



**PATIENTS REDEFINING**  
**THE FUTURE OF HEALTH CARE IN CANADA**  
**6TH ANNUAL SUMMIT**

**November 15, 17, 18 & 19**

**2021 SUMMARY REPORT**

Report prepared by Leah M. Stephenson Consulting

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## INTRODUCTION

The sixth annual [Patients Redefining the Future of Health Care in Canada Summit](#) (“the Summit”), took place virtually on November 15, 17, 18, and 19, 2021. This year’s theme was “Echo Pandemics: The Way Forward.” 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.

This event builds on the [2016](#), [2017](#), [2018](#), [2019](#) and [2020](#) 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. For an overview of the history and evolution of the Summit, read Appendix 2.

This year, the co-organizers expanded the pre-Summit webinar series, which contributes towards the achievement of the event objectives. On June 29, 2021, members of Equity Mobilizing Partnerships in Community (EMPaCT) presented “[Social Determinants of Health: Key Concepts and Practical Considerations](#)” ([version française](#)). Dr. James Makokis was the keynote on “Indigenous Social Determinants of Health: Impacts of COVID-19” (webinar not recorded) on September 29. On October 26, a webinar entitled “[Canadian Jurisdictional Roles in Health & Determinants of Health](#)” ([version française](#)) by Louise Binder and Leah Stephenson helped to convey key concepts related to the roles of different levels of governments in health care and some of the determinants of health in Canada as well as to remind participants about the definition of value-based health care and its enabling pillars in preparation for the upcoming Summit.

The objectives for the 2021 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.

## SUMMIT OVERVIEW

This section of the report offers an overview of the 2021 Summit, including the participants and themes that emerged from the Summit.

### PARTICIPANTS

Forty-five individuals representing patients, patient representatives and advocates, caregivers and their groups attended the Summit. These individuals represented twenty-five distinct patient, caregiver, or citizen groups. They represented a range of disease and disability areas across Canada, as well as at one group representing citizens.

Thirty-two 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.

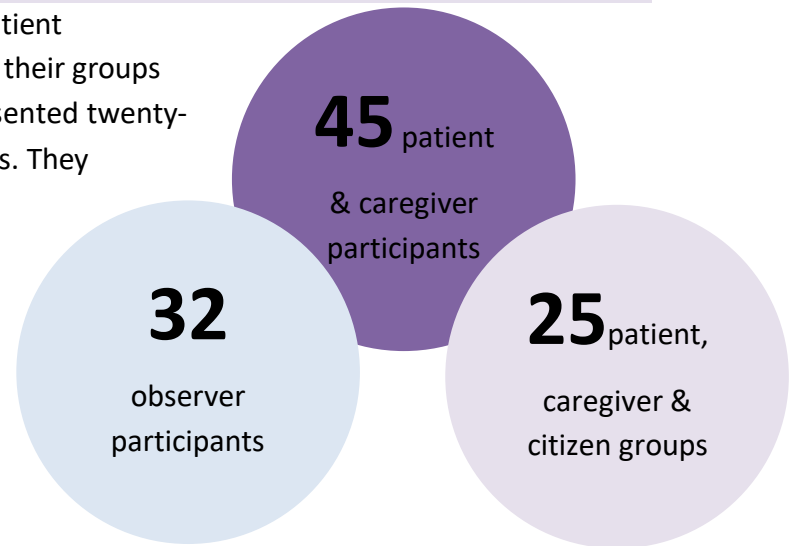


Figure 1: A snapshot of 2021 Summit participation

### THEMES

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

Adelsteinn Brown shared evidence for **four major waves of echo pandemics** that Canada will face over the next five to fifteen years:

- Wave 1: Healthcare backlogs (including chronic diseases and oncology),
- Wave 2: Mental health and addictions,
- Wave 3: "Long COVID",
- Wave 4: Socio-economic effects.

It was acknowledged that the mental health and addictions effects are not fully understood, but that there are already significant increases in eating disorders and opioid overdoses, for example. Fundamentally, the whole continuum of care has been backed up and needs addressed. The impacts of the pandemic have been deeply inequitable, with racialized, low income, and Indigenous people far more affected, due to factors including multigenerational

households living in inadequate housing and ‘essential’ work.

**The pandemic is demonstrating how urgently our healthcare systems need to be radically re-constructed.** Public healthcare, as it stands, is unsustainable. There is an implementation gap, not a knowledge or evidence gap. Healthcare systems in Canada have failed to systematically implement what works. **Collaborative governance** that is sustained over the long-term beyond political cycles is required. Planning for implementation, monitoring performance against outcomes, and public reporting are needed. Policy and regulatory changes, capacity building, and an overall problem-solving approach are needed. **Investments across the continuum of care, especially for prevention and people-driven, integrated care** are required. There is a lot of room for improvement related to clinical and service integration.

**Patient partnerships** need to be deeply embedded at all levels of planning, implementation, and monitoring to ensure that the reforms are inclusive, equitable, and effective. This means that patients and people who face barriers to accessing the system are acknowledged and actively incorporated into planning, implementation, and monitoring as subject matter experts bringing real-world evidence. Patient partnership requires equitable representation in order to understand systemic barriers and sustainably solve them to co-create more inclusive healthcare systems. Fundamentally, the maxim “**nothing about us without us**” remains central, including **self-governance and self-determination** for Indigenous communities including the [OCAP \(Ownership Control Access Possession\) principles](#).

Currently, our public healthcare systems are poor investors. **There must be a move from a rigid and fragmented cost-focus to a flexible and responsive value-focus.** Funders must invest for outcomes across the care continuum, with accountability and communication. The development of processes and infrastructure that support **learning health systems** for collaboration of the ecosystem with inclusive patient partnerships and champions across stakeholder groups will move us further, faster, together. **Local adaptation with a common accountability framework based on outcomes (e.g. Quadruple Aim<sup>1</sup>) that can be applied across local networks** is important to balance responsive flexibility with system-wide alignment. Misaligned incentives need to be identified and removed while incentives must be added into the system to increase the types of behaviour

**Value-Based Healthcare** is a patient-focused approach to healthcare with a goal of improved value, measured by health outcomes of importance to patients as compared to the costs to achieve those outcomes across the continuum of care.

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<sup>1</sup> For a definition of the Quadruple Aim and an example of how it’s being incorporated into the vision for Ontario’s healthcare system: <https://www.ontario.ca/document/healthy-ontario-building-sustainable-health-care-system/chapter-2-vision-health-care-ontario>

changes that need to be systematically implemented, e.g. salaried and capitation physician payment models tied to outcome-based performance instead of fee-for-service; and bundled payments tied to the achievement of outcomes rather than global budgets for hospitals and other healthcare institutions. Within local networks, **patient-defined outcome measures for different populations** are vital for healthcare providers to learn from each other over time to improve individual and population health.

**Personal health data** that are easily accessible by people/patients, proactively shared with their circle of care, and that follow people, including in emergency situations, are necessary enablers of these systemic reforms. Standardized data collection that includes racialized and other populations is required, as being led by CIHI at the national level, to ensure the ability to disaggregate data and understand trends and outcomes for different populations. For example, Indigenous socio-demographic and health data in Saskatchewan greatly differs from the data for the general population. Planning and interventions based on general population data will not meet the needs of the Indigenous population in that province. Unless one can disaggregate data and understand the trends within discrete populations, systemic inequities will continue unabated. As Dr. Kwame McKenzie warned at the 2020 Summit, “if you’re not counted, you don’t count.”

All of these approaches, if properly undertaken and sustained, support the development and nourishment of **trusting relationships**. Adelsteinn Brown reminded everyone that “change happens at the speed of trust.” Don’t wait to act to develop relationships, rather work with existing strengths and identify the steps you can take now, individually, and organizationally. Allyship with Indigenous communities and organizations is a form of trust that supports reconciliation and must be earned. As Marion Crowe encouraged, “Rise against racism. Stand with us as allies.” Part of what supports the development and sustaining of trust is transparency about what one doesn’t know and the ability to be thoughtful with people who admit they don’t know. Creating environments that allow stakeholders to be more open about their limitations so that solutions can be co-developed together are important to nurture and sustain the trust needed for collaborative governance and learning health systems.

## MOVING FORWARD

The 2021 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 2021 Summit. Three Working Groups were renewed with clear next steps. They are:

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

- Encourage further endorsement of Declaration of Personal Health Data Rights by patient groups
- Consult with industry representatives on “consent” section and revise Declaration as appropriate with support of all endorsers
- Develop and launch annual Report Card for data custodians to endorse Declaration
- Continue to engage with national and provincial reforms (especially the panCanadian Health Data Strategy)
- Identify patient(s) willing to be media spokespeople based on lived experience

## **2. PROMs/PREMs Working Group activities include:**

- Focus on analyzing and summarizing current Patient-Reported Experience Measures (PREMs) used by patient groups and contribute to existing understanding of best practices. More specifically:
  - ❖ Examine the submitted Health Technology Assessment PREM questionnaires to identify:
    - Recurring questions
    - Finding similarities & differences
    - How general and how specific should questions be?
    - Questions about specific treatments
      - Choices/side effects/disease-symptom change/infections
      - Dependent on each specific type of cancer
    - General Questions:
      - Patient experience
      - Quality of life
  - ❖ Identify best practices amongst patient groups & main themes in questionnaires
  - ❖ Do a preliminary analysis of the pros and cons of each type of patient experience consultation methodology (ex. surveys, interviews, focus groups)
  - ❖ Develop simple guidelines for patient organizations
    - Publish article on Patient Group Submissions to HTA and share insights with other groups
  - ❖ Collate methods for “finding” patients to participate in patient group submissions

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

- Identify the World Health Organization (WHO) lead from Canada that participated in and endorsed their Integrated, People-Centred Health Services Framework
- Adapt WHO Framework for Canada, including exemplars, into a consensus document
- Seek endorsements by patient groups

- Develop a communication and/or knowledge mobilization plan for the consensus document

The pre-Summit webinar series will continue in 2022 and should consider topics such as food security and nutrition. All working groups should aim for greater diversity in representation (i.e. underserved communities, people living in remote areas). Anyone wanting to join one of the three working groups or with webinar topic ideas, should contact [leahstephenson@gmail.com](mailto:leahstephenson@gmail.com)

For the working groups, it would be good to investigate and consider how to improve our internal communications (e.g. Slack groups) and external communications (e.g. jointly developed communications plans).

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 second time due to the COVID-19 pandemic, this year's Summit was divided into four shorter sessions over four days. The first day focused on **Echo Pandemics in Health Care** and featured a keynote followed by a panel and guest speaker. The second day focused on **Echo Pandemics in Indigenous Health** featuring two keynotes and guest speakers. The third day focused on **Echo Pandemics: The Way Forward**, featuring keynote speakers, a panel focused on data's role in resilient health systems, and updates from patient-led working groups related to Patient Reported Outcome Measures (PROMs), Data, and Integrated Models of Care (IMOCs). The first three days also 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 during breakouts.

The fourth and final day was open to patients, caregivers, and patient representatives and focused on sharing themes from the Summit, discussing them, and ensuring there was consensus on them. The ongoing need for the three established patient-led working groups (PROMs/PREMs, Data, IMOCs) was re-confirmed by the participants.

## AGENDA

Echo Pandemics in Health Care		
Monday, November 15, 2021		12:00-3:00 PM ET
Summit Opening		12:00-12:20
Keynote Address and Q&A	<b>Adalsteinn Brown</b> , Professor and Dean, Dalla Lana School of Public Health, University of Toronto	12:20-1:00
Panel on Echo Pandemics in Health Care and Q&A	<b>Linda Wilhelm</b> , CAPA President and person living with Rheumatoid Arthritis  <b>Dr. Sandy Sehdev</b> , Medical Oncologist, Assistant Professor The Ottawa Hospital Cancer Centre, lead of breast medical oncology group  <b>Julia White</b> , 2021-2022 Jack.Org Network Representative for Newfoundland and Labrador	1:00-2:00
Canadian Partnership Against Cancer Session	<b>Dr. Craig Earle</b> , CEO, Canadian Partnership Against Cancer	2:00-2:15
Breakout Sessions		2:15-3:00
Echo Pandemics in Indigenous Health		
Wednesday, November 17, 2021		12:00-3:00 PM ET
Opening Remarks		12:00-12:05
Keynote Address	<b>Dr. Veronica McKinney</b> , Director, Northern Medical Services, University of Saskatchewan	12:05-12:40
Keynote Address	<b>Marion Crowe</b> , Chief Executive Officer of the First Nations Health Managers Association	12:40-1:10
Moderated Q & A		1:10-1:40
Canadian Institute for Health Information Session and moderated Q&A	<b>Dana Riley</b> , Program Lead, Population & Indigenous Health, Canadian Institute for Health Information  <b>Victoria Tenasco-Commanda</b> , Program Consultant, Indigenous Health, Canadian Institute for Health Information	1:40-2:20
Breakout Sessions		2:20-3:00
Echo Pandemics: The Way Forward		
Thursday, November 18th, 2021		12:00-2:30 PM ET
Opening Remarks		12:00-12:05

<b>Keynote Speakers and Q&amp;A</b>	<b>EMPaCT</b> Dr. Ambreen Sayani, Postdoctoral Fellow, Women’s College Hospital, Toronto, Canada  <b>Alies Maybee</b> , Patient Partner	12:05-12:45
<b>Panel on Data’s Role in Creating a More Resilient Health System and Q&amp;A</b>	<b>Eric Sutherland</b>  <b>Haley Armstrong</b> , Senior Specialist of Stakeholder Engagement at <i>Canada Health Infoway</i> & <b>Angela Jonsson</b> , Senior Director of Stakeholder Engagement at <i>Canada Health Infoway</i>  <b>Eva Villalba, MBA, MSc.</b> Directrice générale / Executive Director Coalition priorité cancer au Québec / Quebec Cancer Coalition	12:45-1:30
<b>Summit Working Groups Session</b>	Showcase the <b>Data and Integrated Models of Care Working Group’s</b> efforts	1:30-1:40
<b>Breakout Sessions</b>		1:40-2:20
<b>Closing Remarks</b>		2:20-2:30
<b>Patient Planning Session—restricted to patients/caregivers and their groups</b>		
<b>Friday, November 19th, 2021</b>		<b>12:00-1:30 PM ET</b>
<b>Group Action Planning (Patients, Caregivers, and Patient/Caregiver Organizations)</b>		12:00-1:30

## Appendix 2: Summit History & Evolution

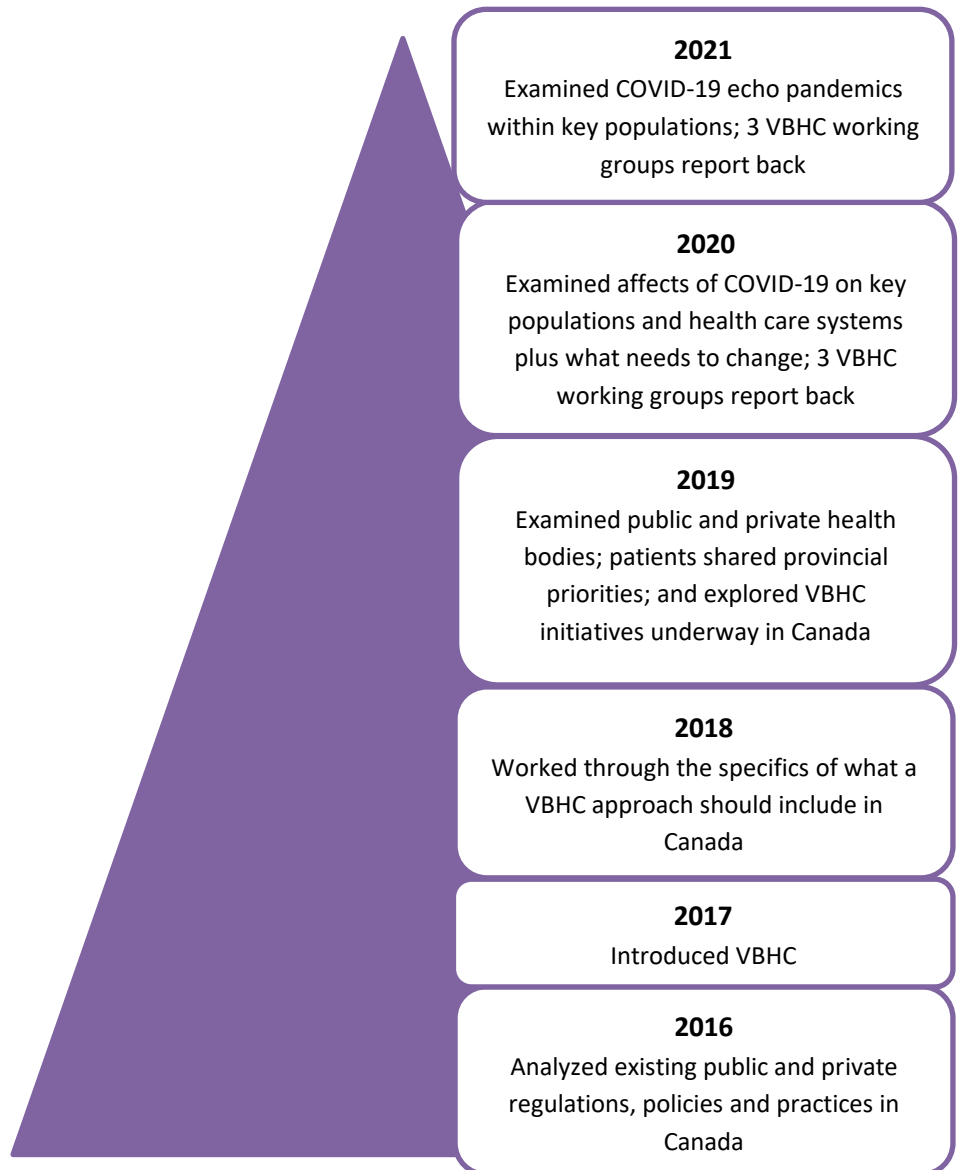
The 2016 Summit examined and constructively critiqued existing public and private regulations, policies and practices at the national and provincial/territorial levels that have had either a direct, or an indirect, impact on drug pricing, drug costs and ultimately drug access in Canada. From this Summit, 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. 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 decolonization of knowledge and, therefore, health care. 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 focused on integrated models of care, patient-reported outcome measures, and data reported on their progress. A multi-stakeholder panel followed with recommendations for opportunities to build on such initiatives.

## **Appendix 3: Declaration of Personal Health Data Rights in Canada**

**Executive Summary in English:** [bit.ly/declaration-summary-en](https://bit.ly/declaration-summary-en)

**Full Declaration in English:** [bit.ly/declaration-en](https://bit.ly/declaration-en)

**Executive Summary in French:** [bit.ly/resume-declaration-fr](https://bit.ly/resume-declaration-fr)

**Full Declaration in French:** [bit.ly/declaration-fr](https://bit.ly/declaration-fr)

## Appendix 4: Summary of Evaluation Results

Electronic evaluation surveys were sent to participants at the close of each session — Echo Pandemics in Healthcare, Indigenous Health, The Way Forward, and the Patient Planning Session.

### **November 15, 2021 – Echo Pandemics in Healthcare**

The benefit of event participation to you:	2 Very Beneficial 2 Beneficial 2 Somewhat Beneficial
The benefit to your organization:	2 Very Beneficial 4 Beneficial
The benefit of the presentations:	2 Very Beneficial 3 Beneficial 1 Somewhat Beneficial
Quality of breakout facilitation:	4.75 / 5
Quality of breakout discussion:	4.75 / 5
Time allotted for breakouts:	5 / 5
Audio-visual quality of presentations:	4.3 / 5
Quality of French interpretation:	N/A

*“Insights from Steini Brown were so clear, profound and considered. I thought that really set the tone for the conference.”*

### **November 17, 2021 – Echo Pandemics in Indigenous Health**

The benefit of event participation to you:	5 Very Beneficial 3 Beneficial
The benefit to your organization:	6 Very Beneficial 1 Beneficial 1 Somewhat Beneficial
The benefit of the presentations:	6 Very Beneficial 1 Beneficial

	1 Somewhat Beneficial
Quality of breakout facilitation:	4.6 / 5
Quality of breakout discussion:	4.8 / 5
Time allotted for breakouts:	4.6 / 5
Audio-visual quality of presentations:	4.5 / 5
Quality of French interpretation:	3.0 / 5

*“Dr. Veronica McKinney and Marion Crowe's talk - eye opening and tangible resources provided; breakout sessions.”*

**November 17, 2021 – Echo Pandemics: The Way Forward**

The benefit of event participation to you:	2 Very Beneficial
	1 Beneficial
The benefit to your organization:	1 Very Beneficial
	1 Somewhat Beneficial
	1 N/A (individual)
Quality of breakout facilitation:	4.0 / 5
Quality of breakout discussion:	4.0 / 5
Time allotted for breakouts:	3.5 / 5
Audio-visual quality of presentations:	4.7 / 5
Quality of French interpretation:	N/A

*“More moderation in group discussion. Got stuck in discussion on 1 topic with mostly 2 ppl talking.”*

**November 18, 2021 – Patient Action Planning**

The benefit of event participation to you:	4.0 / 5
The benefit to your organization:	4.0 / 5
Audio-visual quality:	5.0 / 5



## Appendix 5: Sponsors

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