



# 5<sup>th</sup> Annual Patients Redefining the Future of Health Care in Canada Summit

Nov 30<sup>th</sup>, Dec 3<sup>rd</sup>, Dec 8<sup>th</sup> & Dec 10<sup>th</sup>

[#PatientsRedefiningHealthcare](#)

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Psoriasis  
Network



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## 2020 SUMMARY REPORT

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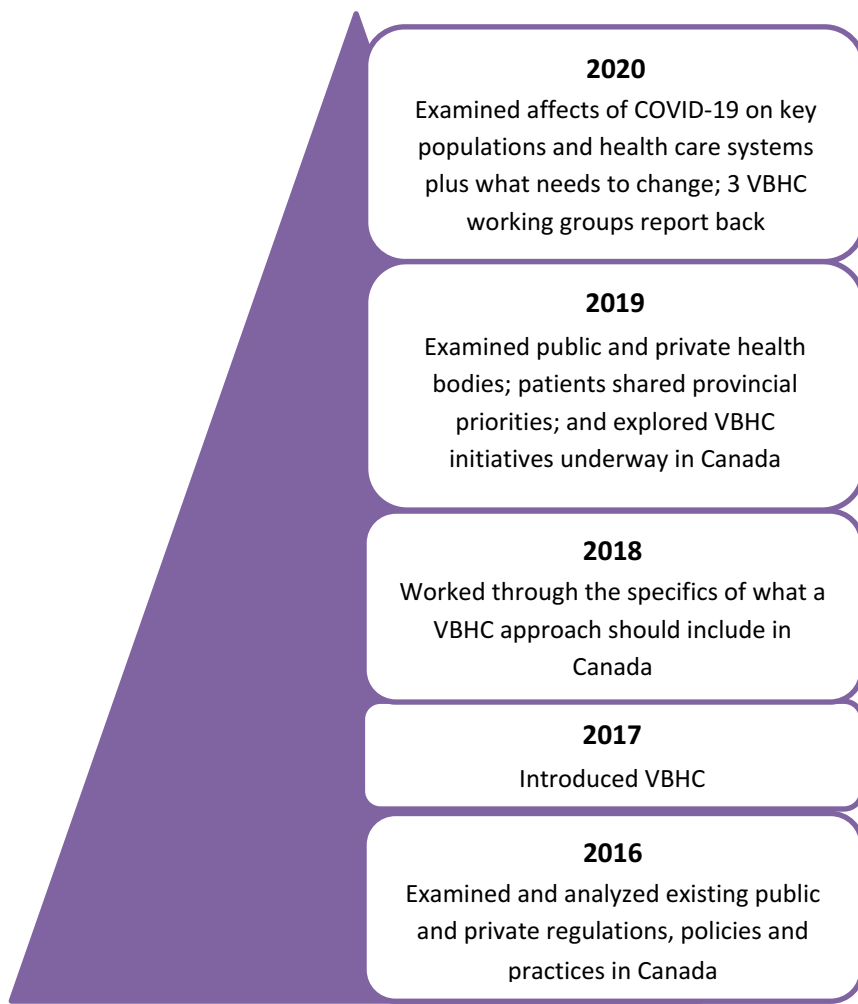
## INTRODUCTION

The fifth annual Patients Redefining the Future of Health Care in Canada Summit (“the Summit”), took place virtually on November 30, December 3, December 8, and December 10, 2020. The Summit is an initiative led by Save Your Skin Foundation in collaboration with the Canadian Psoriasis Network and Queen’s University Office of Indigenous Initiatives. The December 8<sup>th</sup> value-based health care panel was co-hosted with the Conference Board of Canada. The Summit also received generous contributions from volunteers, speakers, panellists, facilitators, and other collaborators.

This event builds on the [2016](#), [2017](#), [2018](#) and [2019](#) Summits, which provided unprecedented 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 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 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 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 in greater depth the principles underlying value-based health care in Canada based on the VBHC approach introduced in 2017. It explored ideas developed by Working Groups about introducing VBHC in the Canadian context, including a proposed vision and principles, strategic considerations for its 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 some of its focus 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 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. (See Appendix 1 for the Summit Programme, Format and Agenda.) 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. Carol Hopkins, Executive Director of Thunderbird Partnership Foundation, discussed Indigenous knowledge, the importance of the

**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.

The objectives for the 2020 Summit were to:

- Enhance participants' knowledge about health and determinants of health systems in Canada, the effects of COVID-19, and the impacts of both on key populations of people living in Canada;
- Create synergies and recognition of common issues and opportunities across patient groups and other health care stakeholders;
- Engage policy makers and foster collaboration between patient and caregiver communities and other relevant groups, including researchers, governments, non-governmental agencies, and other partners; and
- Support the conversation about how patients and caregivers can influence the design of the health systems they deserve.

decolonization of knowledge and, therefore, health care. She recommended respect for human rights, leadership among all stakeholders, and Indigenous-led alliances between Indigenous and non-Indigenous stakeholders to address issues. Kwame McKenzie, Chief Executive Officer of the Wellesley Institute, explained that “if you are not counted, you don’t count”. 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 disproportionately represented among those infected; and being more disproportionately socio-economically affected by the virus. Following the keynote session, three diverse panels of experts looked at the experiences of health and health care of specific populations before COVID and during the pandemic. In addition, they gave their recommendations for meaningful changes to our health systems as we move forward: for older

adults; people living with mental health conditions; and people living with income insecurity. Finally, the three working groups that had been focusing throughout the year on patient-led VBHC initiatives, including integrated models of care, patient-reported outcome measures, and data rights and obligations, reported on their progress. The data working group presented a draft Declaration of Personal Health Data Rights & Obligation in Canada for patient input and approval. (See full Declaration in Appendix 2.) A multi-stakeholder panel followed with recommendations for opportunities to build on such initiatives. The Summit concluded with patients, caregivers, and patient groups reviewing themes and discussing an action plan for next year in a closed-door session.

## SUMMIT OVERVIEW

This section of the report offers an overview of the 2020 Summit, including the participants and the themes that emerged from the Summit.

### PARTICIPANTS

Sixty-six individuals representing patients, patient representatives and advocates, caregivers and their groups attended the Summit. These individuals represented forty-two distinctive patient, caregiver, or citizen groups. They represented a range of disease and disability areas across Canada, as well as at least one group representing citizens.

Eighty-seven observers from stakeholder groups attended the Summit, including a variety of government bodies, health care providers, pharmaceutical, medical technology and health insurance industries, and academia.

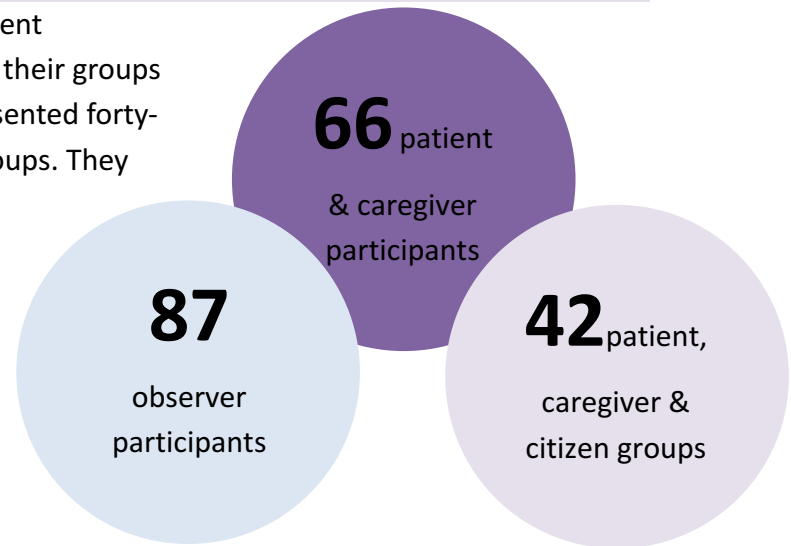


Figure 1: A snapshot of 2020 Summit participation

### THEMES

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

#### Equity-based strategies

The need for equity in health care was a theme throughout the Summit. The failure, both before COVID-19 and now during the pandemic, of one-size-fits-all strategies for health care have led to disparities for people across Canada, including people living with income insecurity, people who are racialized, older adults, Indigenous peoples, and people living with mental health conditions. All interventions and innovations will increase disparities unless they are designed with key populations and social determinants of health from the outset. Indigenous worldviews and knowledge are distinct and evidence-based, with languages, lands, and cultures all necessary for healing and health. Alliances and partnerships between self-determined, mutually respectful equals are required for equity in Indigenous health. With the growing importance of virtual care, digital equity is part of health equity. Equity should not be a choice by governments, policy makers, public health officials, or health care providers. It should be legislated.

There are needs for better, disaggregated data and research to support equity-based strategies. There is also a need for an equity-based pandemic recovery plan, including a pan-Canadian mental health strategy that is properly implemented. There is a need for an equity-based pandemic preparedness strategy that integrates all aspects of wholistic health, including the physical, emotional, mental, and spiritual. COVID-19 has heightened the public's awareness that equity-based strategies must recognize the particular needs of various populations, including those of older adults in areas of long-term care reform, protection from detention, and physical and financial abuse.

### **Data issues**

As mentioned as part of “equity-based strategies,” digital equity is essential to health equity, including data to monitor equitable access to virtual care, and especially ensuring connectivity across Canada. Quality data that inform equity-based strategies are essential. “If you are not counted, you don't count” was a key message from Kwame McKenzie. Patient-relevant and patient-reported data and outcomes are imperative. Having good quality data includes collecting relevant demographic data and data regarding determinants of health for research and development of patient-reported outcome measures (PROMs), and for ongoing learning and improvement using this data. The Declaration of Personal Health Data Rights & Obligation in Canada (Appendix 2) must be followed by all data custodians. There must be one interoperable electronic health record for each person. OCAP, and in particular the ownership of data as a community, not just individually, is an Indigenous principle to which stewards of Indigenous data must adhere.

### **Determinants of health**

The determinants of health were a consistent theme throughout the Summit, including racism as a determinant of health. Participants heard from Angela Robertson that “social policy is health policy” requiring solutions such as higher minimum wage, a job strategy to end precarious employment, disability support programmes that increase based on cost of living, rent geared to income, pharmacare, and childcare programmes. Community Health Centres (CHCs) integrate determinants of health into primary care and many CHCs also advocate for social policy as part of overall health policy. All levels of government and policy makers, including municipalities, need education on the determinants of health as integral to health policy. Poor social determinants are exacerbated in rural and remote regions, with a complete lack of public transportation, poor or absent connectivity, and few or no services.

### **Wholistic approaches to health**

The theme of taking “whole person” approaches to health was predominant. Participants talked about the need to integrate physical, mental, emotional, and spiritual health, which is especially urgent with the coming “echo pandemics”. Health services need to address co-morbidities. Community-based solutions along the care continuum, including prevention, health promotion, and chronic disease management, that focus on addressing the determinants of health are required — rather than a “blame” mentality that lacks an understanding of lives impacted by lack of, or inadequate access to, determinants of health.

In addition, wholistic approaches include understanding costs based on entire systems, not on silos within health care or on silos across other government departments that impact health such as housing, social services, and justice. Resources, including information, technological infrastructure, human, financial, or capital infrastructure, are not always easily accessible or available. When costs and savings are analyzed and taken into account across the system and care continuum, resource allocation choices are made feasible.

**“Nothing about us without us”: Patient-led co-creation and co-design for equitable solutions**

As long as people living without, or with inadequate, access to determinants of health are not consistently at decision-making tables with meaningful authority, health disparities will grow. Until equity-based solutions are consistently co-designed with these groups, gaps will not begin to close. For example, harm reduction approaches must be developed, implemented, and monitored by people with lived experiences and peer support programmes in mental health are essential. Community Health Centres (CHCs) take a bottom-up approach, whereby communities are in control and have the ability to shape service delivery, as opposed to other models that take a more top-down approach. Tools must be developed collaboratively with impacted communities to provide opportunities for patients to take power in their health care decision-making. There is also a need to generate real world evidence to demonstrate the direct and indirect health care delivery contributions of families and caregivers, including caring for older adults and people living with mental health conditions.

**Indigenous knowledge systems as evidence and Indigenous self-determination in health**

Participants learned how culture, language, and land are medicines for good health. During the pandemic, for example, some First Nations communities relied on land-based activities, such as harvesting medicines from the land, drumming for each other from a distance (connecting), intensifying local food security or food sovereignty efforts, and implementing harm reduction measures. These efforts reflect an Indigenous wholistic view of health. The need to decolonize Western concepts of “evidence” and “knowledge” and to respect and honour Indigenous worldviews and creation stories, not as myths but as evidence and knowledge, were emphasized.



Indigenous determinants of health also include the impacts of colonization, intergenerational trauma, and clean water. Public health workers' attempts at intervention have triggered memories of residential school traumas of disease and death that was rampant in residential schools. Lack of access locally to harm reduction services requires community members to travel, often long distances, usually without access to public transportation, thereby increasing danger due to hitchhiking and missed appointments. Moreover, compounded by poor housing, unsafe drinking water and lack of social and health services, youth suicide is on the rise.

Partnerships and alliances between healthcare providers, government jurisdictions, other stakeholders and Indigenous peoples needs to be established or strengthened. As Maamwesying North Shore Community Health Services has been able to achieve, Indigenous agencies must be at government planning tables with power placed in their hands to plan with local partners for local responses, to build capacity within communities, and to offer a fuller continuum of services with and for communities. The recommendations in both the Truth and Reconciliation Commission Report and the National Inquiry into Missing and Murdered Indigenous Women and Girls must be implemented. The Indigenous culturally based *Mental Wellness Framework* must be implemented and supported across Canada using flexible, needs-based funding, not *per capita*, funding. Provincial/territorial governments must enhance engagement, and provide adequate, equitable investments in mental wellness programmes. Internet connectivity for all First Nations communities is critical now, not by 2030, as stated in the Prime Minister's Mandate Letter.

Self-determination over their health and wellness for First Nations requires data on which to make sound decisions. First Nations developed and articulated the OCAP Principles of data Ownership, Control, Access, and Possession in response to lack of access to their own data and and/or instances of Indigenous data being used inappropriately and unethically. The OCAP Principles encompass data as communities and nations, as well as individually. Because community-level, collective ownership, control, access and possession of data are not recognized by any data legislation in Canada as yet, First Nations community members are continually at risk of their individual data being exposed in ways that other Canadians are not.

## MOVING FORWARD

The 2020 Summit provided an opportunity to renew the mandates of the three Working Groups formed in 2019 and to consider creating new ones based on the outcomes of the 2020 Summit. Three Working Groups were renewed with clear next steps. They are:

### 1. Data Working Group activities to include:

- Receiving feedback to finalize the Declaration of Personal Health Data Rights & Obligation in Canada
- Seeking broad patient, patient group and support endorsement
- Publishing and sharing with data custodians

**2. PROMs Working Group activities include:**

- Continuing to refine existing PROMs (*e.g.* lung) and develop new ones (*e.g.* psoriasis, melanoma)
- Preparing abstracts and presenting findings at conferences
- Targeting health technology assessment bodies as an audience for education about the value of PROMs in their deliberations

**3. Integrated Models of Care Working Group activities include:**

- Focusing on sharing promising and good practices in integrated models of care (CHCs) with other jurisdictions of Canada, including rural and remote regions
- Interfacing with CHCs regarding integration of PROMs
- Identifying government champion(s) and understanding their perspectives/challenges and addressing these in the proposed solution(s)

**Rural and remote** health has discrete issues that must be addressed in all Working Groups' Terms of Reference, with clear definitions of these terms. Recruitment of members for all Working Groups with lived experiences of rural or remote Canada is paramount.

**Digital equity** considerations, including those related to adoption, adaptation, access to devices, and connectivity must be woven throughout all three Working Groups. Libraries, librarians, and municipalities were named as potential partners in digital equity, with privacy considerations paramount in the context of accessing virtual care in public spaces.

Creating a stand-alone **Indigenous** Working Group with cross-appointments to the three current Working Groups should be added based on advice from potential Indigenous colleagues.

In addition, it was proposed that **webinars** throughout 2021 would be beneficial. Topics generated include specific populations; impact of determinants of health on individual life choices and health behaviours; government jurisdictions and responsibilities, including municipal governments, for health and determinants of health; discrete rural and remote health issues; and advanced care planning.

All working groups will require strong **communications** support. It was suggested that someone be appointed as the communications support person for all Working Groups.

Patients, caregivers, 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: Summit Programme, Format and Agenda

### PROGRAMME AND FORMAT

Going virtual for the first time due to the COVID-19 pandemic, this year's Summit was divided into four shorter sessions over four days. The first day featured two keynote speakers. The second day featured three panels, including Indigenous presenters, focused on (i) older adults; (ii) people living with mental health conditions; and (iii) people living with income insecurity. The third day featured three patient-led working groups reporting back on their efforts related to VBHC: (i) integrated models of care; (ii) patient-reported outcome measures; and (iii) data rights. A multi-stakeholder panel sponsored and moderated by Value-Based Healthcare Canada (an initiative of the Conference Board of Canada) featured a government thought leader, a data and integrated models of care thought leader, and two Indigenous data governance thought leaders who shared their thoughts and advice on opportunities to grow these VBHC initiatives across Canada. Each day featured moderated questions and answers as well as facilitated breakout groups to surface themes from each session. Patients, caregivers, and patient groups were in their own breakout rooms, while other health care stakeholders gathered separately.

## AGENDA

### Keynote Session Monday, November 30, 2020 10:30-12:45PM ET

Summit Opening	Kathy Barnard, Save Your Skin Foundation	10:30-10:40
Agenda Overview & Housekeeping	Leah Stephenson, Facilitator	10:40-10:55
1 <sup>st</sup> Keynote Introduction	Louise Binder, Save Your Skin Foundation	10:55-11:00
Keynote Speech	Carol Hopkins, Executive Director, Thunderbird Partnership Foundation	11:00-11:15
2 <sup>nd</sup> Keynote Introduction	Louise Binder	11:15-11:20
Keynote Speech	Kwame McKenzie, CEO, Wellesley Institute	11:20-11:35
Moderated Q & A	Louise Binder, SYSF (moderator)	11:35-12:00
Break (Mindfulness Meditation)	Reena Ruparelia	12:00-12:10
Breakout Sessions		12:10-12:45

### Population Panels Thursday, December 3, 2020 12:00-3:15PM ET

Recap from Keynote Session & Housekeeping	Leah Stephenson	12:00-12:05
Opening Remarks	Sharon Clarke, Office of Indigenous Initiatives, Queen's University	12:05-12:10
Introduction of Mental Health Panel	Antonella Scali, Canadian Psoriasis Network	12:10-12:15
Mental Health Panel	Brenda Restoule, CEO, First Peoples Wellness Circle  Ellen Cohen, National Coordinator, National Network for Mental Health  Mary Alberti, CEO, Institute for Advancements in Mental Health	12:15-12:45
Introduction of Older Adult Panel	Antonella Scali, CPN	12:45-12:50
Older Adult Panel	Edith Mercieca, Director of Home and Community Support Services, Maamwesying North Shore Community Health Services  Laura Tamblyn Watts, CEO, CanAge  Jane Meadus, Staff Lawyer, Advocacy Centre for the Elderly	12:50-1:20
Break (videos)	<a href="#">Homeward Bound</a> in Hamilton <a href="#">Social Prescribing</a> in Kirkland Lake	1:20-1:30
Introduction of Income Insecurity Panel	Antonella Scali, CPN	1:30-1:35
Income Insecurity Panel	Angela Robertson, Executive Director, Parkdale Queen West Community Health Centre	1:35-1:55

	Tracy Smith-Carrier, Associate Professor, School of Social Work, King's University College at Western University	
Moderated Q & A	Antonella Scali, CPN (moderator)	1:55-2:30
Breakout Sessions		2:30-3:15
<b>Value-Based Health Care Tuesday, December 8, 2020 12:00-2:30PM ET</b>		
Opening Remarks	Margaret Peters, Founder and Director , Unmasking Psoriasis  Jennifer Graham, Vice- President and Interim President, Canadian Congenital Heart Alliance	12:00-12:15
Integrated Models of Care	Scott Wolfe, Executive Director, Canadian Association of Community Health Centres	12:15-12:45
Patient-Reported Outcome Measures	Eva Villalba, Executive Director, Coalition Priorité Cancer au Québec	12:45-1:00
Personal Health Data Rights and Obligation in Canada	Shaneel Pathak, Co-founder and CEO, Zoelnsights	1:00-1:10
Moderated Q & A	Leah Stephenson (moderator)	1:10-1:25
Break (Mindfulness Meditation)	Reena Ruparelia	1:25-1:35
Opportunities for the Growth of Value- Based Health Care across Canada	Monika Slovinc D'Angelo, Director of Healthcare and Wellbeing, Conference Board of Canada (moderator)  Paul L'Archevêque, Director of Innovation, Québec Health Ministry  Rodney Burns, Chief Information Officer, Alliance for Healthier Communities  Maria Santos, First Nations Data Centre Program Manager and Kristine Neglia, Manager, OCAP and Information Governance, First Nations Information Governance Centre	1:35-2:00
Breakout Sessions		2:00-2:30
<b>Patient Planning Session (restricted to patients, caregivers, and their groups) Thursday, December 10, 2020 12:00-1:30PM ET</b>		

## Appendix 2: Draft Declaration of Personal Health Data Rights & Obligation in Canada

Find the **full draft of the Declaration** here, including definitions and references:

[https://mcusercontent.com/bfafb9315f3a0cd9d5533d679/files/f4184edc-8094-4bf9-b8d1-66cfa12dc302/Draft Declaration of Health Data Rights v November 2020 Summit.pdf](https://mcusercontent.com/bfafb9315f3a0cd9d5533d679/files/f4184edc-8094-4bf9-b8d1-66cfa12dc302/Draft%20Declaration%20of%20Health%20Data%20Rights%20v%20November%202020%20Summit.pdf)

Find the one-page **Executive Summary** here:

[https://mcusercontent.com/bfafb9315f3a0cd9d5533d679/files/abd893c0-ee2a-4f13-82d8-784f641c49b5/Executive Summary Draft Declaration of Health Data Rights v November 2020 Summit.pdf](https://mcusercontent.com/bfafb9315f3a0cd9d5533d679/files/abd893c0-ee2a-4f13-82d8-784f641c49b5/Executive%20Summary%20Draft%20Declaration%20of%20Health%20Data%20Rights%20v%20November%202020%20Summit.pdf)

### Appendix 3: Summary of Evaluation Results

Electronic evaluation surveys were sent to participants at the close of each session — Keynote Speakers, Key Populations Panels, and Value-Based Health Care. A final survey of all four sessions was sent at the end of the 2020 virtual Summit.

The Keynote session on November 30, 2020, had between 52-71 attendees. The breakouts had 34 patients/caregivers/patient groups; 3 industry; and 3 other stakeholders.

The Key Populations Panels on December 3, 2020 had between 61-83 attendees. The breakouts had 33 patients/caregivers/patient groups; 4 industry; and 4 other stakeholders.

The Value-Based Health Care session on December 8, 2020 had between 72-78 attendees. The breakouts had 41 patients/caregivers/patient groups; 4 industry; and 4 other stakeholders.

The final Group Action Planning session on December 10, 2020, which was restricted to patients/caregivers/patient groups, included 27 patients/caregivers/patient group representatives.

For the Keynote session, all survey respondents found the content either “beneficial” or “very beneficial”. They found the moderated questions and answers to be of high quality. For breakouts, audio/visual (A/V) issues for at least one room made them lose time and decreased the quality of their discussions. One person ranked the A/V as “very poor” and 2 ranked it as “poor”. Respondents ranked the quality of the speakers and presentations very highly. They found the content, including about “equity and culture, new and interesting.” A small number of people experienced technical issues during both the event and during the breakout session.

For the Key Populations Panels, 83% of respondents found the content either “beneficial” or “very beneficial”; 8% found it “somewhat beneficial”; and 8% found it “not beneficial”. For the moderated questions and answers, 90% ranked them of high quality and 10% ranked them a bit below their quality expectations. Respondents ranked the presentations very highly. One person stated “I was shocked to see some of the statistics.” The breakout sessions continued to have A/V and technical issues. One person found they experienced “information overload” and suggested “more time to process.”

For the Value-Based Health Care session, all respondents ranked the content as “beneficial” or “very beneficial”. They all found the moderated questions and answers to be of high quality. Everyone ranked the content very highly. For breakouts, people enjoyed the facilitation and discussion but wanted more time. One person would have appreciated more time for everything: presenters, questions and breakouts. Some experienced A/V and technical issues. One person suggested making it easier to transition to breakouts.

Respondents to the final evaluation asking about the entire event ranked the content as “very

beneficial” or “beneficial” (90%) or “somewhat beneficial” (10%). The moderated questions and answers ranked between 6-10 on all days. For breakouts, 55% felt they were “beneficial” or “very beneficial” while 44% found them “somewhat beneficial”. More time was suggested. For A/V during the presentations, all respondents had an okay to good experience. For breakouts, 78% of respondents had a “good” to “excellent” experience with the A/V, while the remainder indicated that they had a “poor” experience.

Overall, the content of all sessions was very much appreciated. However, the user experience and functionality of the virtual platform needs improvement if the event continues in a virtual format.

There were mixed comments by a couple of respondents about whether it’s preferable to spread the content over a number of days versus condensing it all into fewer days. For scheduling purposes, fewer days is easier, but too much content at once can be overwhelming.



## Appendix 4: Sponsors

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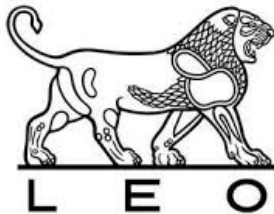
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