

SUMMARY REPORT

4TH ANNUAL SUMMIT

A Dose of Reality: Patients Redefining the Future of Health Care in Canada

November 12 - 13, 2019
Toronto, Ontario

save your skin
FOUNDATION



LA FONDATION
sauve ta peau

Canadian
Psoriasis
Network



Réseau
canadien
du psoriasis



SCHIZOPHRENIA
SOCIETY OF ONTARIO
A REASON TO HOPE

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INTRODUCTION

November 12-13th, 2019 marked the fourth annual event, A Dose of Reality: Patients Redefining the Future of Health Care in Canada (“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 Psoriasis Network with contributions from several generous volunteers, panelists, facilitators, and other collaborators.

This event builds on the [2016](#), [2017](#) and [2018](#) Summits, which provided unprecedented opportunities for patients, patient representatives, advocates, caregivers and their representatives from diverse disease and disability groups across Canada 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 the national and provincial/territorial levels 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 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

2019

Examined public and private health bodies; patients shared provincial priorities; and explored VBHC initiatives underway in Canada

2018

Worked through the specifics of what a VBHC approach should include in Canada

2017

Introduced VBHC

2016

Examined and analyzed existing public and private regulations, policies and practices in Canada

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' roles in moving this approach forward and with whom they should partner and collaborate to move closer to VBHC in Canada. 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 allies.

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

Finally, in 2019, after numerous provincial and territorial elections, the Summit updated participants on what's happening with health bodies – private and public – across Canada, including how they're inviting patients and caregivers to be engaged in their work. Patient representatives from each province shared the most pressing health policy issues impacting patients and caregivers in their region, and made recommendations to address them. Indigenous health and the social determinants of health received special attention. Value-based health care initiatives in Canada were highlighted, with particular momentum in integrated primary health care and a partnership between Value-Based Health Care Canada (VBHC Canada, convened by the Conference Board of Canada) and a Quebec patient group focused on validating and implementing, with patient co-leadership and co-design, Patient Reported Outcome Measures (PROMs). The event dove deeper into PROMs, with education and a breakout session for participants to explore and provide feedback on them.

Overall, the objectives for the 2019 Summit were to:

- Enhance participants' knowledge about health systems in Canada and impacts on patients and caregivers;
- Create synergies and opportunities for recognition of common issues and opportunities across patient groups and other health care stakeholders;
- Engage stakeholders, including policy makers, and foster collaboration between patient and caregiver communities and other relevant stakeholders, including researchers, private sectors, health care providers, governments, non-governmental agencies, and

other partners; and

- Support the conversation and ideation about how patients can influence the design of the health care systems they need.

PROGRAM AND FORMAT

The 2019 Summit program was developed by building upon the concepts first presented at past Summits. Even more excitingly, the impact of past Summits emerged and became part of the 2019 program. An idea, related to value-based health care (VBHC), born at the 2018 Summit took shape into a demonstration project co-led by a patient group, which was presented in 2019 among the VBHC initiatives in Canada.

Once again, an impressive roster of experts representing diverse stakeholder groups offered short presentations on what they are doing and how patients are engaged in their work (see Appendix 1 – Summit Program, for the full list of presenters). Speakers also explained fundamental concepts of how Canada's health systems are designed; what are the social determinants of health and how they impact access; what is VBHC and why is it important; and what are Patient Reported Outcome Measures (PROMs) plus how are they developed. Importantly, a focus on Indigenous health in Canada was incorporated into this year's program — through a standalone presentation; the inclusion of an Indigenous provincial panelist; as well as a lunch and learn focused on Indigenous health.

The afternoon of the first day spotlighted exciting examples of VBHC being implemented in Canada. One presenter from the Alliance for Healthier Communities highlighted Ontario's Community Health Centres, and related primary health care teams committed to the Model of Health and Wellbeing or Indigenous Model of Wholistic Health and Wellbeing, and their initiatives that support VBHC through integrated, equity-focused primary health care (both within health care and with social determinants of health) and primary care PROMs.

The second panel shared the launch of VBHC Canada as a multi-stakeholder hub convened by the Conference Board of Canada to link opportunities in Canada in order to build on VBHC efforts rather than duplicate them. One of their priorities is the support of VBHC demonstration projects. Spotlighted was their exciting demonstration project with a patient group, Coalition Priorité Cancer au Québec. After attending the 2018 Summit, which focused on VBHC, the Coalition's Executive Director realized that Quebec currently has a positive environment for VBHC. Building on the momentum of the 2018 Summit and this positive environment, a group of patient representatives met in Montreal. Out of that meeting, an agreement between the Coalition and VBHC Canada was developed for a patient-led demonstration project, which was shared.

The morning of the second day, patient panelists from different provinces across Canada

presented on their jurisdictions from their perspectives — what are the greatest health policy issues for patients in their provinces and what are recommendations to move the needle forward?

The 2019 Summit followed a similar participatory format as previous years, while adding some innovative features. One new exercise this year involved participants writing newspaper headlines, inspired by the content of presentations including question and answer periods, which were posted on the wall for everyone to read.

After learning about PROMs at the end of the first day, patient and caregiver participants formed breakout groups based on health conditions (chronic and associated acute conditions, cancers, mental health) or on a patient population (“older person”). They reviewed concrete examples of PROMs and provided feedback on them — both strengths and gaps. To create a space where patients, patient representatives and advocates, caregivers and their groups could independently share their feedback and ideas and develop action items, observers were invited to attend a parallel facilitated breakout session to engage in their own dialogue on PROMs for the patient population, “older person”.

The Summit ended with patients, patient representatives and advocates, caregivers and their groups independently determining what they wanted to work on together to advance opportunities for change towards VBHC and other common priorities.

Finally, the event offered two optional lunch and learns with the Canadian Partnership Against Cancer on the first day and Indigenous Health on the second day.

SUMMIT OVERVIEW

This section of the report offers an overview of the 2019 Summit, including the participants and the themes that emerged from the event.

PARTICIPANTS

Forty-five individuals representing patients, patient representatives and advocates, caregivers and their groups attended the Summit. They represented a range of disease and disability areas. Eight out of 10 provinces plus three territories were represented (see Figure 1). All 17 patients and patient representatives that applied for scholarships received them.

Forty observers from stakeholder groups including government bodies and public payers, health care providers, pharmaceutical and medical technology industries, academia and private health insurance 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 breakout discussions amongst themselves.

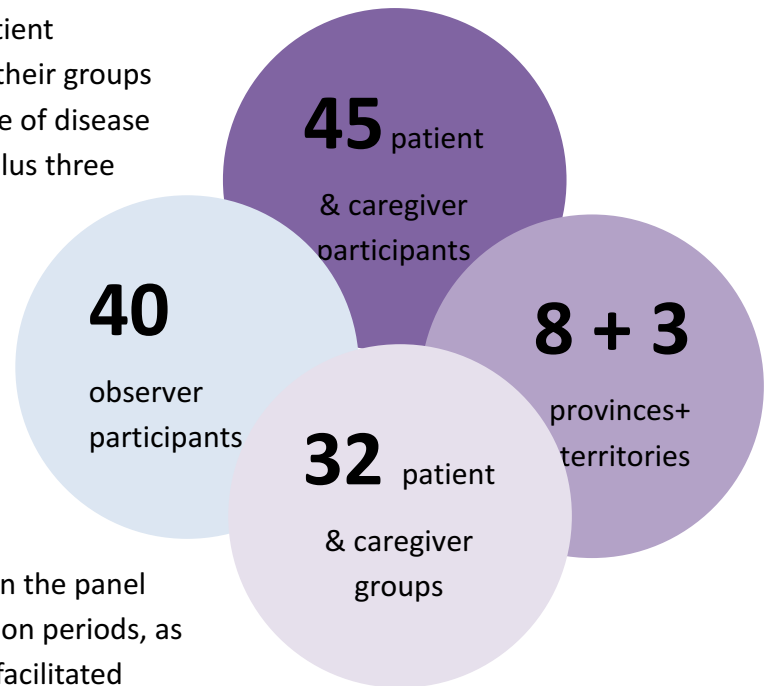


Figure 1: A snapshot of 2019 Summit participation

THEMES

The following themes emerged throughout the two-day Summit in presentations and participants' feedback through questions and answers, newspaper headlines, and breakout sessions.

Health System Reforms

Almost every government agency that presented at the 2019 Summit highlighted reforms that they were in the process of undertaking or, in one case, had successfully completed with promising results. These reforms all aim to reduce process duplication and increase timeliness. To varying degrees, reforms also relate to patient and/or citizen engagement in the agency's fulfillment of its mandate. This second topic is its own theme that will be explored separately. Health Canada is streamlining and reducing duplication through internal and external

collaboration; aiming to use data better; creating a new therapy pathway for products that are not currently regulated (e.g. artificially intelligent medical devices, customized 3D tissue printing at the bedside); enabling remote clinical trials; and engaging patients on expert advisory panels. The pan-Canadian Pharmaceutical Alliance (pCPA) is working on increasing timelines and adding some transparency through a website. The Institut national d'excellence en santé et en services sociaux (INESSS) has completed reforms resulting in a continuous evaluation process that creates efficiencies and doubles the time patient and caregiver groups have to make submissions, while ensuring patient and caregiver recommendations are always presented to the Minister of Health.

Meanwhile, the Patented Medicine Prices Review Board (PMPRB) has added three new factors, including pharmaco-economic analysis based on Quality of Adjusted Life Years (QALYs), to its excessive pricing mandate, which duplicates functions undertaken by Canada's health technology assessment bodies, the Canadian Agency for Drugs and Technologies in Health (CADTH) and INESSS for Québec. This reform appears to go against the overall trend by national bodies to streamline. There is the potential for confusion in the health systems environment should CADTH and PMPRB draw different value conclusions from the pharmaco-economic data, particularly for specific populations. This is causing significant concern to participants.

A couple of participants were blunt in articulating both the problem and the opportunity when they said that duplication and the unnecessary complexity in the national health care system must be reduced in order to move from a service-centric to patient- and citizen-centric system. The fact that the creation of a new Canadian drug agency has been recommended was flagged as an opportunity to amalgamate the functions of health technology assessment, pricing, and negotiations for treatments under one streamlined and harmonized roof. The danger is that a new national drug agency will be formed that will add more complexity, confusion as to roles and responsibilities, process delays, and increased system costs.

What are the Goals for Reform?

Value-Based Health Care (VBHC)

Participants again validated VBHC as the direction towards which all reforms should head. Quite simply, value should be the focus of all actors in the health system and value means outcomes of importance to patients over the cost to deliver those outcomes. As presenters from Boston Consulting Group and the International Consortium for Health Outcomes Measurement (iCHOM) shared, the act of simply measuring outcomes that matter to patients improves those outcomes and decreases the costs to deliver them. The urgency for VBHC is driven by the fact that, across the globe, health care spending is growing faster than gross domestic product, with

inefficiencies adding significant costs to the overall treatment pathway while having negative or at best neutral impacts on patient outcomes.

To be implemented, VBHC requires data on outcomes to drive promising and best practices. iCHOM is playing a global leadership role with the mission of defining a minimum standard set of outcomes by patient population. They have completed 28 so far, which tackle over 50 percent of the global disease burden by spend. In addition, incentivizing payment models need to be developed to enable the delivery of VBHC. Policies and regulations must also support VBHC.

In Canada, integrated models of care like Community Health Centres (CHCs) and their further integration efforts across the care continuum as well as their efforts to begin measuring primary care PROMs were identified as exciting seeds of VBHC that need to be nurtured and spread.

In addition, a new national hub convened by the Conference Board of Canada, called Value-Based Health Care Canada (VBHC Canada), has been launched. Its current priorities include partnerships, information exchange between jurisdictions, developing strategic research and capacity development agendas, creating a repository for VBHC initiatives, and supporting demonstration projects to provide the methodological structure of a standard evaluation framework for the projects.

One of these demonstration projects is being co-led by the Coalition Priorité Cancer au Québec. After attending the 2018 Summit, which focused on VBHC, the Coalition's Executive Director realized that Quebec currently has a supportive environment for VBHC. Building on the momentum of the 2018 Summit and this positive environment, a group of patient representatives met in Montreal. Out of that meeting, an agreement between the Coalition and VBHC Canada was developed for a patient-led demonstration project.

Early adopters and best practices have been identified in order to validate standard sets of PROMs (breast cancer, lung cancer, and colorectal cancer) recommended by the International Consortium for Health Outcomes Measurement with patients. Key partners for implementation include four centres of excellence in cancer care, two in Montreal and two in Québec City. They were chosen as change leaders that can mobilize their teams and embrace the culture changes required by VBHC. Once the PROMs are validated by patients, issues in achieving those outcomes across the care continuum will be identified, including bottlenecks, delays, gaps, and unnecessary costs. By measuring outcomes, gaps, and timelines at baseline and throughout, the group will learn, improve, and develop the data, processes, policies, procedures, and tools to support better achievement of those PROMs. All levels of government are being kept closely in the loop to ensure the demonstration project's data and results inform future systems changes.

What are the Goals for Reform?

Determinants of Health

Health outcomes are different for different populations. This is because about fifty percent of health is shaped by social and other determinants of health. Access to resources shape health outcomes in at least three ways: (i) by shaping the prerequisites to health like food and shelter; (ii) by living with constant deprivation that continuously activates the body's distress response negatively impacting it; and (iii) by limiting opportunities to make choices.

In health care, access is the use of health services to achieve the best possible health outcomes. This encompasses entry into the system, utilization, and outcomes. Entry, utilization and outcomes are negatively impacted by factors like age, gender, ethnicity, disability, resources like income, food, housing, and security. In order to improve health, proportional attention and resourcing are needed to address the determinants of health, especially their root causes. Geography was named as a determinant of health in many rural, remote and isolated parts of Canada.

Reform Enabler & Driver:

Data

The Canadian Institute for Health Information (CIHI) laid out the main drivers moving the health system towards increased capacity to measure and improve upon value using Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs):

- Exponential data growth;
- Health systems evolving from service-centric to citizen-centric and patient-centric;
- Emerging analytical capability with artificial intelligence; and
- Ability to get information to people.

Key enablers are privacy-enabled access to data sharing and rigorously keeping patients at the centre. CIHI prepares reports that compare jurisdictions on PROMs and PREMs to identify positive outliers that can become best practices.

As previously mentioned, VBHC requires good quality data on outcomes to drive best practices through PROMs. This relies upon health informatics with interoperability to share data across systems in order to use data to benchmark and identify promising and best practices, do more research on treatment development, and to improve care pathways and decision support tools. Everyone benefits from PROMs. With public sharing of outcomes, patients can choose providers based on performance. Providers can improve performance, resource allocation, and

differentiation/expertise. Payers can negotiate better contracts based on outcomes rather than volumes for uncertain results.

i. Patient Reported Outcome Measures (PROMs)

iCHOM presented on Patient Reported Outcomes (PROs), PROMs and PREMs, defining each, and explaining how PROMs are developed, including how patients are part of the co-design process. The presenter shared that the use of enough PROMs helps create a roadmap for patients and providers, including timelines and trajectory to a person's return to their normal activities, if possible. This roadmap improves patients, caregivers, and providers' experiences. Because patients complete a PROM pre-visit, the quality of the appointment is improved as the clinician arrives prepared and conversations that may not have happened in the past are now happening, thanks to the prompting of the PROM.

ii. Participant Feedback on iCHOM Standard Sets

Overall, participants validated PROMs and recognized their importance. They also appreciated the work done to date. It was mentioned that they should also be incorporated into clinical trials. However, everyone also acknowledged that there remains a lot of work to do, both in terms of re-evaluating existing PROMs with patient groups using real-world data and developing new PROMs for more health conditions and patient populations.

There was also a fundamental question asked by everyone about how co-morbidities and concurrent disorders are handled, with different PROM sets potentially being managed by different providers. How does one prevent the silo-ization of PROMs?

Participants identified many gaps and improvements, including:

- Determinants of health need to be addressed (including food security, nutrition, cost barriers, housing, mobility, transportation)
- Quality of life measures need to include sleep and exercise
- Quality of death measures cannot just rely on place of death; choices of how, when, and with whom one dies are important
- Measures should look at whether care is being received in appropriate settings (not just not in hospitals)
- Measures related to participation and decision-making must look at supports, information, and time to ensure these are enabled and providers "can't game the system"
- Rehabilitation was missing in some sets
- Palliative care was missing in some sets

- Early diagnosis/time to diagnosis/access to care were missing
- Wait times or timelines are important
- Mental health (e.g. depression) were missing for some conditions like kidney disease or inflammatory bowel disease
- Screening for prevention or worsening of disease were missing for some conditions
- Sometimes complications or follow-up measures were missing
- Integration of care may need to be measured

There were language issues flagged by different participants. “Disutility of care” should be better described, such as “care that isn’t working”. Overall, language should be adapted for patients, not just providers, in order to reflect patients’ values. Also, cultural adaptations are very important. In the mental health set, the recovery language was identified as problematic. Recovery is an ongoing, individual process, not an end state. Cognitive function is affected by the recovery process. As part of social functioning, “sense of belonging” should be incorporated. Also, for mental health, the PROM set needs to include self-reported health and wellbeing measures that the individual assesses for themselves.

In addition, it was mentioned that PROMs need to be able to be stratified to look at different equity-seeking or disproportionately impacted groups (e.g. low income, indigenous, different ethnic backgrounds, different genders). Common socio-economic data needs to be collected by all providers implementing PROMs in order to stratify PROMs for equity considerations like income, ethnicity, gender, and age.

When it comes to data related to First Nations in Canada, the [OCAP \(Ownership Control Access and Possession\)](#) principles must be applied. Often, OCAP principles are applied to any and all Indigenous data, not only First Nations data. For example, CIHI is working with the First Nations Information Governance Centre and the Métis Nation on implementing OCAP.

Patient-centricity or “Whole Person Care”

Several presenters from different government agencies talked about their efforts in this area. CIHI set the stage by stating that health care systems are moving from service-centric to patient- and citizen-centric. CADTH highlighted a range of patient engagement mechanisms using the [International Association for Public Participation’s tool](#). pPCA highlighted their engagement with patients related to biosimilars. Health Canada talked about their inclusion on expert advisory committees. INESSS described how their reforms resulted in patients groups having double the amount of time to prepare a submission and ensuring that therapeutic value, which

includes patient input, is always presented in their letters to the Minister of Health. The Canadian Life and Health Insurance Association (CLHIA) flagged the opportunity for patient groups to educate and raise awareness amongst its membership of health and life insurance companies. There was frustration expressed by one participant in the gap they felt between their expectations versus what they actually experience when being engaged.

A lesson was, no matter the engagement type, ensure the people participating know they were heard. At a minimum, always report back to them on what you heard and what was done with the input, whether it was used or not. Ideally, move towards more meaningful engagement closer to the “empowerment” end of the IAP2 spectrum.

The point was made a few times that people privileged to be at different tables where there is power in planning, decision-making, policy development etc. need to find ways and make every effort to create participatory ways to bring the voices of people with poor determinants of health to those tables.

A key concept and set of competencies to support equitable whole person care is cultural safety. This was named specifically in the context of Indigenous health. However, cultural safety applies to many diverse cultures requiring health care in Canada. Cultural safety is when all people feel respected for who they are and receive the services they need. Cultural safety relies upon creating trust and belonging between providers and clients. Cultural safety training is needed for everyone in health care and must be part of policies and procedures throughout health care systems to enable this. In British Columbia and Ontario, Indigenous Cultural Safety training for the health system has already been developed. Indigenous Navigators were named as helpful providers to include on a team, people who help Indigenous people navigate the systems and support them with cultural safety. Trauma-informed care was also named as an important approach to better supporting Indigenous health in Canada.

Key actions for everyone to take in order to have a more positive impact on Indigenous health in Canada include bringing both truth and reconciliation to life in our daily lives. To support “truth”, one must educate one’s self on Canada’s and North American’s colonial history, its contemporary issues, and the implications and impacts of these. There are a wealth of resources available and suggested by the presenters, including the [Truth and Reconciliation Commission’s Calls to Action](#). Reconciliation in our everyday lives includes the implementation of cultural safety through training and revised policies and procedures, ongoing self-reflection on one’s own beliefs, experiences, and biases/assumptions, exploring how one can better bridge differences between cultures, and finding ways to be pragmatic to make changes where one can, for example during the annual renewal of policies and procedures, and recruiting

Indigenous staff to serve Indigenous clients.

Finally, community health centres (CHCs) were identified as a model of integrated care that reflects what one participant called “whole person care” (rather than patient-centric). CHCs are interprofessional primary health care teams, including different professionals like family physicians, nurse practitioners, RNs, RPNs, social workers, dietitians, health promoters, peer workers, plus administrative staff. They focus on health promotion and community development alongside of primary care. CHCs are built by and governed by the communities they serve, which are sometimes geographic (e.g. a large rural region or an urban catchment area) and sometimes population based (e.g. Francophones, Indigenous, racialized, low income, LGBT) and often a combination, depending on the needs of a community. Their [Model of Health and Wellbeing](#) and [Model of Wholistic Health and Wellbeing](#) address the determinants of health, including loneliness and social isolation, and emphasize people and communities first as well as reaching the “hard to reach”.

Ontario CHCs are increasing access to CHC’s non-primary care services through an initiative called “Team Care”, which is connecting socially and medically complex clients of solo family physicians with CHC’s non-primary care services while the solo family physician remains the primary care provider. They are increasing access to opportunities that address the determinants of health, including loneliness, through “Social Prescribing”, primary care practitioners deliberately connecting clients with social and other non-medical supports they need both inside and outside the walls of the CHC. People may need help with housing or income. They may need a senior’s exercise group or nutritional support. They may want to go fishing, visit a museum, or learn to knit. People who receive social prescriptions are often inspired to give back and volunteer as a community champion, creating a new social prescribing network based on their passions and interests.

Common Issues Across Provinces

There were many commonalities in issues being faced by patients and caregivers across Canada. The magnitude of particular problems varied from place to place, depending on the economic health and size of budget of a province, as well as its geography. Different people chose to highlight different issues, but they were, on the whole, common across the country.

- **Access to Care:** including significant rural and remote gaps; primary care gaps; gaps in access to diagnostic tests for different treatments; significant mental health and addictions gaps and lack of capacity; and health inequities, particularly for Indigenous people, refugees, newcomers, people living on low incomes, LGBT. The access issues play

out in poor timeliness of care, with wait times for care and treatments and a lack of early diagnoses

- **Quality of Care:** including care that removes one's sense of agency, of being an actor in their own care; care that is clinical and not wholistic or human; care that exacerbates equity issues (in terms of entry, utilization and outcomes) because privilege needs regularly examined to identify and dismantle inequitable aspects of our systems so wide-spread training in decolonization, cultural safety, anti-racism, trauma-informed care; and user co-design and partnership in all aspects of care planning, implementation, and learning
- **Continuity of Care/Patient Journey:** including fragmentation and lack of coordination; lack or delayed treatment coverage and inequitable access across Canada; lack of information sharing between providers; and widespread, nationwide gaps in mental health and addictions services as well as the failure to integrate mental and physical health approaches
- **Affordability of Care:** including related to medications and other treatments (e.g. co-pays, not covered privately or publicly)
- **Provider Shortages:** including family physicians, nurse practitioners, nurse navigators, mental health counsellors, specialists
- **Drug Shortages:** including concerns related to the US plan to import Canada's drug supply
- **Lack of Meaningful Patient and Caregiver Partnership and Client Co-Design**
- **Increasing Rates of Cancers, Chronic Conditions, Mental Health and Addictions**
- **The Decrease in Vaccination Rates due to "anti-vax" sentiment and impacts on the healthy population and people living with health conditions**
- **Top-down, Structural Approaches to Reorganizing Health Care**

Common Opportunities Across Provinces

Similar to issues, there were common opportunities across provinces, including:

- **Value-based health care** for culture change, including outcome-based payment models and performance measures
- **Integrated services that are more wholistic and coordinated across the care continuum** (including CHCs, chronic disease hubs, integrated cancer centres of excellence)
- **Services that address rural and remote health needs**, including satellite sites, mobile health clinics, telemedicine (which requires internet infrastructure in many regions)
- Supporting **indigenous self-determination** in health and **building self-awareness**,

organizational readiness, relationships and partnerships to further this

- Improved **recruitment and retention** of diverse providers across geography, including rural strategies and indigenous strategies
- **Private-public partnerships for health technology and investing in data infrastructure**, including and especially for rural and remote regions
- Investing in **community-based capacity**, especially for **mental health and addictions**
- Investing in **determinants of health**, including transportation for rural and remote areas, and housing (e.g. Homes First)
- **Tying transfer payments** to targeted investments
- Improving **treatment coverage across the country**
- **Co-designing and partnering with diverse patient and caregiver groups** and community agencies on health policies, planning, implementation, and learning

Moving Forward

The 2019 Summit, *A Dose of Reality: Patients Redefining the Future of Health Care in Canada*, provided an opportunity for patients, patient representatives and advocates, caregivers and their groups to continue to explore the concepts of VBHC and PROMs as potential ways forward in transforming Canada's health care system so that it is driven by patient needs and desired health outcomes while simultaneously updating themselves on the health care landscape across the country.

The 2019 Summit also provided an opportunity to create a series of Working Groups to develop strategies and tactics together. Six Working Groups were identified and patients, patient representatives and advocates, caregivers and their groups signed up to join them. They are:

1. **Integrated models of care:** including integrating mental and physical health, determinants of health, trauma-informed care, cultural safety, indigenous models of care, health equity and social justice along the continuum (prevention, screening, diagnosis, treatment, rehabilitation, palliative)
2. **PROMs and PREMs**
3. **Vaccinology** (education and advocacy)
4. **Data** (including CanREValue)
5. **Educating Private Health Insurers on VBHC**
6. **Communications**

Moving forward, patients, patient representatives and advocates, caregivers and their groups

will continue to strive to take a VBHC approach in Canada in its most fitting form – led, driven and realized by and with patients. The group was inspired by the significant momentum that was gained between last year’s Summit and this year’s in moving forward a patient-led proof of concept or demonstration project focused on VBHC and PROMs.

Patients and caregivers 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

Day 1: Tuesday, November 12th

08.00	Breakfast and Registration
08.30	Welcome Summit Organizers
08.35	Overview of the Summit Leah Stephenson
08.45	101 on Health Systems Louise Binder
09.00	Panel 1 Updates on Health Care in Canada Megan Bettle , Director, Centre for Regulatory Excellence, Statistics and Trials (CREST), Biologics and Genetic Therapies Directorate, Health Products and Food Branch, Health Canada Wayne Critchley , Senior Associate, Global Public Affairs Eric Sutherland , Executive Director, Data Governance and Strategy, Canadian Institute for Health Information (CIHI)
09.30	Q&A
09.40	Introduction to Ontario's Deputy Premier and Minister of Health Hon. Christine Elliott
09.45	Greetings on behalf of the government from Ontario's Deputy Premier and Minister of Health, Hon. Christine Elliott
09.55	Sharon Clarke , Program Lead, Indigenous Health, CIHI
10.10	Panel 2 Updates on Health Care in Canada (cont'd) Sarah Berglas , Manager, Patient Engagement, Canadian Agency for Drugs and Technologies in Health (CADTH) Marie-Claude Aubin , Coordonnatrice scientifique en pharmacoéconomie, Direction du Médicament, Institut national d'excellence en santé et en services sociaux (INESSS) Anchalee Srisombun , Senior Negotiator, The pan-Canadian Pharmaceutical Alliance Office (pCPA)
10.40	Q&A
10.50	Jennifer Clawson , Partner & Associate Director, Health Systems and Value-Based Health, Boston Consulting Group
11.20	Q&A
11.30	Karen Voin , Vice President Group Benefits and Anti Fraud, Canadian Life and Health Insurance Association (CLHIA)
11.40	Q&A
11.50	LUNCH – Optional lunch and learn with Canadian Partnership Against Cancer
12.50	Highlights from morning presentations
13.00	The Determinants of Access to Care Dr. Ambreen Sayani , Health Strategist and Consultant; Coordinator Lung Cancer Screening Study, St. Michael's Hospital, Toronto
13.15	Q&A
13.25	Focus on Value-Based Health Care in Canada

	Jennifer Rayner, Director, Research & Evaluation, Alliance for Healthier Communities
13.55	Q & A
14.05	Focus on Value-Based Health Care in Canada
	Monika Slovynec D'Angelo, Ph.D., Director of Health, Conference Board of Canada Eva Villalba, Executive Director, Coalition Priorité Cancer au Québec
14.35	Q&A
14.45	Break
15.00	Focus on Value-Based Health Care Stacie Myers, Manager of Outcomes Research & Development, International Consortium for Health Outcomes Measurement (iCHOM)
15.30	Q&A
15.40	Breakout Session and Report Back
16.40	Closing Remarks for Day One Leah Stephenson

Day 2: Wednesday, November 13th

07.45	Breakfast and Networking
08.15	Welcome Back and Our Objectives for Today Leah Stephenson
08.20	Starting to Put Ideas from Day One Together Antonella Scali
09.00	Patient Panels from across Canada (BC, AB)
09.30	Q&A
09.45	Patient Panels from across Canada (SK, MB)
10.05	Q&A
10.15	Patient Panels from across Canada (ON, QC)
10.35	Q&A
10.45	Break
10.55	Patient Panels from across Canada (NL, NB, PEI NS)
11.35	Q&A
11.45	Thank You and Closing Remarks to Observers Summit Organizers
11.50	LUNCH – Optional lunch and learn, Indigenous Issues in Health Care, Sharon Clarke
12.45	Regional Breakout Session (for patients, caregivers and patient groups)
13.30	Larger Group Breakout Session
14.20	Break
14.35	Report Back and Action Planning
15.35	Next Steps Leah Stephenson
15:50	Closing Remarks Louise Binder

Appendix 2: Summary of the Summit Evaluation Results

An electronic evaluation survey was sent to participants at the close of the 2019 Summit. A total of 21 participants responded to the survey. 71% of respondents were from Ontario, 19% from Quebec, 5% from Alberta, and 5% from Saskatchewan.

The majority of respondents (62%) indicated that they found the overall Summit “very useful” to them or their organization; about 19% found it “useful”; and 19% found it “somewhat useful”.

For Day One’s presentations, the majority (62%) found the presentations “very useful”; while 24% found it “useful”; 9.5% of participants found them “somewhat useful”; and one person did not find them useful.

For Day Two’s presentations, half (50%) of respondents found them “very useful” and the other half (50%) found them “useful”.

Qualitative responses from participants on what they liked about the Summit included:

- Information sharing from various stakeholders – what agencies are doing and opportunities to participate; provincial challenges and opportunities from patients’ perspectives; special focus on indigenous health, social determinants of health, and a patient-led, multi-stakeholder VBHC proof of concept
- Energizing networking opportunities
- Solution-focused and action-oriented event

The overall highlight was spending 2 days in a room with over 100 people willing to effect change and make a difference; meeting so many extraordinary people that are fighting against all odds not only to have themselves a better life but to make sure others do as well. It was also useful to hear the “common threads” among the issues all provinces are having, and learning about different initiatives happening around the country.

While all was good and well organized, I particularly like the topics that we chose to work on going forward...

Respondents also provided feedback for future Summits, including:

- Providing more time for networking (which was shared by numerous respondents)
- Aiming for even more balanced geographic and patient population representation on

panels

- Exploring more deeply how to allocate funds within health care as well as the financial benefits of access
- Skipping the basic information (e.g. mission/mandate) of national health bodies

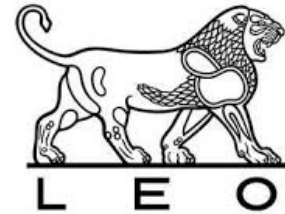
The majority of respondents (81%) found the venue “excellent” or “very good”, while 18% found it “good”. Constructive feedback on the venue and logistics included the issue of noise due to the open concept layout of the meeting room; considering finding a venue that is co-located with the accommodations; and ensuring the readability of all slides. One respondent expressed particular appreciation for the event being free of charge with travel grants to facilitate access for patients and caregivers.

Appendix 3: Sponsors

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