pharmaceutical industry, academia and private health industry attended the Summit. In addition to sitting in on the panel sessions and participating in subsequent question periods, as with previous Summits, observers took part in facilitated discussions amongst themselves.

Figure 1 A snapshot of 2018 Summit participation



Through facilitated discussions as a large group and in smaller breakout groups, patients, patient representatives and advocates, and caregivers were invited to reflect upon the themes and issues raised by the panellists, and to identify opportunities for VBHC in Canada. During breakouts, both the patient and observer groups reflected on panellist presentations and on questions related to the implementation of VBHC in Canada.

Objectives for breakout groups were to:

- Review and refine proposed VBHC vision and principles
 - Do the proposed vision and principles seem correct based on what participants heard from panelists?
 - What is missing or needs to be changed?
- Consider the Canadian projects presented
 - Do they fit with VBHC?
 - In light of these examples, what are enablers and barriers to moving VBHC forward in Canada?
 - What are considerations for the idea of a potential patient-led, multi-stakeholder VBHC catalyst project in Canada?
- Examine possible strategies for moving VBHC forward in Canada
 - How does what participants heard from panellists fit in with the draft VBHC strategies proposed?
 - What are the implications, if any, for the idea of a potential, patient-led, multi-stakeholder VBHC catalyst project in Canada?

KEY THEMES

The following key themes related to VBHC and its potential implementation in Canada emerged throughout the two-day Summit in patient group discussions and observer deliberations as well as Huddol survey responses. Although there was general consensus about the proposed vision and principles of VBHC and potential strategies that were presented, revisions were made to the original draft to reflect the themes that were heard (see Appendix 2 for a final version of the revised draft).

The Role of Patient Communities

Coming out of all three Summits is the general agreement that the current health care systems in Canada fall short of achieving optimal health outcomes that matter most to patients despite increasing costs and investments. Moreover, certain groups are disproportionately affected by inadequacies in the system because of structural barriers related to social determinants of health. As pointed out at the introduction of the Summit, this is not a criticism of any stakeholder group or system – it is simply a reality, and all stakeholder groups will have to work

together to resolve the issues they are facing in health care with the best tools that they have. While health care systems cannot solve social determinants of health gaps, they must be taken into account in developing and implementing health policy and systems.

The 2018 Summit recognized that incremental improvements to the current systems are not going to achieve the transformative change that is needed to health care systems in order to truly meet patient needs, achieve optimal health outcomes and accommodate emerging trends, including personalized medicine, enhanced rare disease policies and longer life expectancies, all of which will be future health care cost drivers. As such, there was general agreement among 2018 Summit participants that a VBHC approach is a potential solution for Canada. There was also consensus that the greatest drivers to move this approach forward are patients and patient groups. Indeed the Summit keynote speaker highlighted areas in which patients and their representatives have the most impact including sharing critical information about what matters most to patients, identifying particular outcomes that are the most important to them and, as a result, prompting people who are in positions to create change to notice and to become more involved with addressing these needs.

Over the course of the Summit, there was general agreement that patients and their groups are positioned to lead a multi-stakeholder approach to VBHC in Canada in collaboration with caregivers and other allies, clinicians, private industry, government and other key stakeholders. There was also acknowledgement that although patients are the drivers of change, they will need resources and expertise to help them move this forward.

VBHC Vision and Principles

A principle of VBHC that garnered much discussion is that patient-reported outcomes are determined by patients. In fact, panellists described the two most important values in VBHC as organizing around patient segments and measuring outcomes that matter most to patients. Speakers reflected on the importance of patient-defined outcomes including three general benefits to patients: improved care overall, knowing what is coming (i.e., shared decision-making) and being able to select the right care team for one's needs. Some of the benefits to this approach identified in group discussions included the ability to identify gaps in care more easily, to address health needs more effectively and to spend health care dollars more efficiently. A major point of discussion was that current outcome measures in health care are not defined by patients directly and therefore are not reflective of patient needs and values.

Other principles of VBHC that led to a lot of discussion are that optimal health outcomes are different for different populations and medical conditions and that better health outcomes are achieved when expert care is focused on particular medical conditions or patient segments.

Participants raised questions about the assumption that patients identify with certain conditions or patient segments, since this is not necessarily the case for many. For example, people with complex and chronic health and social needs may not identify with specific conditions or diagnoses. Along these lines were questions about how we support individuals who do not identify with traditional labels, do not identify as patients at all and/or have multiple health conditions and social needs that interact to create poor health. An example provided from an urban Indigenous health care setting described the approach of referring to all “patients” as “humans” in its health outreach work. To address some of these concerns, the point was raised that populations are important, and that there is the need to incorporate considerations of equity-seeking groups/social determinants of health, not just medical conditions.

VBHC Principles Related to Service Delivery

Feasibility of realizing a vision for VBHC in Canada

Although participants generally endorsed the proposed vision and principles of VBHC, in addition to barriers to implementation that were identified and which will be described in a subsequent section, there were some general questions and discussions raised about the feasibility of realizing this vision in Canada.

One concern that emerged was about the perception that in a VBHC framework patients would have to actively participate in health and health care management more so than they do already, which would place a “huge and unrealistic” burden on them. A further concern was that there is a risk of certain groups being unintentionally excluded from VBHC approaches, for instance, people who are not tech-savvy; groups who may not be as attuned to health care language and processes; groups whose access to new technologies or system delivery models may be impeded by their geographical location, including those living in remote locations far from major city centres; and those who have been traditionally marginalized from the health care system. Additionally, there was concern that VBHC approaches may create the conditions for health care providers to “cherry-pick” patients with less complex health needs in order to achieve better health outcome results. Adding further complexity to moving toward VBHC in Canada is the fact that our health care “system” is made up of a number of provincial/territorial and federal health systems, each at different stages of readiness to accept and/or to move forward on VBHC.

Engagement strategies

One theme that emerged to address some of the general concerns about the feasibility of moving toward a VBHC approach in Canada was the importance of stakeholder engagement.

Some general feedback on examples of VBHC provided by panellists was that patients seemed to be absent from the development of certain initiatives, or at least their engagement was not explicitly clear. Patient group participants highlighted that VBHC initiatives need to include patients at every stage and that there should be a strategy for building capacity among patients to participate fully in the development, implementation and use of these initiatives. This strategy should include a plan for obtaining the resources to engage patients, presenting concepts and information using language that is accessible to all patients who may be affected by the initiative, and leveraging existing enablers, such as peer-led strategies and initiatives, for engaging patient populations, to share this information.

Additionally, the theme of developing engagement strategies extended beyond patients to all stakeholders, including health care providers and government, in order to enhance interest and collaboration in this work. One example provided for engaging various stakeholders was to create focus groups with clinicians, medical students, senior government officials, researchers, patient representatives and others in order to identify champions for VBHC among these groups.

Strategies

Social determinants of health

There was significant discussion around how a VBHC approach addresses inequities related to social determinants of health, including the economic and social conditions that influence the health of individuals, communities and jurisdictions as a whole. As highlighted in Dr. Ambreen Sayani's presentation, 50% of what determines the health of a population is life factors and the determinants of health (compared to, for instance, access to health care which determines 25% of health outcomes). Questions were raised by the speaker and by participants about how the root causes of marginalization and vulnerability of some populations can be addressed through VBHC.

Another question that was posed is whether, by basing outcomes on those who are interacting with the system, we are inadvertently ignoring or neglecting people who are traditionally marginalized from the health care system even if their health and social needs may be high. In addition, how do we think about a patient holistically and recognize that often their social needs outweigh their medical needs? Promising practices provided by panellists such as the approach taken by the Alliance for Healthier Communities to performance management and data management, offered models for how data can be used to address health care holistically and shared to encourage improved performance, so that the health and well-being of people

and communities facing barriers to health are improved.

Data

Data is a critical underpinning of a VBHC approach. Patients' data across the continuum of care must be collected and managed within a robust and secure framework that pays the utmost respect to privacy and confidentiality. Indeed, examples were provided by panellists of the various applications of data in a VBHC framework, including measuring progress to ensure that patient needs are met, informing clinical and shared decision-making, comparing results across services, regions and conditions and helping patients self-advocate and interact more effectively with the system. The benefits and challenges of collecting and using data to achieve an effective data framework that can actually inform care decisions was a theme that was repeated throughout the two-day discussions.

In group discussions, some perceived barriers to the collection, security and accessibility of data were raised including inconsistencies related to the data that is currently collected across Canada, privacy considerations and willingness to share data, security of data, ethical considerations about data collection and ownership as well as questions about what kind of data are not being collected but should be *e.g.*, regarding social determinants of health. Approaches to mitigating or minimizing these risks were discussed including leveraging data systems that already exist, consulting with experts on how to implement "privacy-by-design" in any databases and establishing a data strategy as part of moving VBHC forward in Canada.

Enablers and barriers to implementing VBHC

Several enablers to implementing a VBHC approach in Canada were identified by participants including the fact that there are patients and patient groups at the Summit who are ready to be leaders in this work. It was clear from the engagement and enthusiasm in group discussions that there are already strong patient advocates ready to work on moving VBHC forward in Canada, many of whom have existing mechanisms for engaging patient communities that can be leveraged *e.g.*, peer support models to build engagement.

Another major enabler identified was the opportunity to leverage and learn from early adopters of VBHC in Canada such as the multi-stakeholder project All.Can which engages policy makers in identifying ways to direct resources to what matters most to patients in order to achieve optimal patient care and to optimize system efficiencies. Additionally, the patient-driven data tool HAnalytics which enables patients to collect, manage and use their health data to more effectively interact with the health care system while creating real-world evidence that can help

to inform patient-reported outcomes and that can be used to influence health policy.

There are also several system enablers that already exist for moving VBHC forward including the Canadian Institute for Health Information's (CIHI's) work on Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS) programs, which was initiated a few years ago and will continue to be pursued pending funding; and existing pockets of consumer e-health systems.

Barriers to VBHC in Canada included entrenched system processes such as fee-for-service payment models. In fact "entrenched mindsets" was identified as the most important thing to change in our system by Huddol survey participants. Moreover, entrenched system silos, specifically health budgets, are not conducive to a VBHC approach. With VBHC, health dollars must follow people, meaning that funds are used for care and innovations that most successfully achieve patient-defined outcomes versus continuing to invest funds in traditional ways without gaining new and enhanced results.

In addition, the lack of data integration across health care systems and the fact that there is no comprehensive and holistic health data strategy were viewed as major barriers to achieving VBHC. Participants discussed the fact that although some data collection and standards exist, they need to be expanded, integrated and improved over time to incorporate specific patient considerations.

Moreover, concerns about resources to support patient-informed practices and strategies were raised as a barrier to implementing VBHC in Canada. In addition to resources that are required to develop a patient-led, multi-stakeholder VBHC catalyst project, there is also the need for resources to support patient engagement, including knowledge and skills-building as appropriate.

Moving Forward

Overall, the 2018 Drug Pricing Policy Summit: Patients Redefining Health Care provided an opportunity for patients, patient representatives and advocates, caregivers and their groups to dive deeper into the concept of VBHC as a potential way forward in transforming Canada's health care system so that it is driven by patient needs and desired health outcomes. The 2018 Summit also provided an opportunity 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 2019 and beyond that are focused on VBHC.

Four main areas for action were identified as opportunities for patients, patient representatives and advocates, caregivers and their groups to build on past Working Group efforts and toward an action plan for 2019 and beyond:

1. **Develop a patient-led multi-stakeholder VBHC catalyst project.** Overall, patient participants were very enthusiastic about developing a catalyst project that is patient-driven to move VBHC forward in Canada and to build evidence for the adoption of VBHC. There was much discussion about what this might be, for instance, developing a patient-driven approach to establishing patient-defined outcomes (PROMs).
2. **Develop a data strategy to understand the current gaps and opportunities in Canada.** There was general agreement that data are essential aspects of any catalyst project because the use of data is a fundamental underpinning of VBHC. It was agreed that a data strategy would be an integral part of a patient-driven catalyst project, either as a main component or as a parallel strategy to the project. Ideas for what this could look like include an environmental scan of where data are presently housed, privately and publicly, how they can be integrated, what data are being collected and gaps in data collection from a patient-reported health outcomes perspective.
3. **Communications strategy.** A major theme to have emerged over the two days was the importance of effective engagement with various stakeholders in the health care system to move VBHC forward. As such, revitalizing the existing Communications Working Group was proposed as an area of action.
4. **Knowledge and skills development.** Another major consideration for action included creating opportunities for building patients' and patient representatives' understanding and skills about VBHC either through the adoption of a certification program or other types of training and development. Potential opportunities and possible partners for achieving this were discussed.

Moving forward, patients, patient representatives and advocates, caregivers and their groups will strive to take a VBHC approach in Canada in its most fitting form – led, driven and realized by and with patients. This is not to say that patient groups will act alone, as VBHC requires a multi-stakeholder approach as does all transformative change, but patient participants were clear that they want and need to be the drivers of this change.

They know that this is not going to happen overnight. A patient-led multi-stakeholder VBHC catalyst project is a step in the direction toward transformative change that they want to see in Canada. That is, transformative change whereby health care, including drug pricing policy and beyond, is responsive to individual and communal needs, views patient-defined outcomes as the greatest measure of value and success, cuts across silos in systems and addresses health care in an ethical and holistic way.

To help get them get there, patients will continue to embrace the mantra that was introduced at the beginning of the 2018 Summit, **“Think Big, Act Small, Don’t Wait”** – Dr. Henk Veeze .

Appendix 1 – Summit Program

Agenda Day 1: Tuesday, November 13th

7.45	Breakfast and Registration	
8.15	Welcome to “Patients Redefining Health Care”	Kathy Barnard , Founder and President, SYSF
8.35	Our Objectives for the Event and for Today	Melissa Egan , Summit Facilitator
8.40	Leveraging Technology to Collaborate at the Summit – Huddol	Mark Stollow , CEO Huddol
8.50	Setting the Stage	Louise Binder , Health Policy Consultant, SYSF
8.55	Value-Based Health Care: What Is It and How Can We Move It Forward? (Live Feed) Scott Wallace , Associate Professor, co-founder and Managing Director of the Value Institute for Health and Care, Dell Medical School, University of Texas, Austin	
9.40	Q&A with Scott Wallace	
10.15	BREAK	
10.30	VBHC: What’s Happening in Canada and What Could Happen? Fred Horne , Principal, Horne and Associates, and Senior Advisor, 3 Sixty Public Affairs, and Former Minister of Health, Alberta (2011-2014) Andre Dias , Head of Commercial and Regulatory Development at MYIA Labs where he is responsible for developing & implementing the commercial model, managing regulatory compliance, and providing oversight for R & D activities	
11.00	Q&A with Fred Horne and Andre Dias	
11.15	What are “Determinants of Health”? Why Do They Matter So Much? Dr Ambreen Sayani , Health Strategist & Consultant, Specialist Cancer Research; Co-Founder, A Healthy Peel; PhD Candidate York University, Toronto; Lung Cancer Screening Study Coordinator, St. Michael's Hospital, Toronto	
11.40	Q&A with Ambreen Sayani	
11.55	Breakout Sessions 101	Melissa Egan , Summit Facilitator
12.00	LUNCH (Optional) Discussion with Nicole Beben , VP Strategy, Canadian Partnership Against Cancer, Location: Observer Breakout Room, Second Floor	
13.00	Group Breakout Session # 1	
13.45	Reporting Back from Breakouts	Group Facilitators
14.15	Value-Based Health Care in Canada: Promising Practices Shaneel Pathak , Co-Founder, HAnalytics Solutions Rodney Burns , Chief Information Officer and Chief Privacy Officer, Alliance for Healthier Communities Kathy Barnard , Founder and President, Save Your Skin Foundation	
15.00	Q&A with Shaneel Pathak, Rodney Burns, Kathy Barnard	
15.15	BREAK	
15.30	Group Breakout Session # 2	
16.15	Reporting Back from Breakouts	Group Facilitators
16.45	Closing Remarks for Day One	Melissa Egan , Summit Facilitator

Agenda Day 2: Wednesday, November 14th

7.45	Breakfast	
8.15	Welcome Back and Our Objectives for Today	Melissa Egan , Summit Facilitator
8.20	Starting to Put Ideas from Day One Together	Ron Rosenes , Consultant
9.00	You Can't Measure What You Don't Collect <i>Andre Dias</i> , VP Strategy & New Program Development, Benchmarking Lead, International Consortium for Health Outcomes Measurement (ICHOM)	
9.30	Q&A with Andre Dias	
9.45	BREAK	
10.00	Real World Evidence and the Canadian Institute for Health Information (CIHI): What We Have and What We Don't <i>Greg Webster</i> , Director of Acute and Ambulatory Care Services, CIHI	
10.30	Q&A with Greg Webster	
10.45	Don't Think of Privacy as a Barrier: Health Data Deserves the Strongest Protection (video) <i>Dr. Ann Cavoukian</i> , Distinguished Expert-in-Residence, Privacy by Design Centre of Excellence, Ryerson University	
11.00	Protecting Patient Data at CIHI <i>Cal Marcoux</i> , Chief Information Security Officer, CIHI	
11.30	Q&A with Cal Marcoux	
11.45	Group Breakout Session # 3	
12.45	LUNCH	
13.45	Reporting Back from Breakouts	Group Facilitators
14.45	BREAK	
15.00	Framework, Action Plan and Organizational Structure for DPPS Work in 2019 <i>Ron Rosenes</i> , Consultant <i>Antonella Scali</i> , Executive Director, Canadian Psoriasis Network (previously, Health Policy, SSO)	
16.00	Thanks and Closing Remarks CCSN	Jaymee Maaghop

Appendix 2 Vision, Principles, Strategies and Tactics

Vision

Everyone in Canada achieves optimal health outcomes through an equitable, value-based approach to health and health care across the life cycle.

Principles

1. Value-based health care means achieving optimal health outcomes relative to the costs over the full cycle of care from prevention to management/recovery/support.
2. Optimal health outcomes are different for different populations and medical conditions.
3. Patient-reported outcomes are determined by patients.
4. Since costs relate to achieving optimal health outcomes, money in the health budget follows people. People don't follow the money. Remove silos in the health budget.
5. Decision-makers don't just lower prices and costs for the sake of saving money, but because it increases value.
6. Maintaining health is the ultimate cost savings.
7. High quality care, including prevention, leads to optimal use of resources and better health outcomes.
8. Providers achieve better health outcomes by focusing their expertise on particular medical conditions or population segments ensuring seamless and timely coordination across the full cycle of care.
9. Providers organize themselves to deliver care for different medical conditions or population segments based on the areas of expertise required.
10. Providers compete for patients based on results. Transparency and dissemination of results are required for all stakeholders.
11. All health system stakeholders realign themselves to be consistent with achieving these value-based health care principles.

Strategies

People

1. Inter-professional teams, in partnership with patients, work together to define the populations they serve, the full cycles of care and develop the service delivery models to achieve optimal health outcomes.
2. These teams use results information to continuously improve.

3. Inter-professional teams, in partnership with patients, develop joint accountability processes.
4. Health policy decision-makers, in partnership with patients, develop policies and models to support inter-professional teams to plan, deliver and be accountable for delivering results.
5. Patients access results information about providers to make informed provider choices.
6. Referring physicians access results information to make referrals.

Process

1. Results are measured and made easily accessible and widely available to patients and providers.
2. Competition on results is regional, national, international, not just local.
3. Decision-makers create an integrated approach to health budgeting, based on optimal health outcomes relative to the costs across the full cycle of care.
4. Innovations that increase value are recognized.
5. Patients develop a pro-active stakeholder engagement plan, including government relations, to develop a sense of co-ownership among key stakeholders.
6. Data partners have a robust privacy and security risk management framework, policies, and practices.

Technology

1. A value-based health care data strategy is developed to enable data collection, integration from all relevant public and private sources, storage, analysis, and dissemination.
2. This integrated data and evidence support health care decisions, including pricing, budgeting, care delivery, and outcomes measurement.
3. Patient information is extensively, securely and seamlessly shared to achieve value while maintaining patient confidentiality.

Tactics Consideration

Work to prevent/mitigate gaming by providers to achieve what seems like great outcomes at reduced costs by cherry-picking easier-to-serve people.

Appendix 3 Summary of the Summit Evaluation Results

An electronic evaluation survey was sent to participants at the close of the 2018 Summit. A total of 15 participants responded to the survey with 73% representing a patient or caregiver group. The majority of respondents represented national organizations.

The majority of respondents (about 67%) indicated that they found the Summit “very useful”; about 27% found it “somewhat useful” and one person indicated that they did not find it useful. Qualitative responses from participants on what they liked about the Summit included:

- Format – good cross-section of presentations, panels and group discussion
- Good networking opportunity
- Solution-focused and action-oriented
- Learning about potential projects and ideas that could be developed to improve health outcomes
- Presentations and opportunity to work collaboratively towards moving forward with a catalyst project

Respondents also provided feedback for future Summits, including:

- Reintroduce a patient panel to respond to panelists
- Ask breakout groups to report back on only one or two key points – it was observed that having full reports from each group made the information difficult to retain; it was also noted that some of the feedback did not seem fully addressed in the second day re-cap, probably because there was too much information to digest in a short amount of time despite the efforts of the group that worked on putting this together
- Make a clearer connection to drug pricing policy and how participants can apply what they are learning to their current work
- Have more opportunity to interact with and plan with speakers
- Include more information about content earlier on in advance of the Summit to help people prepare for what will be discussed

Other general feedback was provided on the structure of the Summit. Although many people identified the breakout sessions as a positive aspect of the event, others shared that they would prefer fewer breakout sessions. Another suggestion was to have all panels in the morning that could be attended by all so that observers could have the option of attending only the mornings.

When asked about one thing they learned at the Summit, participant responses included:

- What value-based health care (VBHC) is and what it can look like in Canada
- What value means (to different stakeholders) and how to bridge the gaps between the stakeholders to get a better understanding of how everyone can work together to improve our health care system
- We have a big job ahead of us - convincing all stakeholders (clinicians; patients; government officials; pharma; medical technology; etc.) to move in a value-based direction
- Good examples for illustrating what VBHC looks like, and advice on simple ways to protect data, and data ownership

When asked to rate their organization's understanding of VBHC and initiatives in Canada, about 47% respondents indicated "very good", about 27% indicated "good" while the remainder rated their understanding as "fair".

Respondents were invited to identify any issues that were raised at the Summit, or any other area of VBHC, that they would like to learn more about. Responses included:

- The theory was all very interesting, but I would like to know more about how to apply it to my current work in the current health care system
- How to start small – action
- Social determinants of health
- It would be good to see if there are patient groups who have successfully developed and implemented value-based projects in a panel. Not only would this help the participants to have a better idea of what value means, but an idea of what to aim for
- I would like to learn how you execute the strategy
- Gathering data and measuring outcomes from community-based health service providers not just in hospital settings

Respondents were also asked about their experience using the social platform, Huddol. About 64% of respondents indicated that they used Huddol at the Summit. For those who did not, they identified various reasons for why including "too many apps and finding that they are not useful for long"; challenges navigating the app; and choosing to sign on as a group versus individually. Many respondents who used Huddol indicated that their overall experience was "very good" with the majority indicating that it was "average". The majority of Huddol users also found the platform to be "somewhat useful" in allowing them to collaborate during the Summit.

Overall, respondents provided positive feedback on the Summit including comments that it was well-organized, that speakers were engaging and that the audience was passionate. Many also expressed appreciation to the organizers for “making this happen for all patients in Canada”.

Constructive feedback on the logistics included being mindful of reducing waste during meals, ensuring that observers understand the structure of breakout sessions, increasing opportunities for patient participants and observers to interact and considering a location that is more central to transportation options like the subway.

Appendix 4 Event Sponsors

Thank you to our sponsors

