PATIENTS REDEFINING
THE FUTURE OF HEALTH CARE IN CANADA

November 13, 15, 16 & 17

2023 SUMMARY REPORT

Written by Leah M. Stephenson

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INTRODUCTION

The [eighth annual Patients Redefining the Future of Health Care in Canada Summit](#) ("the Summit") took place virtually on November 13, 15, 16, and 17, 2023. This year's theme was **"Meeting People Where They're At: Modernizing Health Care to Meet the Needs of All."** The Summit is an initiative led by Save Your Skin Foundation in collaboration with the Canadian Psoriasis Network and an Indigenous volunteer from Kiyasiw Consulting. The Summit received generous contributions from volunteers, speakers, panellists, facilitators, sponsors, and other collaborators. A special thank you is due to our keynote speaker, Dr. Naheed Dosani, who generously shared his time with us to help us shape our content, particularly on the first day of the Summit.

> The objectives for the 2023 Summit were to:
>
> - Enhance participants' knowledge about health, social determinants of health in and associated systems in Canada, and their impacts on key populations to support greater equity and inclusion addressing Canada's diversity;
> - Create synergies and recognition of common issues across patient groups and other health care stakeholders;
> - Engage policymakers and foster collaboration between patient communities and other relevant groups, including researchers, government, non-governmental agencies and other partners; and
> - Support conversations about how patients can influence policy and design to build the health systems they deserve.

This event builds on the [2016,](#) [2017,](#) [2018,](#) [2019,](#) [2020,](#) [2021](#) and [2022](#) Summits, which provided opportunities for patients, patient representatives, advocates, caregivers and their representatives from diverse disease and disability groups to come together to discuss a shared vision for health care in Canada. The Summit has evolved over time. For an overview of this year's agenda as well as the history and evolution of the Summit over time, please read Appendices 1 and 2.

EXECUTIVE SUMMARY

The eighth annual Patients Redefining the Future of Health Care in Canada Summit included three pre-Summit webinars, three days of online content, and an action planning session with patients, caregivers, and patient organizations. This year's themes again demonstrate how intersectional discrimination, including systemic racism plus implicit and explicit bias against First Nations, Inuit, and Métis (FNIM), results in negative health outcomes and poor access to health care. Patients and patient-centred providers struggle with the paternalistic culture of health and social systems. Health care teams that are specifically designed to address structural and social determinants of health make a difference, as do ongoing cultural safety initiatives; meaningful co-design; leadership by affected communities; broader integration between health and social systems; and data integration that includes health and social data, with equity

stratifiers for disaggregated analyses.

Fifty-four patients, caregivers, and patient group representatives registered to attend Day One, forty-nine on Day Two, and fifty-six on Day 3. Forty-eight patients, caregivers, and patient group representatives registered for the action planning session. In addition, forty-nine stakeholders from other sectors registered for the Summit on Day One, forty on Day Two, and sixty on Day Three. There was twenty-two percent growth in individual patient and caregiver registration and nineteen percent growth in patient groups. There was 61.5 percent growth in attendance by other interested health care stakeholders, including a variety of government bodies, health care providers, pharmaceutical, medical technology and health insurance industries, researchers, and non-profit organizations.

Recordings of all the content in English and French have been made publicly available for those who missed sessions and for more people to access the content over time. Find all the videos in English and French on Save Your Skin Foundation's YouTube playlist. After only a couple of weeks of posting, there have been 148 views of these videos.

WEBINAR SERIES

The co-organizers continued the pre-Summit webinar series that contributes towards the achievement of the event objectives. On October 12, 2023, "**Family Advocacy in the Midst of the Drug Poisoning Crisis**" was presented by Petra Schulz, co-founder of Moms Stop the Harm, a network of Canadian families impacted by substance-use-related harms and deaths who advocate for drug policy reform. It was a discussion about the experiences of people and families affected by the toxic drug crisis in Canada, and the role of advocacy from organizations like Moms Stop the Harm in offering solutions and strategies.

On October 30, 2023, Dr. Rachel Asiniwasis presented "**Our Skin Tells Many Stories: An Evidence-Based Approach to Addressing Indigenous Health Disparities and Pathways Towards Solutions.**" Dr. Asiniwasis shared evidence-based approaches to addressing Indigenous health disparities. As she explained, skin health in Indigenous peoples is "not just a skin problem". She provided context, challenges, and pathways towards solutions for all stakeholders in health care to consider. Dr. Asiniwasis is a dermatologist and clinician researcher based in Regina, Saskatchewan. She is the founder of Origins Dermatology Centre, a combined multidisciplinary model that services both the general population and provides outreach clinics (in-person and virtual care) for underserviced remote and rural First Nations and Métis communities. Dr. Asiniwasis is of Plains Cree, Saulteaux and English background.

On November 6, 2023, Louise Binder, lawyer, health policy advocate, and Health Policy Consultant with Save Your Skin Foundation, and Carolyn Roberts, Ottawa Hospital's first Indigenous Nurse Navigator for the Indigenous Cancer Program whose 25-year nursing career has been predominantly set in northern Quebec and Nunavik, co-presented "**Jurisdictional**

Roles in Canadian Health care, Including Specific to First Nations, Inuit, and Métis Communities." The webinar described the roles of federal and provincial/territorial governments in health care law and policy as well as health care delivery, including for First Nations, Inuit, and Métis peoples of Canada.

SUMMIT OVERVIEW

This section offers an overview of the Summit in 2023.

PARTICIPANTS

Across all three days of content, 58 individuals representing patients, patient representatives and advocates, caregivers and their groups attended the Summit. Thirty-one different patient, caregiver, and engaged citizen groups representing a range of health conditions across Canada were in attendance. **This represents 22 percent growth in individual patient and caregiver registration and 19 percent growth in patient groups.**

58 patient & caregiver participants

65 observer participants

31 patient, caregiver & citizen groups
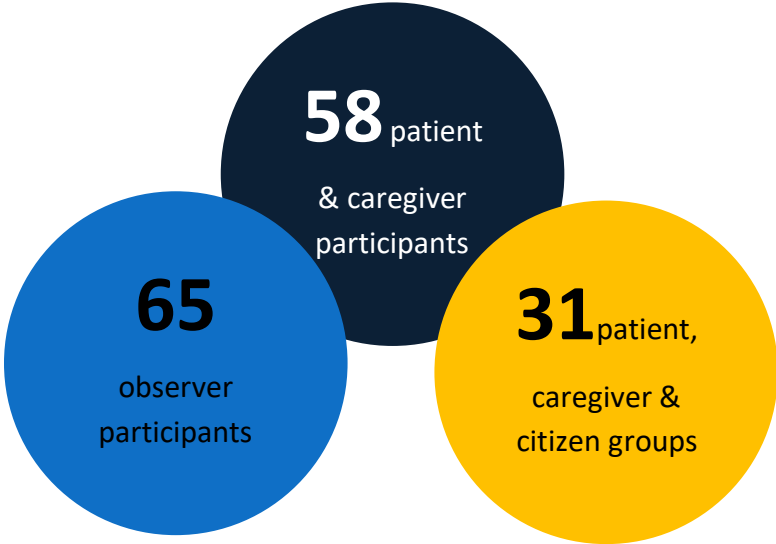
Sixty-five observers from diverse stakeholder groups participated in the Summit, including a variety of government bodies, health care providers, pharmaceutical, medical technology and health insurance industries, researchers, academia, and non-profits. **This represents 61.5 percent growth in attendance by interested health care stakeholders.**

THEMES

The following themes emerged throughout the Summit in presentations plus participants' feedback through questions and answers and breakout sessions. Numerous themes continued from previous Summits.

Intersectional discrimination, including systemic racism plus implicit and explicit bias against First Nations, Inuit, and Métis (FNIM), results in negative health outcomes. Systemic racism and implicit/explicit bias against FNIM directly contribute to real and disproportionate negative health outcomes and poor access compared to non-Indigenous people. Contentment with and entrenchment of the status quo are major barriers to meaningful progress. As Dr. Jason McVicar stated, "colonization is a living thing. It's baked into everything we do." Day Two's keynote speaker Mackenzie Daybutch explained how "low quality care doesn't just affect one person. Word travels fast. Negative experiences have a ripple effect." Part of the reason for these

negative outcomes is that people don't enter the health care system in the first place. When they do, they experience high degrees of anxiety due to their own negative past experiences or those of their family and community members, which can be misunderstood as hostility, thereby continuing the negative spiral of poor experiences and outcomes. On the other hand, as Mackenzie shared, "positive ripple effects will result from more people having better experiences and outcomes. We'll see the full change in seven generations."

Structural and social determinants of health are major factors in accessing any kind of health care, including mental health care. Dr. Naheed Dosani, the keynote speaker for the first day, set the stage for this and shared many insights into the work of his team at [Palliative Education and Care for the Homeless (PEACH)](#) in addressing the needs of unhoused people in Toronto. As he shared, **if we do nothing about addressing the social disparities in our healthcare system, nothing that we do will be sustainable.** The more the determinants of health intersect, the less opportunities for access one experiences. **Health care teams that are specifically designed to address determinants of health make a difference**. These teams should be in primary health care (e.g. community health centres) and in specialized care (e.g., PEACH for palliative care, psychosocial oncology, psycho-dermatology). **The opportunities to access them need to be proactively provided in a way that address people's realities**, such as the street and shelter outreach provided by PEACH to serve homeless and housing insecure patients.

An additional theme that came through both the first and second days was the **paternalistic culture of health and social systems.** Diana Chan McNally shared that being unhoused means that you are barred from decision-making. For example, unhoused people do not control when or what they eat on a given day. The paternalistic culture of health and social systems is another barrier to Indigenous people engaging with and navigating these systems. It is also a barrier to health care providers trying to provide care based on the needs of the patient. Carolyn Roberts shared how, as a patient navigator for FNIM clients, she must work against the sense of "patient ownership" by providers to facilitate meeting the needs identified by patients themselves.

Patient partnerships, meaningful engagement of people with lived experiences, and co-design are a recurrent theme from this year and past events. To meet people where they are at, partnerships and co-design must be inclusive of people experiencing poor structural and social determinants of health. Co-design and leadership with and by specific FNIM communities that support and contribute to reconciliation, instead of surface-level demonstrations, are foundational. FNIM leaders and community voices must be at the centre. As Kerry Kuluski explained, part of effective co-design is the ability to implement what is learned and/or decided. Dr. Jason McVicar shared that "reconciliation is a verb" meaning reconciliation requires action.

As Dr. Kuluski shared, **co-design creates better processes and results, increasing the likelihood of improved health outcomes**. It is important to understand what co-design is (e.g., involve or empower) and why it is beneficial. It is also essential to ensure all the right people are involved, including the people being affected by the problem and the decision-makers in a position to do something to support solutions. Moreover, include people who don't trust public systems and/or don't access health care services and find the channels to build relationships with these communities.

The benefits of co-design mean more accessible and culturally relevant approaches to care. For example, Rebecca Lonsdale explained how pain scales using numbers don't work for Inuit people. It would be more effective to instead ask about their ability to live daily life, like sleep and appetite. Without meaningful co-design, health care is missing these vital insights for more effective, high quality, and culturally relevant care. In addition, through meaningful co-design, providers and health care decision-makers can unearth and make explicit tacit knowledge that can improve experiences and outcomes without necessarily adding further requirements from the health care system. For example, Rebecca also shared that there are micro-systems of strength related to Inuit caregivers, families, and communities. Health care providers/settings/ systems need to identify, understand, support, and formalize such strengths. Co-design can also reveal the importance of understandable, accessible interpretation and translation. As Rebecca Lonsdale shared, "It's very difficult to make informed decisions in a second language" and, when it comes to patient information, "Use visuals! Pictograms are helpful for many Inuit patients."

Leadership by people with lived experiences and people from affected communities, above and beyond partnership, co-design, or other forms of engagement, is key to transforming our systems to become more inclusive. Leadership means that people have decision-making power, not only as health care professionals, but also as executives and governors on boards. It is vital to recognize the value of diversity in the workplace. As Dr. McVicar shared, "The more we know about the populations we serve and the more we can hire people from those populations and improve people's care, the better we will do." FNIM health care providers and in leadership positions must be supported to achieve better health outcomes for FNIM individuals and communities and to ensure rights-based data approaches.

The need for **integration between health and social systems** was another theme. The point made by Dr. Dosani was demonstrated repeatedly by other presenters namely that, if nothing is done about addressing the social disparities in our health care systems, nothing that is done will ever be sustainable. Siloed decision-making including within health budgets, within individual ministries, and within and between jurisdictions fuels inaction and harm. The challenges that people are facing are integrated so the systemic fragmentation makes effective responses more

difficult. Some of the integrated challenges people face will also challenge common assumptions that fuel current decision-making within the different silos. Understanding the intersections can enhance the effectiveness of solutions. As Bee Lee Soh shared, "I became homeless with a full-time job." What are the opportunities to prevent homelessness and mitigate housing insecurity through minimum wage that is a living wage and other income-related initiatives like basic income? How can healthcare providers working with homeless people help connect them to the range of social supports they need in terms of housing and income and -- vice versa – how can social support services be supported to identify healthcare needs and connect people with needed care?

Related to the need for integration between health and social systems, among the solutions to better health and health care include living wages, publicly funded dental care, and publicly funded medicines and medical devices. Intra- and inter-jurisdictional collaboration is needed to reduce fragmentation and increase integration. Team-based models of care are examples of integrating health and social systems at the level of service delivery. **Prevention is fundamental** and is lacking from health and social systems. These systems must focus and invest upstream to prevent downstream issues, for example, palliative care needing to be delivered on the streets. Many end-of-life patients being served by PEACH could have survived and thrived had they been supported earlier and they would never have become homeless with an appropriate supportive housing option available when needed.

The need for **data integration** is an additional recurrent theme that ran throughout this Summit and past Summits. Without interoperable health data that can be stratified to assess differences between segments of the population, individuals and communities will suffer. Moreover, providers will continue to burn out and service delivery organizations, plus the various bodies supporting them, will not be able to improve quality and performance. Public education to improve data literacy is crucial in this effort.

One province that is boldly taking the lead on this is Newfoundland and Labrador through its 10-year Health Accord, which aims to link health and social data to address the relationships between health and social determinants. As Dr. Marcia Anderson shared, "We need rights-based data." As Mackenzie Daybutch pointed out, collecting those data is hampered by colonial impacts, resulting in mistrust and concerns of possible harms in how the data are used. Health data collection must start with FNIM communities themselves. It cannot cause harm. OCAP (Ownership Control Access and Possession) must be meaningfully implemented. There are many lessons to learn from the work being led by Dr. Anderson in Manitoba. The benefits of collecting and using race/ethnicity/Indigenous identifiers were shown throughout the COVID pandemic so now the work has expanded across the province. As Dr. Anderson shared, this type

of work is highly publicly acceptable. From her experience, the most resistance to collecting and using this data comes from healthcare providers, which can be overcome through change management practices. Strong relationships with FNIM communities and bilateral agreements between First Nations, Inuit and BIPOC groups and the province helped to meaningfully implement OCAP and community-led data governance. These bilateral agreements need to be monitored for compliance. The use and release of the data need to be timely and relevant so that communities can see how data is being used to benefit their communities. Data governance that brings needed expertise and community participation into structures and processes helps to earn and maintain trust.

Education was the final theme that ran throughout this year's Summit. Some topics that were identified as important and requiring continuous education include:

- the diversity of FNIM across Canada – including 650 different First Nations and a diversity of Inuit communities -- to support specific solutions by these communities,
- cultural safety to unlearn implicit biases and create more culturally safe health care, health care environments, and patient/caregiver resources, and
- health data literacy, including for the public at large.

For example, when it comes to cultural safety, Rebecca Lonsdale shared her mother's experiences of re-traumatization as she went through her oncological care. Rebecca's Inuit mother, as a young woman, was taken by force by boat from her community for tuberculosis care in an urban sanitorium. As a result of this traumatizing experience specific to certain Inuit communities, the smells, sounds, and procedures in a hospital are re-traumatizing triggers. Through cultural safety training, health care providers can better understand their different patients and the experiences they may be having when accessing health care to better meet people where they are at.

ACTIONS MOVING FORWARD

The 2023 Summit, particularly the fourth day with patients, caregivers, and groups representing them, provided an opportunity to update on the progress and renew the mandates of the Working Groups and to consider creating new ones based on the outcomes of the 2023 Summit. Two Working Groups were renewed with clear next steps. They are:

1. **Health Data Working Group** activities could include:

- Develop a knowledge mobilization plan for the Declaration of Personal Health Data Rights in Canada
- Assess opportunities to support health data literacy amongst patients and caregivers

- Learn more about Newfoundland and Labrador's 10-year Health Accord and approaches to linking health and social data sets to address the relationships between health and determinants of health to implement effective interventions

2. **Integrated Models of Care Working Group** **activities could include:**

- Finalize Indigenous Primary Health Care Organizations case study
- Analyze PEACH and consider creating a case study
- Develop a knowledge mobilization plan for all case studies of integrated models of care

The possibility of continuing or further developing a webinar series to address relevant educational topics for patients and caregivers should be considered by Summit organizers.

Anyone interested in joining one or more of the three working groups, should contact leahstephenson@gmail.com

In summary, patients, caregivers, engaged citizens and the groups that represent them will continue to embrace the mantra from Dr. Hank Veeze that was introduced at the beginning of the 2018 Summit:

"Think Big. Act Small. Don't Wait."

Appendix 1: Agenda

<table>
<tr><td colspan="3" align="center">**AGENDA**</td></tr>
<tr><td colspan="3">**Day 1: Challenges to "Meeting People Where They're At"**</td></tr>
<tr><td colspan="2">**Monday, November 13, 2023**</td><td>**11:00 AM -4:00 PM ET**</td></tr>
<tr><td>**Summit Opening**</td><td>Kathy Barnard and Sharon Clarke</td><td>11:00-11:10</td></tr>
<tr><td>**Agenda Overview**</td><td>Leah Stephenson</td><td>11:10-11:15</td></tr>
<tr><td>**Keynote Introduction**</td><td>Louise Binder</td><td>11:15-11:20</td></tr>
<tr><td>**Keynote Speaker**

"Living & Dying on the Streets: Towards health justice in our communities"</td><td>**Dr. Naheed Dosani**, Palliative Care Physician, Department of Family & Community Medicine, St Michael's Hospital at Unity Health Toronto; Founder & Lead, Palliative Education And Care for the Homeless (PEACH), Inner City Health Associates</td><td>11:20-12:05</td></tr>
<tr><td>**Q & A with Dr. Dosani**</td><td>Louise Binder</td><td>12:05-12:20</td></tr>
<tr><td>**Introduction to Panel**</td><td>Antonella Scali</td><td>12:20-12:25</td></tr>
<tr><td>**Panel 1: Intersecting Oppressions**</td><td>**Hani Ataan Al-Ubeady,** Cross Cultural Mental Health Specialist with Winnipeg Regional Health Authority

Birgit Umaigba, RN BScN MEd, Course Instructor, Adaptive Health Leadership at the Graduate School of Medicine, Cumming School of Medicine, University of Calgary; Clinical Instructor at Centennial College's School of Nursing

Kahir Lalji, Provincial Director, Government Relations & Government Programs, United Way BC</td><td>12:25-1:05</td></tr>
<tr><td>**Moderated Q&A**</td><td>Antonella Scali</td><td>1:05-1:20</td></tr>
<tr><td>**Breakout Session 1**</td><td></td><td>1:20-1:40</td></tr>
<tr><td>**Break**</td><td></td><td>1:40-1:45</td></tr>
<tr><td>**Introductions to Housing Insecurity Panel**</td><td>Antonella Scali</td><td>1:45-1:50</td></tr>
<tr><td>**Panel 2: Housing Insecurity**</td><td>**Bee Lee Soh,** EMPaCT member and anti-poverty advocate</td><td>1:50-2:20</td></tr>
</table>

	Diana Chan McNally, Community and crisis worker in Toronto's downtown east side. Instructor in George Brown College's Community Worker program. Fellow of Maytree Canada and the McNally Project for Paramedicine Research	
Introduction to Income Insecurity Panel	Antonella Scali	2:20-2:25
Panel 3: Income Insecurity	**Dr. Trevor Morey**, Palliative care physician with the PEACH team (Palliative Education and Care for the Homeless) **Alexa Ferdinands,** PhD, RD, Assistant Professor, Faculty of Science & Technology at Athabasca University	2:25-3:00
Q & A with Panels 2 & 3	Antonella Scali	3:00-3:15
Breakout Sessions		3:15-4:00

Day 2: Highlighting Indigenous Health Needs		
Wednesday, November 15, 2023		**12:00-4:00 PM ET**
Opening Remarks & Introduction to Keynote Speaker	Sharon Clarke	12:00-12:05
Keynote Speaker "Unearthing the Past, Shaping the Present and Paving the Future: Indigenous Health care Inequities"	**Mackenzie Daybutch**, Program Coordinator for the Regional Indigenous Cancer Program at the Ottawa Hospital	12:05-12:50
Moderated Q&A with Keynote	Sharon Clarke	12:50-1:15
Speaker Introduction	Sharon Clarke	1:15-1:20
Differences in Surgical Outcomes for Indigenous Peoples in Canada	**Dr. Jason McVicar**, Anesthesiologist at the Royal Inland Hospital in Kamloops, British Columbia; Trustee of the Canadian Anesthesiologists' Society International Education Foundation	1:20-1:40
Moderated Q & A	Sharon Clarke	1:40-1:55
Introduction to Panel	Sharon Clarke	1:55-2:00

Cancer Care Challenges for Remote Communities: Current Realities of Nunavut Patients	**Rebecca Lonsdale**, Registered nurse and family caregiver in Nunavut **Malaya Zehr,** Executive Director, Larga Baffin Ottawa **Carolyn Roberts**, RN, Aboriginal Patient Nurse Navigator, Ottawa Hospital **Dr. Tim Asmis**, Medical Oncologist at The Ottawa Hospital Cancer Centre	2:00-3:00
Moderated Q&A with Panelists	Sharon Clarke	3:00-3:15
Breakout Sessions		3:15-4:00

Day 3: Opportunities to modernize health care to meet the needs of all		
Thursday, November 16, 2023		**12:00-4:15 PM ET**
Opening Remarks & Agenda Overview	Louise Binder & Antonella Scali	12:00-12:05
Introduction to Keynote	Leah Stephenson	12:05-12:10
Keynote Speaker "Patients and Caregivers as Core Components of Learning Health Systems"	**Kerry Kuluski,** Dr. Mathias Gysler Research Chair in Patient and Family-Centered Care, Associate Professor, Institute of Health Policy, Management and Evaluation, University of Toronto	12:10-12:40
Moderated Q&A with Kerry Kuluski	Antonella Scali	12:40-12:55
Introduction to Panel	Louise Binder	12:55-1:00
Got Data? Data Saves Lives	**Anne Forsyth,** Manager of Data Standards, Canadian Institute for Health Information (CIHI) **Ewan Affleck,** Senior Medical Advisor - Health Informatics, College of Physicians and Surgeons of Alberta	1:00-1:20
Moderated Q&A with Panelists	Louise Binder	1:20-1:35

Introduction to Panel	Louise Binder	1:35-1:40
Data Spotlight Practices	**Allison Fitzgerald,** Director of Operations, GlobalSkin Foundation **Michael Cooper**, Vice-President, Development & Strategic Partnerships, Mental Health Research Canada **Sister Elizabeth Davis,** Co-Chair, Newfoundland Health Accord & member of the Congregation of the Sisters of Mercy of Newfoundland **Dr. Marcia Anderson, MD MPH FRCPC**, Vice-Dean, Indigenous Health, Social Justice and Anti-Racism, Rady Faculty of Health Sciences, University of Manitoba	1:40-2:20
Q&A with Panelists	Louise Binder	2:20-2:35
Introduction to Panelists	Antonella Scali	2:35-2:40
Addressing People's Mental Health Needs: the Importance of Team-Based Care	**Carmen G. Loiselle, RN, PhD, FCAHS, FCAN,** Full Professor in the McGill's Faculty of Medicine and Health Sciences; President of the Canadian Association of Psychosocial Oncology (CAPO), 2021-2023 **Sarah Allard-Puscas,** Founder of The Collaborative Group for Psychodermatology in Canada **Nicci Stein,** Founder and Principal at Connected Circles	2:40-3:20
Q&A with Panelists	Louise Binder	3:20-3:35
Breakout Sessions		3:35-4:15

Day 4: Patient Planning Session–restricted to patients/caregivers and their groups	
Friday, November 17, 2023	**12:00-1:30 PM ET**
Group Action Planning (Patients, Caregivers, and Patient/Caregiver Organizations)	12:00-1:30

Appendix 2: Summit History & Evolution

The inaugural 2016 Summit examined and 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 drug access in Canada. From this Summit, Working Groups were created to develop action plans from the themes.

The 2017 Summit 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 systemic concerns. Working Groups continued and a virtual book club was organized to read, discuss and analyze the principles and strategies in the Canadian context.

The 2018 Summit was a forum for patient groups and health care stakeholders from across the country exploring in greater depth the principles underlying value-based health care in Canada. It explored ideas developed by Working Groups about introducing VBHC in the Canadian context, including a proposed vision and principles, strategic considerations for implementation, perspectives about patient groups' roles in moving this approach forward as well as partnership and collaboration ideas.

In 2019, following numerous provincial and territorial elections, the Summit agenda shifted to updating participants on the impact of these elections on mandates and activities of health bodies, private and public, across Canada, including evolving patient engagement processes. In addition, patient representatives from each province shared the most pressing health policy and health services 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

2023
Structural & social determinants of health; FNIM challenges; foundational reforms

2022 & 2021
COVID-19 echo pandemics within key populations + examples and progress on value-based health care

2020
Effects of COVID-19 on key populations and health care systems

2019
Public and private health bodies; patients' provincial priorities; VBHC initiatives in Canada

2018
Specifics of what a VBHC approach should include in Canada

2017
Introduced VBHC

2016
Existing public and private regulations, policies and practices in Canada

particular focus on integrated primary health care and a pilot project initiated between the newly formed Value-Based Health Care Canada (VBHC Canada), convened by the Conference Board of Canada, and the patient group, Coalition Priorité Cancer au Québec. The project focuses on validating and implementing, with patient co-leadership and co-design, Patient Reported Outcome Measures (PROMs) in specific cancer areas. The Summit also included a deeper consideration of PROMs, and a breakout session for participants to explore and provide feedback on them in different disease areas.

In 2020, with the COVID-19 pandemic's second wave rolling across Canada and the globe, the first-ever virtual Summit was held. The Summit featured keynote speakers characterizing the inequitable health outcomes and access to health care experienced by key populations facing lack of, or inadequate access to, determinants of health across Canada. They described how the pandemic has had disproportionate impacts on these populations. Before the pandemic, the impact on people who are racialized and experiencing low income or income insecurity was that they were less likely to get health care services they needed, which continues. Since the pandemic, they face additional challenges including being disproportionately at risk for infection; being disproportionally represented among those infected; and being more disproportionately socio-economically affected by the virus. Finally, the three Working Groups that had been focusing throughout the year on patient-led VBHC initiatives focused on integrated models of care, patient-reported outcome measures, and health data reported on their progress.

In 2021 and 2022, the virtual Summits explored the ongoing barriers and systemic issues in Canadian health care systems experienced by patients in Canada that have become starkly clear in light of the COVID-19 pandemic and its long-term effects, termed by one presenter as "echo pandemics". The events focused on the current state of health and health care in the midst of COVID-19's echo pandemics in particular for Indigenous communities as well as specific patient communities including chronic disease, oncology, and mental health. These Summits shared inspiring examples of value-based health care enablers in action in the context of Canada's health care systems becoming less fragile by moving towards outcomes that matter most to patients relative to the costs across the care continuum.

In 2023, the virtual Summit dove more deeply into the structural and social determinants of health, including the specific challenges faced by First Nations, Inuit and Métis peoples across Canada – with a particular focus on the territories – in accessing health care and achieving good health outcomes. Co-design, interoperable health data, and team-based care were spotlighted as foundational reforms to modernize health care to better meet the needs of all.

Appendix 3: Evaluation Survey Results

Summary of Results:

Across all three days, people consistently expressed satisfaction with all of the content that was shared through the Summit.

There were mixed feelings about the virtual breakouts. People also would have appreciated more breaks throughout the three days of content.

Below are a few comments from the three days that reflect people's feedback related to programming.

Day 1: Challenges to "Meeting People Where They're At" (November 13, 2023)

The concept of Structural Determinants of Health as leading to Social Determinants of Health.

Because I strongly acknowledge that homelessness causes so many health problems that are all not visible from the outside. Healthcare systems need to acknowledge that homelessness does cause a burden on the Healthcare systems. Healthcare systems need to also acknowledge and change the barriers faced by homeless people when trying to access healthcare. Healthcare should be actively involved in the solutions for homelessness.

Day 2: Highlighting Indigenous Health Needs (November 15, 2023)

The significant health inequalities that currently exist in Canada with the indigenous peoples.

Too few people are doing the heavy lifting - only 2 people at The Ottawa Hospital cancer program; Dr. McVicar's statement that he can count Indigenous anesthesiologists on one hand, etc. We're failing at representation.

I enjoyed MacKenzie Daybutch's talk - it was personal and provided a lot of insight but also gave guidance on what we could be doing to address some of the challenges

The panel representation was distinctions-based and included a caregiver's perspective which I think is important.

A lot of food for thought. Well organized. Great speakers, all frontline workers or people with lived experience. Bravo!

Day 3: Opportunities to Modernize Health care to Meet the Needs of All (November 16, 2023)
Great programs - PEACH, Alberta Virtual Care, EQUIP, NL Health Accord and so many more examples of co-designing and that where there is a will, there is a way

Practical solutions to go about authentic patient/caregiver engagement in research

Appendix 4: Sponsors

Thank you to our sponsors!

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