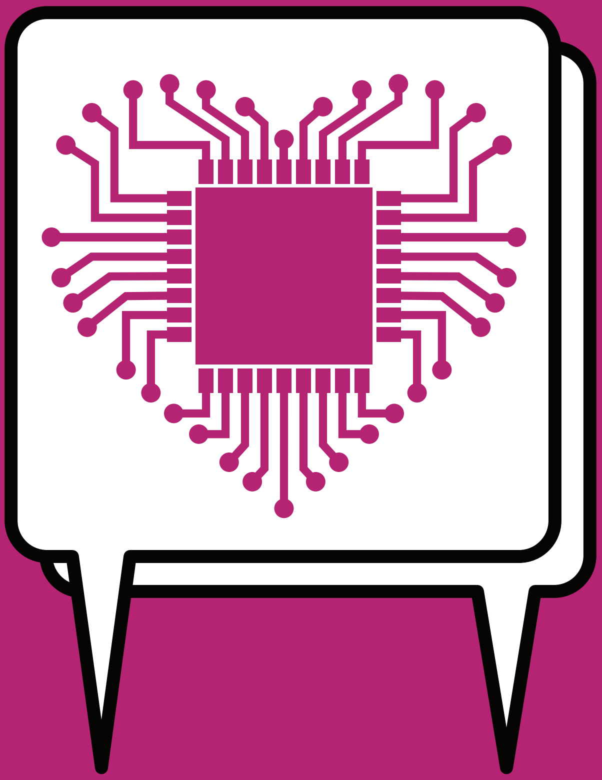
Hearing Your Voices
an AMS Healthcare Conference



Patient and Caregiver Recommendations on Technology & Compassion During COVID-19

AMS
advancing innovative healthcare
with compassion at its core

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Overview

AMS Healthcare has a longstanding commitment to advancing innovative healthcare technologies that serve, rather than threaten, the ideal of compassionate care. The COVID-19 pandemic has made this goal more urgent, more visible and more imperative. It has changed the landscape of both technology and compassion across the healthcare system.

Some of these changes can be celebrated. The pandemic has driven the rapid adoption of technologies that were previously slow to take hold, opening up more diverse and accessible spaces for care. The imperative to pivot quickly to virtual care has dissolved some previously persistent barriers. Healthcare providers, educators and leaders have been applauded across popular media for their compassion, commitment, skill and sacrifice under great strain.

We have also seen devastating failures of compassion and technology. The pandemic has drawn new attention to stark inequities in both access to care and exposure to risk, with some racialized and vulnerable groups bearing far more burden than others. Our health information infrastructure remains dangerously fragmented. Patients, family members, caregivers and healthcare providers have suffered in isolation. Organizational and political responses to the crisis have too often excluded the perspectives, priorities and substantial expertise of these groups.

All of these experiences have the potential to galvanize change. That potential was the impetus for ***Hearing Your Voices***, a virtual conference hosted by AMS in partnership with The Ontario Caregiver Organization, The Change Foundation, and the Canadian Foundation for Healthcare Improvement. Over two days, more than 700 participants logged in to engage with panels of esteemed speakers who shared their expertise as patient partners, caregivers, advocates, leaders, technologists, educators and healthcare providers.

This report distills key insights from the conference and issues a call to action. It lays out 7 guiding principles and 15 recommendations—things that we can do now, together, to create a sustainable and integrated healthcare system that is innovative, inclusive and compassionate by design.

Table 1: Summary of Guiding Principles

1	Healthcare providers should have access to patients' health information, regardless of where in Canada they are located.
2	Patients should have full and unfettered access to their own health information.
3	Canadians should have equitable access to, and choice among virtual and in-person healthcare options.
4	Patients and caregivers should play integral roles in co-designing digital health technologies and programs.
5	Diverse patient perspectives should inform digital health technologies, programs and policies.
6	Leadership, governance and coalitions supporting digital health should be established at a national level.
7	Healthcare providers should be enabled to use digital health technologies in compassionate and equitable ways.

Table 2: Summary of Recommendations

1 Adopt common standards (HL7 FHIR®) for the collection and storage of data and the design of electronic patient records developed and used in Canada.

2 Adopt common standards (HL7 FHIR®) for patient portal systems developed and used in Canada.

3 Implement processes to ensure that information provided in patient portals is complete, accessible, understandable and added in real time.

4 Implement processes to ensure that patients and caregivers are co-leading the design and implementation of patient portals, guided by principles of inclusive design.

5 Develop and implement legal protections through regulatory organizations to support the goal of providing full information to patients.

6 Accelerate broadband Internet access 0to all residents of Canada.

7 Implement sustainable payment models for in-person, phone and video visits and for secure messaging.

8 Implement processes that support patients in choosing their preferred modality of care and accessing the equipment, space, educational programs and/or coaching needed to participate effectively.

9 Implement policies in both the public and private sectors to ensure that patients and caregivers are included throughout the design, procurement, implementation and evaluation of healthcare technologies.

10 Establish strategic advisory roles for patient partners at every level, including co-leadership. Appropriate compensation should be considered for these roles.

11 Recruit patient partners who represent the diversity of patients and caregivers in Canada; prioritize principles of diversity, equity and inclusion in selecting advisors.

12 Establish coalitions between patient advocacy groups and healthcare provider organizations to coordinate activities and advocate for patient-centred health technologies.

13 Enlist more members of the public as allies in advocating for compassionate, digitally enabled care; identify and mentor local leaders who can act as spokespeople and advise government representatives.

14 Establish professional standards of practice for compassionate and equitable uses of digital health technologies.

15 Incorporate compassionate uses of digital health technologies, including health equity and anti-oppressive practices, within core curricula in health professional training programs in Canada.

Contents

24 moderators and speakers brought extensive expertise as patient partners, advocates, educators, clinicians, technologists, informaticians, policymakers and organizational leaders.

Hearing Your Voices – November 3-4, 2020

Over 700 participants took part in discussions about digital health technologies in the lived experiences of people receiving healthcare.

Introduction

The COVID-19 pandemic has had immense impact on healthcare in Canada. Not only has it created great demand for intensive care in hospitals, but it has also affected how all health services are planned and delivered. The risk of in-person contact has meant that many ambulatory care services need to be delivered virtually.[1] Healthcare professionals have had to quickly adopt new ways of providing care, exacerbating longstanding challenges with workload and burnout.[2] The imperative to act quickly led to patient voices being excluded from planning tables where decisions were made about health policy.[3]

These and other challenges provide an opportunity to reenvision the future of healthcare from a person-centered perspective. That is: How can our health technologies and services best meet the needs of patients and caregivers? In what ways might they frustrate those needs or cause new harms? How can we design sustainable healthcare technologies and systems that help to cultivate trusting relationships and that reach the people who need them most?

These questions are not new. Before the pandemic, they had become increasingly important with the proliferation of digital health technologies. The unique challenges of COVID-19, and the accelerated uptake of technologies for providing healthcare, have made these questions more urgent and yielded new insights upon them.

The ***Hearing Your Voices*** virtual conference sought to capture those insights by gathering patients and caregivers together with healthcare providers and other experts. The conference was co-designed by AMS Healthcare in partnership with patient and caregiver leaders. AMS Healthcare is committed to advancing innovative and compassionate healthcare in Canada by bringing people together, developing the next generation of health innovation leaders, and funding important work on compassionate uses of technology.

This report summarizes key insights from the rich discussions that unfolded over the course of two days and four panel discussions in November 2020. (Video recordings can be viewed in full at https://www.ams-inc.on.ca/hearing-your-voices-virtual-conference/.) Participants generously shared their stories and their diverse expertise with the goal of fostering change. To serve that goal, we present 7 guiding principles and 15 recommendations that arose from the conference (see Table 1 and Table 2). These aims and actions are critical for achieving compassionate, innovative, integrated and inclusive healthcare in Canada. We hope this report will serve as a guide and as a call to collaborative action for the many individuals and groups who can advance and advocate for this vision.

Compassion in the context of COVID-19

The two central concepts underlying the conference — compassion and technology — warrant brief introduction. Here, we explain our use of these terms and illustrate their importance with the help of powerful stories that were shared during the opening panel of the conference. The stories are retold here, in brief, with permission; they can be heard in the tellers' own words on the conference website.

Compassionate healthcare involves a commitment to respect the patient and caregiver experience as central to effective and meaningful care.[4] In compassionate care, healthcare providers communicate in ways that earn patients' trust. The system is structured to recognize the perspectives and full humanity of people who receive care, as well as those who provide it.[5] Compassionate healthcare attends to the emotions at the root of our health and wellbeing.

This description may seem simple or self-evident. Most people try to be compassionate toward others, and compassion is a defining purpose of healthcare work. In practice, however, compassion can become complex, especially when different sets of needs come into conflict

— or when systems and technologies are at odds with those needs. Such tensions are not peripheral to the effectiveness of healthcare; they threaten its foundations. Within a health system strained by the intense demands of the COVID-19 pandemic, compassionate care has often broken down.

The story of Denise McCuaig and her family illustrates the consequences. Denise has extensive experience as an Indigenous Advisor to healthcare programs. Her father passed away in 2020, during in the early months of the pandemic in British Columbia. He was admitted to hospital when he suffered a stroke. None of his family was permitted to visit and advocate for his care. Concerned that he would be unable to advocate for himself, as he suffered from dementia, they wanted terribly to learn about his comfort and his bedside care:

> ***"We needed to hear what the person with eyes on my dad had to say. Not just a physical report, but his mental wellbeing. Was he being kept comfortable? Was his pain being managed? Did he respond when being spoken to? We do these things at the bedside as caregivers. It's not that healthcare professionals don't want to do this. It's that they're so busy."*** — Denise McCuaig

The family's communication, however, was limited primarily to phone calls with the charge nurse, which focused on transactional questions about whether to carry out specific medical interventions. Denise's family felt pressured to answer immediately, without time for discussion among themselves. Without any opportunity to talk to the bedside nurses who interacted directly with Denise's father, they were left with a wrenching absence of connection to his mental, emotional and spiritual needs.

While technologies such as tablets have been used throughout the pandemic to enable video visits, these options were not made available to the McCuaig family. Such simple technologies—combined with a more relational approach to communication—would have enabled compassionate and culturally appropriate care. Denise described poignantly how the chance to drum her father out on his spirit journey would have brought the family deep peace. Instead, they received a final transactional phone call informing them that he had died.

The story of the McCuaig family illustrates what happens when compassion is not upheld as the foundation of effective healthcare. The lack of compassion expressed to the McCuaig family took many forms: the way they were treated by healthcare providers seeking quick medical decisions, the absence of communication about what was happening with Denise's father's bedside care, the lack of effort to enable him to see his family even virtually before the end of his life, and the lack of consideration for the family's cultural and spiritual needs.

This story also shows us that compassion must exist at many levels. It is about relationships between providers and patients, communication within healthcare teams, the ways that patients and caregivers access information about their care, and policies put in place by healthcare organizations. It is also about support for the healthcare team, who may themselves be distressed or overwhelmed. Each of these represents an opportunity to build compassion into the fabric of healthcare. Too often, we have seen these opportunities missed as the needs and wishes of patients and caregivers are overlooked amidst the pressures of everyday healthcare work. All of them together are integral to protecting and sustaining compassion as a priority. This report takes its starting point in the urgent need to build compassion into every aspect of health systems, enabling better care for all.

Technology in the context of COVID-19

In this report, we use the phrase “digital health technology” to describe the group of digital technologies that allow patients and healthcare providers to collect, share and understand health-related information. These include technologies that are very common, such as a smartphone or laptop, as well as those that are rare or emerging, such as artificial intelligence (AI) used in “chat bots” (automated computer programs that interact with people online in ways that mimic a real person). Sometimes care can be delivered from a distance without using digital technologies, such as when a simple phone call can meet important needs. Both digital health technologies and “lower tech” options are important for a compassionate, patient-centred healthcare system.

Many of the recommendations presented in this report apply, in principle, to all digital health technologies. However, three kinds of technology stood out as foci throughout the conference because of their prominence during the pandemic and their importance to achieving patient-centred care: virtual care technologies, electronic health records and patient portals.

Virtual care most commonly includes either a phone call or video visit between a healthcare provider and a patient.[6] All regions in Canada provided payment options to physicians for virtual care during the pandemic. As a result, we have seen a dramatic shift toward virtual care, with digital technologies being adopted at rates higher than ever before.[1,7] Data suggest that more than half of patient visits, psychotherapy sessions and consults between physicians took place virtually during the early months of the pandemic.[8] According to a survey by Canada Health Infoway in late 2020, 64% of people had received care virtually in the previous 12 months.[7]

Canadians appear to be happy with the care they have received: the same survey showed that 90% of people were satisfied with their care at their most recent virtual visit.[7] These preliminary data suggest that virtual options can serve the aims of compassionate care. However, as the 2020 report from the Chief Public Health Officer of Canada clearly states, there are also important risks to relying on digital technologies for healthcare.[9] For example, many marginalized and vulnerable communities face challenges in accessing healthcare through technology. Reliance on virtual care has the potential to worsen existing inequities for these groups. This is not a reason to slow the use of technologies, but it underscores the importance of establishing the infrastructure, education and support that will allow all people in Canada to benefit from digital health and virtual care.

The shift to virtual care has also proven difficult for many healthcare providers. Technology has the potential to free up healthcare providers’ time and enhance attention to patients and families,[10] but poorly designed technology can be a drain on their energy and disrupt their focus on person-centered care.[11] During the pandemic, choices of care modality have often been shaped by necessity and availability, without the time or support to consider different options and their implications. Most healthcare providers lack the training needed to navigate major technological and digital changes. Such changes have been expected within the health professions (even if this specific pandemic was unforeseen).[12]

As the conference proceedings highlight, the COVID-19 pandemic exposed a lack of technological readiness not only among healthcare providers but also across the healthcare system and its information infrastructure. This theme was most apparent during discussions of two related technologies: electronic health records and patient portals. Electronic health records gather patient information, including test results and clinical notes, in a digital form. Patient portals provide access to that information. They may also serve other functions including secure messaging, appointment booking, and helping patients to understand their illness, test results or care.[13]

Currently, most electronic health records and patient portals in Canada are particular to specific hospitals or regions. Patients may have multiple records, each accessible, to varying extents, through a different interface. The experiences of Claire Dawe-McCord, both before and during the pandemic, illustrate the dangers of poorly integrated electronic records, along with the potential of well-integrated records to support exemplary compassionate care. These themes resonated throughout the conference and are elaborated in later sections of the report.

Claire lives with rare chronic health conditions that were diagnosed in her early teenage years. When she turned 18, Claire could no longer go to the paediatric hospital that knew her. She arrived at a new hospital suffering a severe electrolyte imbalance that she knew to be life threatening. Because the hospital had no access to her extensive records, she found herself fighting to convince the triage team of the seriousness of her condition. After waiting four hours, she found herself having to explain her complicated medical history to the doctor while vomiting profusely and in acute pain. The event was dire and she had to be resuscitated. As Claire put it:

> *"A failure of technology and communication almost cost me my life."*
>
> — Claire Dawe-McCord

Claire now carries binders wherever possible containing summaries of her medical history — a solution that would not be necessary if she had reliable access to her full patient records.

Claire also told a second and far more hopeful story. She again had to visit an unfamiliar emergency room, this time in a new city during the COVID-19 pandemic. This hospital's electronic health record system was capable of calling up her records from her usual hospital. It quickly became apparent to Claire that the team knew about her specific risks and care needs. She described how foreign it felt to be able to let her guard down in a critical situation for the first time.

Claire's story shows us that compassionate care, and the technologies that enable it, are not peripheral to other aspects of medical treatment: they are critical to the quality and safety of care.

The Hearing Your Voices conference

The *Hearing Your Voices* virtual conference was held November 3–4, 2020. The conference was conceived and co-designed by AMS Healthcare working in partnership with patient and caregiver leaders. The selection of speakers and topics was driven by patient and caregiver input, in keeping with the charter for Patients Included™ events.[14]

The conference had two overarching objectives:

1. **To learn from patients', families' and caregivers' experiences of the intersection between digital technology and compassion, especially in relation to COVID-19, and**
2. **To identify what changes and strategies are most needed to advance a person-centered digital healthcare system.**

These objectives served to anchor discussions about digital health technologies in the lived experiences of people receiving healthcare. Beyond this experiential wisdom, speakers brought extensive expertise as patient partners, advocates, educators, clinicians, technologists, informaticians, policymakers and organizational leaders. A full list of speakers can be found on page 26.

The conference was built around four themes, each the focus of a panel discussion (see conference agenda). Each session featured opportunities for the panellists to address questions submitted virtually by participants. Over 700 participants from across Canada registered for the conference, representing patients, caregivers, healthcare providers, organizational leaders, policymakers and technology innovators.

Key insights from these sessions, and the recommendations that emerged from them, are presented in the remainder of this report. Video recordings of each session are available online at: https://www.ams-inc.on.ca/hearing-your-voices-virtual-conference/.

Hearing Your Voices conference agenda*

Panel 1. The power of lived experience

This session focused on listening to, and learning from, the experiences of patients and caregivers related to the intersection of compassion and technologies in healthcare.

Moderator	**Maggie Keresteci**
Speakers	**Denise McCuaig, Robin McGee, Claire Dawe-McCord**

Panel 2. Is technology truly a solution?

This session grappled with potential, and the limits, of technology for supporting compassionate care—along with the changes that are needed to realize that potential.

Moderator	**Amy Coupal**
Speakers	**Ewan Affleck, Carole Ann Alloway, Anna Foat, Maurine Parzen, Fraser Ratchford**

Panel 3. Digital health: How do we get there together?

This session explored how patients, caregivers, healthcare providers and developers can work together to build compassionate and equitable technologies.

Moderator	**Julie Drury**
Speakers	**Alika Lafontaine, P. J. Mierau, Melissa Ngo, Dominik Nowak, Laura Williams**

Panel 4. How do we make it happen?

This session focused on the large-scale changes that are needed to advance a compassionate, digitally-enabled healthcare system.

Moderator	**Brian Hodges**
Speakers	**Sandy Buchman, Susan Fitzpatrick, Alies Maybee, Heather Thiessen, Roberta Timothy**

* See page 26 for more information about the speakers.

Conference proceedings

This section of the report distills key insights related to each of the four conference themes. While each panel was organized around a distinct theme, the discussions were interconnected and built upon one another. For that reason, the proceedings are organized by theme, with some summaries drawing from multiple conference panels.

Theme 1. The power of lived experience

As moderators emphasized throughout the conference, retelling personal stories takes courage and generosity. The three speakers in the first session modelled this courage. Their stories resonated across all subsequent sessions.

Two of these stories — told by Denise McQuaig and Claire Dawe-McCord — were described in the opening sections of this report. The experiences shared by Robin McGee offered another stark account of the significant harms that can result from failures of compassion and technology. (Many of these experiences are also chronicled in Robin's award-winning book, The Cancer Olympics.[15])

Robin's story spans 12 years and multiple systemic failures. She described how her initial symptoms of colorectal cancer were dismissed and belittled. As formal investigations have confirmed, negligent practice and communication by multiple physicians resulted in delayed diagnosis and treatment. When her cancer recurred years later, a misread scan led to further delay and disease progression. These failures have had the gravest of consequences for Robin, whose cancer has advanced to an inoperable stage. Management of this recurrence, and of treatment side effects, has been hamstrung further through the pandemic.

Robin has made powerful use of her negative experiences to benefit others. She was described during the conference as a "gently fierce" advocate for change. She emphasized how full access to her own health records would have made it possible to expose the multiple errors in her care:

> ***"Patients can correct errors and can fight for things that were supposed to happen and didn't. For me, patient portal and access to [our] own records are critical. … We can help ourselves and also our healthcare providers. People do not want to create errors in practice."***
> — Robin McGee

All three of the speakers' stories featured a lack of compassion in which healthcare professionals either did not see, or actively dismissed, the needs and symptoms of patients or caregivers. In all three cases, technology had the potential to enable safer and more compassionate care, whether in quite simple ways (connecting patients to families with a tablet) or more complex ones (obtaining timely critical information from an electronic health record).

The speakers also shared important insights about the process of changing healthcare practices and systems. All have used their experiences to provide feedback and advocate for improvement. They shared how these efforts can be met by an adversarial culture of denial and self-defense from healthcare professionals and organizations. This adversarial stance is, itself, a failure of compassion at an organizational level — as well as a missed opportunity for the system to learn from its failures.

A related problem is the culture of paternalism that is still common to the medical profession and can thwart the efforts of patients to gain access to their own health data, such as test results. While some patients may need "safety nets" to interpret this information — or may prefer not to access it independently — the majority of people want independent access.

> ***"Who decided for me that I would rather hear bad news in a doctor's office than at home in the bosom of my family? … There's still an element of paternalism in how medical records are shared."***
> — Robin McGee

This perspective was echoed in later sessions. For example, during panel 3, Laura Williams reported that 94% of portal users at UHN said they preferred to receive their results in real time, even if it included bad news.

Although it grew from difficult experiences, this session also conveyed considerable hope. Speakers were encouraged by the new channels of virtual care that have been made possible during the pandemic. As Robin noted, "Cancer patients have been asking for this for a long, long time."

Robin's own positive experience with virtual care was echoed by other speakers throughout the conference. Many expressed their sense of relief and gratitude for virtual appointments that had allowed them to be present with loved ones while removing the risks and costs associated with travelling to in-person appointments.

Simple video technology also promises to reduce the impact of isolation by linking patients to their family and loved ones. These links have been tremendously important during the unique conditions of the pandemic, but they may endure as a valuable tool. As Denise noted, Indigenous Canadians often have to travel long distances to obtain medical treatment or to give birth. Bringing technologies to the bedside can help to reduce the sense of isolation when physical distance cannot be avoided.

While virtual care options promise to reduce barriers for many people, speakers were also careful to note that others are at risk of falling through the cracks — a concern that was discussed in more detail in the third panel discussion.

Beyond the specific benefits of virtual care, speakers also found great hope in the speed of change that the pandemic has shown to be possible. As Claire noted, "What takes years normally, in COVID times has taken weeks." This opens a window of possibility:

> ***"COVID has given us an opportunity to change the entire system. … The next 12 months is when we can lay some incredible groundwork for patient partnering and improving patient care. I hope we can see more patients as decision-makers in the coming year."***
> — Claire Dawe-McCord

Finally, speakers shared insights about the challenges of acting as a patient advocate. In a time of crisis, even those with extensive experience in the healthcare system can face significant challenges in advocating for themselves and their families. More broadly, patient partners face a learning curve in working with healthcare organizations. Participants asked:

How can we ensure that patients and caregivers are engaged in meaningful ways and are not reduced to a checkbox on the "patient engagement to-do list"?

Panellists discussed a variety of strategies, such as pursuing diverse roles (ranging from completing surveys to becoming members of government); reaching out to the public; mentoring new advocates; and above all ensuring that patients and caregivers are included at decision-making tables as co-designers of healthcare technologies and systems.

They also noted how nongovernmental organizations can be allies in this work and how social media has offered new and powerful channels to advocate for change by drawing attention to failures of compassion, ranging from unnecessary barriers to egregious discrimination. For example, Denise found hope in the bravery of Joyce Echaquan, the Indigenous Canadian woman who livestreamed the racist treatment she received in hospital before her death. “Her courage has launched a conversation about systemic racism in this country.”

Theme 2. Is technology truly a solution?

In this panel, participants were invited to address the question, “Is technology truly a solution?” — that is, can we provide or amplify compassionate care through the use of technology? All of the panellists offered a “yes, and” or an “it depends” response. Drawing upon their personal experiences and professional expertise, they all affirmed that technologies have potential to support person-centred, compassionate care. However, they were quick to emphasize that this question cannot be reduced to a simple yes or no answer. Their collective message was clear:

Realizing the promise of technology will require fundamental changes in the culture and information architecture that shape healthcare practice.

Technology is only meaningful if it actually improves the care of patients and the experience of both patients and caregivers. Underlying this important observation is the reality that technology can support certain tasks, such as faster communication, but cannot alone solve the challenges of healthcare. It simply provides opportunities to better meet patients’ needs.

Technologies should be evaluated according to these criteria. Across multiple panels, speakers discussed an underlying problem. In healthcare, we often develop technologies to serve other interests. For example, hospitals often measure efficiency of care rather than the quality of caregiving relationships. Information systems have too often been designed to meet the needs of healthcare providers, the healthcare system, and developers, without patients having a seat at the table.

> ***“Hospitals are driven by metrics. … But nowhere in any of those metrics are we actually measuring the relationship that we have with our patients or clients, with caregivers and families.”***
> — Maurine Parzen

The barriers to designing technologies around the needs of patients are not primarily technical. As Ewan Affleck noted, a smartphone is basically capable of everything we do in healthcare. Along similar lines, Fraser Ratchford observed that advancements are being driven by the ubiquity of tablets and mobile technologies. Patients increasingly recognize that these technologies, in some circumstances, can facilitate convenient, high quality care.

The true challenge is much larger. It’s rooted in the culture of medical practice, the history of our healthcare system, and the regulation of healthcare practices and technologies. These social and political barriers have kept healthcare “mired in analogue behaviour” while other industries have undergone more comprehensive technological transformations. The COVID-19 pandemic exposed these shortcomings and left the system scrambling.

Panellists cautioned that we shouldn't make the mistake of trying to digitize and automate the existing system. For example, while patient portals have been an understandable starting point, they currently provide many disparate windows onto a fragmented information system.

> ***"In Ontario, there are something like a hundred different portals. If you're someone with complex health issues, you could have a dozen different portals. This is what is burning people out. The information is all over the place. I would suggest that fracturing the information in such a profound way becomes quite dangerous."*** — Ewan Affleck

Several speakers described how healthcare professionals have been stymied in their efforts to provide compassionate care, sometimes adopting risky practices for exchanging information, such as texting each other images and charts, because secure tools are not available.

The solution requires redesigning our information architecture around the needs and rights of patients in a digital age:

> ***"I think that we need to carefully reconsider how we, as an industry, all the different professions, all of the administrators, all the patients, all of us in this ecosystem work together around the design of information use, and then adapt the technology to it. … We currently, frankly, lack human interoperability as the precursor, or foundational element, of a truly compassionate and functional technology system in Canada."***
> — Ewan Affleck

These comments were echoed by Anna Foat. As an innovator, Anna emphasized the importance of engaging in a process of co-design to reimagine what different might look like: "It's a hard place but the right place to start from. I've never seen change not start from the beginning." This approach will require stakeholders to "put down our collective egos" and positions of authority. Although this is difficult, it is possible because we all agree what the outcome should be.

In addition to co-design, the panellists emphasized the need for governance and leadership. While promising actions have been taken by various groups at local and national levels, there has been no centralized leadership governing the design of our health information architecture. This concern was echoed and elaborated during the following session.

Panellists, finally, emphasized that technologies can only support compassionate care if they can be accessed and navigated effectively. In the first instance, this requires careful design. Information should be laid out in a way that offers clarity for both patients and professionals:

> ***"My family doctor doesn't have 35 minutes to go into a portal and hunt and peck around. We need to design so that it's interoperable, not a tsunami of information. Right sized information that you can dig down on."*** – Anna Foat

Beyond design, the implementation of new technologies will need to be supported with education.

> ***"Clinicians and citizens alike need to be prepared, equipped and supported to use technology."*** – Fraser Ratchford

As Maurine Parzen suggested, health professionals such as nurses and personal support workers can play an important role in helping patients and caregivers to gain comfort in using technologies. However,

Virtual care training has been largely absent within medical schools and other health professional training programs.

Theme 3. Digital health: How do we get there together?

Digital health technologies can make important improvements to healthcare when they enable meaningful communication and support positive relationships between healthcare providers and patients. But how can that vision be achieved? Ultimately, it will require a deep commitment to collaboration between patients, caregivers, healthcare providers, healthcare administrators, digital health technology companies and policymakers. This is a complex task, but much discussion at the conference focused on breaking through the complexity with shared purpose and shared power to better understand where challenges lie and strategize how to resolve them.

Members of the third panel were invited to be bold in exploring barriers and their solutions. The discussion was informed by crowdsourcing conducted before the conference, which identified three problems of wide concern: people are frustrated by existing communication modalities, they want access to their own information, and they are worried about who is being left behind. The summary in this section focuses on three solutions that stood out as essential: attending to digital determinants of health, ensuring that patients' needs drive the development process from the beginning, and advocating for legislation to motivate real change.

The digital determinants of health refer to the ways in which digital technologies improve health and healthcare for some, but not all.[16] Many people take Internet access for granted, along with their knowledge of how to use the Internet in ways that make their lives easier. For people who do not have access to Internet-connected devices — whether because their geographical location or financial resources — accessing a video visit or their health information online becomes impossible.[17] People may not know how to use the Internet, or specific digital platforms, effectively. And they may lack private spaces in which they feel free to discuss their health concerns openly.

We need to develop an infrastructure to ensure that technologies work for everyone and do not exacerbate existing inequities.

This may include providing access to technologies, as well as providing choice of care modality — including in-person visits and simple phone calls — wherever possible.

Even people who do have access to the Internet can encounter barriers. For example, the development of digital health technologies that are culturally safe for Indigenous communities in Canada requires great care and attention, and many existing digital health systems have simply not considered Indigenous health specifically.[18] The same goes for many other marginalized communities.[17]

Speakers emphasized the importance of involving diverse voices throughout the co-design process. Who is leading the effort to identify which problems in healthcare should be solved by technology in the first place? Although there are success stories of patients driving the development of innovations such as online peer support networks, conference presenters emphasized that the actual needs of patients and caregivers are often not the central consideration of the companies building these technologies.

Sometimes a digital health company makes a good sales pitch to a hospital executive, which leads to a particular technology being purchased by the hospital. Sometimes a group of healthcare providers identify a need for better communication, and they find a digital tool to help solve the problem.[19] But only rarely are decisions to buy and use digital technologies in healthcare driven by input from patients and caregivers. This creates a system in which technologies are adopted by different organizations in very different ways, and are generally not able to communicate with one another, posing added challenges for coordinating care.

Examples of patient-driven design and procurement of digital health technologies do of course exist. The recent decision to procure the EPIC electronic health record system at University Health Network (UHN) in Toronto, for example, was informed by a group of patients providing input about whether and how the technology could be used in patient-centered ways. Such examples show that patients and caregivers can have important input into decisions about purchasing and adopting technology in healthcare settings, especially a technology as important to an organization as their electronic health record.

Speakers celebrated such examples of leadership within "small islands of excellence," where innovations are being advanced through patient-led processes of co-design, informed by outreach to marginalized groups. These significant advances, however, are typically not transferrable or interoperable. Technologies are written in specialized languages, and they are built upon assumptions that are difficult to undo. No matter how extensively patients are consulted, these underlying conditions present a fundamental barrier. They prevent streamlined and transparent access to personal health information. They also limit our ability to analyze data in ways that would enable system-level improvements.

P. J. Mierau referred to these barriers pointedly as "commercial determinants of health." Echoing the second session of the conference, he emphasized that the goals of compassionate care cannot be truly realized without substantive policies to secure patients' rights:

> *"There is not a single law in this country that grants you the functional access the Supreme Court says you have to your digital health record. Not a one. And there is not a single law that makes every health record talk to every other health record in your city, forget your province. Not a one. Until that changes, we are widgetized. Until our rights are brought in day one to day end, until we co-design with our peers, we will never fix any tool."*
> — P. J. Mierau

For this reason, encouraging efforts to foster change within the healthcare system need to be complemented by national-level leadership along with public education and advocacy.

We need to broadly communicate the importance of patient-centred health technologies and the policies needed to achieve them.

Theme 4. How do we make it happen?

Partnership, collaboration and co-design can support important progress on compassionate uses of digital technologies in healthcare, but these ways of working together will not become the norm without sustained action through leadership. The ways healthcare providers and organizations work are connected to a set of rules and regulations created by healthcare policies on the funding and evaluation of healthcare. Many of these policies are outdated. They have not kept up with the changes in technology that could revolutionize compassionate care. Even beyond the rules in place, healthcare organizations tend to do things the way they have always been done before. Without clear advocacy and coordinated effort to bring about change, the vision of a compassionate, digitally enabled health system cannot be realized. The fourth session of the conference grappled with concrete, system-level strategies for realizing these goals.

Several speakers emphasized the importance of renewing the healthcare system to support fundamental changes in how healthcare is delivered. The Canadian healthcare system was originally designed around the needs of physicians and hospitals. Emerging technologies provide an impetus and opportunity to rebalance roles and reimagine a compassionate system — a system that might, as Susan Fitzpatrick suggested, be free from time spent in waiting rooms, unnecessary travel, and consultations with missing diagnostics. All speakers agreed that diverse patient, family, and caregiver partners must be integral to this process of renewal:

> ***"Patient partners can and should be part of any efforts to redesign systems and data access, in order to remove those systemic barriers to compassionate care."***
>
> — Alies Maybee

Important considerations can be built into future policy to make sure that digital health technologies serve patients and caregivers as a primary focus. For example, patient input can be required when organizations are buying, adopting and evaluating technology systems. Without formalized rules and policies — or other strategies to "weave" patient and caregiver input "into the DNA" of the system — progress in patient engagement remains vulnerable.

> ***"COVID-19 really illustrated to us in a flash how we could go back 10 years and bring back some real paternalistic ways of thinking. … The voices of patients, families, and caregivers were all but forgotten and were not included at the table for discussion, especially with subjects pertaining to us as recipients of care. … It really made me sad as a patient partner that so many years of growth and learning were gone in seconds."***
>
> — Heather Thiessen

Education of healthcare providers is one important piece of the puzzle. A great deal of care and attention goes into healthcare provider training programs and the regulation of healthcare providers to protect the public. The time has come for healthcare provider training programs in universities and colleges to more completely embrace technology as a fundamental part of healthcare. Changes to training programs will shape the next generation of healthcare providers and leaders.

Sandy Buchman emphasized the importance of showing physicians the value of compassionate care. Robust evidence demonstrates the clinical benefits of compassion and offers one way of convincing clinicians. Extending compassion toward clinicians is another way of showing its value. Compassionate leadership — addressing burnout, depression and psychological distress — can allow healthcare providers to experience compassion. The principle of compassion can also be woven into continuing clinical education within workplace settings.

Educators and system leaders will need to go beyond refocusing existing education programs. They will also, as Susan emphasized, "need to take a close look at the workforce of the future."

Existing jobs are changing, and new jobs will be created. For example, in the rapid response to the pandemic, the uptake and management of virtual tools, such as setting up Zoom calls, has often been added onto existing job descriptions. These functions warrant creating new, dedicated roles. Such transitions need to be managed at an organizational and system level.

Speakers also emphasized the importance of addressing the disastrous inequities in our system. Access to emerging healthcare tools is important, but it does not address underlying forms of structural inequity and oppression. For example, poverty, housing shortages, and race-based discrimination run much deeper than access to technology. Care must be taken to ensure that the effort to develop technologies, and to advance compassion, does not retraumatize or further harm black, Indigenous and other marginalized communities.

> ***"The question is, which lived experience are we bringing in? Having a health equity lens is critical to compassion. ... Because we can be very compassionate for certain folks and not compassionate for others, and that's the problem."*** — Roberta Timothy

Reaching out to these groups will require communicating in ways that make people feel safe or safer, acknowledging past experiences of health inequity and healthcare violence. As moderator Brian Hodges summarized, "Our system is fundamentally built in ways that huge swaths of the population don't trust the system. How do health professional organizations help us to systematically build trust?"

There was, again, a note of optimism throughout this discussion. The COVID-19 pandemic has produced promising new models of care, and it has revealed that rapid change is achievable.

> ***"We've been trying to get virtual care going for about 10 years in this country, and within about 10 days of COVID, all of a sudden it was exploding. And all of a sudden, many of us who lacked housing were housed. ... Most of my patients all of a sudden had their own motel rooms, were getting 3 meals a day, their own privacy and bathrooms. We could do that for technology."*** — Sandy Buchman

Nonetheless, enduring, large-scale change remains a formidable challenge. One important strategy is to encourage more members of the public to speak up to their healthcare providers, healthcare organizations and government representatives. Advocacy groups can coach new advocates. They can also mentor and support local leaders who are able to advise government representatives with a strong, collective voice. Those representatives need to know where to turn for guidance and recommendations:

> ***"We have to somehow groom the local leaders. ... Part of it is making it easier for governments of all levels to know who they can reach out to."*** — Susan Fitzpatrick

> ***"How amazing would it be if our health ministries, both federal and provincial, took time to really tap into that wealth of knowledge and lived experience of patients, families and caregivers across Canada?"*** — Heather Thiessen

Recommendations

Many factors have stymied change within Canada's healthcare system. The system is constituted by diverse stakeholders who serve a range of public, personal, professional and commercial interests. Any attempt at change must navigate the complexities of federal, provincial and territorial jurisdiction. It must contend with finite resources and adapt to a wide variety of contexts.

The COVID-19 pandemic has demonstrated, however, that change can happen quickly, despite these complexities, when people take coordinated action toward common goals. The goals defining a compassionate, innovative and inclusive healthcare system are clear — as are the fundamental steps needed to achieve them.

This section of the report distills that common vision into 7 guiding principles. These principles can be pursued in a variety of ways by different advocates for compassionate, digitally-enabled care; we hope they will help to guide the strategies of diverse groups. To focus those strategies, we have identified 15 recommendations that are most essential to meaningful progress. See Tables 1 and 2, on page 2 and 3 of this report, for a summary of all guiding principles and recommendations.

1. Healthcare providers should have access to patients' health information, regardless of where in Canada they are located.

Fully interoperable electronic health records are an important long-term goal. As we saw in Claire Dawe-McCord's story, barriers to accessing health information from other healthcare organizations can be a severe risk to patient safety. The value of the electronic health record lies not only in having comprehensive patient information available at a single organization but also in sharing that information with other healthcare providers as quickly as possible when needed. Without strategies to make sure that information can be safely shared across organizations, electronic health records will never be able to prevent the risks experienced by Claire and others. Patients and providers will remain frustrated, resources will be wasted, and our healthcare system will remain fragmented across geographical areas and healthcare sectors.

While the adoption of electronic health records in Canada is highly complex, clear steps are available to ensure that systems can "speak" to one another, allowing health information to be exchanged easily across organizations. As an immediate priority, electronic health records developed and used in Canada should adopt a common application programming interface (API) and common standards for collecting and storing data. Respected international standards have been established for this purpose: the HL7 (Health Level 7 International) Fast Healthcare Interoperability Resources (FHIR®).[20]

Adopting FHIR® standards would lay the essential groundwork for achieving interoperable health records in Canada. This would require organizations to use an open data standard (as opposed to a proprietary one), containing common definitions, a common set of metadata, and a human readable part. These common standards would ensure that data are "available, discoverable, and understandable" across systems. The FHIR® standards have been successfully adopted in many jurisdictions. Their broader uptake across Canada requires political and organizational leadership, along with public advocacy.

Recommendation 1.

Adopt common standards (HL7 FHIR®) for the collection and storage of data and the design of electronic patient records developed and used in Canada.

2. Patients should have full and unfettered access to their own health information.

Many healthcare organizations provide patients with their health information through patient portals. However, patient portals can be difficult to access and understand. Patients who receive care from a variety of healthcare providers must often navigate multiple different portal systems, each holding a different piece of their health information. Those individual pieces of information can themselves be incomplete and delayed. Patients and caregivers are deeply frustrated by these barriers to accessing their own information and participating more fully in their own care. If patients are to be empowered to better understand and engage in their care, they need complete and timely access to their own health information in streamlined forms that are easy to navigate.

The same actions needed to establish interoperable health record systems (see guiding principle 1) also lay the foundation for creating integrated patient portals. When data are collected and stored using common specifications, they can be presented within any compatible patient portal system. When systems adopt a common API, they can consistently retrieve and exchange information across databases. Adopting common FHIR® standards would therefore provide an essential building block needed to overcome the fragmentation of patient portals currently seen in Canada.

Beyond these technical foundations, additional policy and design strategies are needed to ensure that patient portal systems offer complete and timely information that can be readily accessed and understood. Some barriers to including information within patient portals are rooted in professional cultures and/or medicolegal concerns. For example, some healthcare professionals prefer to retain control over when and how information is delivered to patients, and legal concerns have been raised about the inclusion of free text clinical notes within patient portals. Steps may need to be taken by professional associations and others to shift professional culture and to establish legal protections. Where legal protections are at issue, design solutions can be used to contain information of particular kinds (e.g., free text notes) within designated areas of the patient portal.

Patient portals should, finally, be inclusive in their design. Their interface and content should be accessible and understandable to diverse audiences, including those with different language abilities, sensory abilities and cognitive abilities. Links to trusted resources should be available to help patients understand the information they receive. These goals require time and care. They are best achieved using principles of inclusive design, undergirded by evidence from design-based research.

Recommendation 2.
Adopt common standards (HL7 FHIR®) for patient portal systems developed and used in Canada.

Recommendation 3.
Implement processes to ensure that information provided in patient portals is complete, accessible, understandable and added in real time.

Recommendation 4.
Implement processes to ensure that patients and caregivers are co-leading the design and implementation of patient portals, guided by principles of inclusive design.

Recommendation 5.
Develop and implement legal protections through regulatory organizations to support the goal of providing full information to patients.

3. Canadians should have equitable access to, and choice among, virtual and in-person healthcare options.

The widespread adoption of virtual care that we have seen during the pandemic is very welcome for many people living in Canada. It may forge lasting improvements in access to care and perhaps also quality of care. Virtual care also promises to save time and money—for patients, healthcare providers and the healthcare system alike.

Any strategy for virtual care in Canada must also be accountable to principles of equity and choice. Wherever possible, people should have the freedom to choose among care modalities. In some circumstances, in-person visits may be the most effective and compassionate option. In others, virtual care may be the safest, fastest and/or most comfortable way of connecting to a care provider.

Revised payment structures were an effective tool during the pandemic. They will remain essential for enabling patients and their care providers to make choices about the most appropriate modality of care. Organizations can also encourage patient choice by offering different care options, documenting preferences, and including these preferences within their quality assurance models.

Virtual care is only available to those who have the required resources: access to the Internet, to hardware (e.g., computers, tablets or smart phones), and to private spaces that allow for open discussion. Varied access to these resources has been referred to as the "digital determinants of health." Supporting equitable access to these resources is essential to establishing a compassionate and inclusive health system. Important progress has already been made in expanding high-speed Internet access to reach more Canadians, a commitment that should continue through collaborations between governments and telecommunication companies. Other strategies may include establishing programs to provide or loan necessary hardware; making private, equipped spaces available in the community; and ensuring that phone calls are always an option for virtual care.

Organizations that provide healthcare have an important role in advancing the goal of equity in conjunction with new health technologies. They may need to establish criteria for allocating limited resources and raise funds to provide technology to patients in need. Criteria might include availability, need and likelihood of benefit. For example, digital initiatives may hold particular value for mental health services and chronic disease management.

Organizations should also ensure that healthcare providers and staff are well informed about anti-oppressive and anti-racist healthcare practices. This will help to ensure that existing structural inequities are recognized and addressed, rather than worsened, by emerging forms of care.

Along with access to different options for receiving care, patients will also need support in learning how to use healthcare technologies. These goals may be served by inclusive design, by educational initiatives, and perhaps by new professional roles. As digital health expands, investments in the infrastructure to support its uptake and effective use will become increasingly important.

Recommendation 6.
Accelerate broadband Internet access to all residents of Canada.

Recommendation 7.
Implement sustainable payment models for in-person, phone and video visits and for secure messaging.

Recommendation 8.
Implement processes that support patients in choosing their preferred modality of care and accessing the equipment, space, educational programs and/or coaching needed to participate effectively.

4. Patients and caregivers should play an integral role in co-designing digital health technologies and programs.

The single clearest way to ensure that technologies meet the needs of patients is to involve patients and caregivers in the design of digital health technologies and the programs in which they are embedded. Patients and caregivers should co-lead design initiatives along with healthcare providers and technology developers. Healthcare leaders in Canada (whether they are patients, caregivers, healthcare providers or others) can advocate for patient-centred technologies and programs built with processes that bring patients and caregivers to the table throughout the decision-making process.

Doing co-design in meaningful ways requires a clear understanding of what co-design is and what it is not. True co-design requires collaborating with patients and caregivers from the beginning stages of a design project, working together to determine which problems are the most important to solve and what a new technology or program should look like. Only after this time are prototypes created. Patients and caregivers then have additional opportunities to provide input, trial new developments, inform additional changes, and shape priorities. True co-design embraces early and frequent participation, transparency, and accountability to patients and caregivers in a committed partnership. This true form of co-design is necessary to produce digitally enabled healthcare that is grounded in compassion and that actually works.

Healthcare organizations have varied widely in their commitment to integrating the perspectives of patients and caregivers within decision-making processes. Some organizations have made sustained investments to ensure that patient and caregiver expertise informs all large initiatives, while others have neglected to do so. It is essential that patients and caregivers are at the table as key stakeholders to inform all stages of decision-making, including policy decisions. Only they can provide experiential insight about how decisions affect people who access healthcare services. These insights are essential to achieving and sustaining compassionate care.

Recommendation 9.

Implement policies in both the public and private sectors to ensure that patients and caregivers are included throughout the design, procurement, implementation and evaluation of healthcare technologies.

Recommendation 10.

Establish strategic advisory roles for patient partners at every level, including co-leadership. Appropriate compensation should be considered for these roles.

5. Diverse patient perspectives should inform policies about digital health technology.

While some encouraging progress has been made to incorporate patient and caregiver perspectives into the design, procurement, and evaluation of health technologies, these perspectives seldom reflect the enormous diversity of the Canadian population. As we have seen starkly during the COVID-19 pandemic, healthcare experiences are not equal. Some people have been excluded from or hurt by the healthcare system. Compassionate care cannot be fully realized without attending to how health decisions affect diverse populations, including marginalized groups. Patient and caregiver input into policy decision-making should be equitable, including people from different parts of Canada, different racial and cultural backgrounds, different gender identities, different income levels — and different degrees of trust in the healthcare system. Only a clear and strong commitment to this kind of inclusion can uphold the principles of Canadian healthcare that demand equitable access for all.

Recommendation 11.

Recruit patient partners who represent the diversity of patients and caregivers in Canada; prioritize principles of diversity, equity and inclusion in selecting advisors.

6. Leadership, governance and coalitions supporting digital health should be established at a national level.

Canada has many leaders in digital healthcare. Conference participants described a number of bright spots across the country where patients, caregivers and healthcare providers have worked together to make change. When patients and caregivers join forces — with one another and with other healthcare partners — the momentum for change becomes even more powerful. This work must continue, with growing communities of patients and caregivers advocating for compassionate care.

While many collaborations have been formed, and significant progress has been made at various levels, there is not currently a clear strategy promoting collaboration in digital healthcare on a national scale. Although healthcare systems are generally the responsibility of provinces and territories, digital health is a national issue, especially when it comes to our information infrastructure and patient rights. There is currently a lack of policy needed to protect established rights, such as the right to access personal health information. Continued fragmentation across jurisdictions poses significant risks to patients and professionals. To overcome that fragmentation, we need both grassroots coalitions and proactive governance.

Recommendation 12.

Establish coalitions between patient advocacy groups and healthcare provider organizations to coordinate activities and advocate for patient-centred health technologies.

Recommendation 13.

Enlist more members of the public as allies in advocating for compassionate, digitally enabled care; identify and mentor local leaders who can act as spokespeople and advise government representatives.

7. Healthcare providers should be enabled to use digital health technologies in compassionate and equitable ways.

The COVID-19 pandemic has shown that healthcare providers need a much stronger foundation for using digital technologies. This experience reinforces recent calls for changes in education and professional standards. For example, a recent report from the Royal College of Physicians and Surgeons of Canada advocated for changes in physician education to promote a stronger understanding of emerging digital technologies and their effects on medical practice.[12] Similarly, the Registered Nurses Association of Ontario called for changes to nursing practice, education and leadership to keep compassionate care central in the context of artificial intelligence.[21]

It is not only digital technology that needs a stronger emphasis in healthcare provider training. Training programs also need to emphasize the profound effects of privilege, oppression and the social (and digital) determinants of health. Healthcare providers should understand how healthcare can cause harm when delivered in culturally unsafe ways. They need to develop strategies to create healthcare spaces that are safe and accessible for everyone.

Recommendation 14.

Establish professional standards of practice for compassionate and equitable uses of digital health technologies.

Recommendation 15.

Incorporate compassionate uses of digital health technologies, including health equity and anti-oppressive practices, within core curricula in health professional training programs in Canada.

Conclusion

The ***Hearing Your Voices*** conference grappled with persistent and urgent needs: to address the erosion of compassion as the foundation of healthcare and to ask how digitally enabled health systems can be designed to support compassionate care at all times. Two concluding comments are important to frame the insights of the conference and the recommendations advanced in this report.

First, the conference has illustrated that the lack of compassion in healthcare often derives from a belief that patients and caregivers have only limited knowledge to inform their own care. Healthcare providers are taught to work in paternalistic ways that often minimize the importance of the lived experiences of patients and caregivers. This paternalistic mindset is present in individual patient–provider relationships and in the ways that organizations and governments make investments in healthcare innovation. Compassionate healthcare works against that paternalism by valuing the experience and knowledge of patients and caregivers, who are the rightful focus of healthcare. Patients and caregivers are key stakeholders whose insights should shape the technologies and systems that are designed to help them. Investing in compassion in health systems in Canada is the primary and most important strategy to achieve the many goals we have outlined in this report.

Second, leadership from patients and caregivers will continue to be essential to pushing the compassionate care agenda forward. The work is nowhere near done. Patients and caregivers have already demonstrated innovative thinking and bold leadership across Canada, bringing people together to take concerted action. This leadership must continue to grow and must be supported with meaningful and authentic engagement and partnership opportunities.

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Above all, we are grateful to everyone who took part in this event, generously contributing their time, attention, wisdom and personal experiences. We hope, through this report, that your voices will continue to be heard and, ultimately, transformed into compassionate and equitable healthcare technologies.

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