Smart Health and Wellbeing: A Canadian Policy Roundtable

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Preface

The Information and Communications Technology Council (ICTC) is a not-for-profit, national centre of expertise for strengthening Canada's digital advantage in a global economy. Through trusted research, practical policy advice, and creative capacity-building programs, ICTC fosters globally competitive Canadian industries enabled by innovative and diverse digital talent. In partnership with an expansive network of industry leaders, academic partners, and policy makers from across Canada, ICTC has empowered a robust and inclusive digital economy for over 25 years.

About the Smart Cities Project:

ICTC is leading a multi-year national research initiative on smart cities. Under this project, ICTC investigates the development of smart cities across Canada and internationally, with the ultimate goal of understanding the labour, technology and societal needs and opportunities of Canada's future communities. To guide and shape this research, ICTC has chosen the following areas of focus: Smart Infrastructure, Smart Mobility, Smart Energy & Environment, Smart Health & Wellbeing, Smart Government, and Smart Regulation. During the course of this study, ICTC is hosting policy roundtables on each of these pillars. The first roundtable was on Smart Infrastructure and took place in November 2019. These roundtables engage a variety of stakeholders across Canada to uncover specific policy needs and put forward recommendations that can support a smart future for our cities.

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KEY WORDS

ACCESSIBILITY
DIGITAL HEALTH
DIGITAL TRANSFORMATION
HEALTH DATA
HEALTH DATA LITERACY
SMART CITIES
SMART HEALTH AND WELLBEING
PATIENT-CENTRED DATA
TECHNOLOGY
VIRTUAL HEALTHCARE

Introduction to the Roundtable

ICTC's Smart Health Policy Roundtable was held on October 25, 2021. It was the fifth in a series of events focused on creating a vibrant and inclusive smart economy for Canada. The roundtable opened with two 20-minute talks about digital health and inclusive healthcare.[1] In the event's second hour, an invited group of 30+ experts from industry, government, academic institutions, and civil sector organizations were led in discussion by ICTC facilitators. Participants were separated into three groups of seven to 10 people, each focused on a separate aspect of smart health and wellbeing. The three groups gathered in their respective breakout rooms and for approximately one and a half hours, discussed challenges and opportunities related to rural and remote healthcare, aging and wellness, or health data. The key take aways from those discussions are distilled into this brief.

Breakout Room #1: Smart Health and Wellbeing in Rural and Remote Communities

Rural and remote communities in Canada face unique challenges in providing access to quality physical and mental health services. Residents in these communities must often travel great distances to get the help they need.[2] Where services do exist, they are frequently stretched thin, with long wait lists, high turnover rates, and poor communications infrastructures.[3] Technology can help. Varied benefits of smart health and wellness tech include less travel time, lower costs, fewer missed appointments, improved service availability, increased convenience, and higher perceived confidentiality or privacy.[4] Rural healthcare planning and policy, however, is often based on urban healthcare models that fail to address the specific barriers facing rural communities.[5]

To gain insight into these issues, roundtable participants in the first breakout room were asked five sub-questions to break down the overarching question: How can we best leverage existing health technology and develop new health technologies to improve access to and quality of healthcare in rural and remote communities? Specifically, the eight participants from varied backgrounds, including clinical, mental health tech, and physical health tech, were asked: How has the pandemic impacted technology adoption *in* and development *for* rural and remote communities? What are the most pressing challenges to leveraging technology in rural and remote communities right now? How do or should the needs of rural and remote communities impact the development and deployment of health technologies? What does providing cultural wellness support mean in a health tech context? Looking to the future, what should the key actions be with respect to improving access to and quality of health resources in rural and remote communities?

Three main action items emerged from this discussion about challenges to technology adoption and development in rural and remote communities.

- To increase smart health and wellbeing adoption, the range and quality of internet infrastructure for rural and remote communities must be improved.
- Supporting adoption in rural and remote communities means expanding practitioner education and training to include technology-specific and culturally relevant training opportunities.
- Increasing financial and other supports for industry, particularly small businesses that want to collaborate with rural and remote communities in the tech design

process, is key to encouraging tech development that responds to community needs and cultural wellbeing.

Tech Adoption Challenges and COVID-19

Infrastructure and technology adoption issues became more apparent during the pandemic, highlighting the access disparity between urban and rural spaces. As several participants noted, the pandemic made city dwellers experience some semblance of remote living due to lack of access to in-person resources. According to Statistics Canada (StatCan), “almost one in 10 needing healthcare services were not able to schedule one or more appointments needed during the first year of the pandemic.”[6] The reasons for scheduling delays overlap with access barriers for rural and remote communities (e.g., long wait times, cost, services not available in the area, and transportation).[7] That experience brought many of the technology and infrastructure frustrations that rural and remote communities experience in everyday life to the public eye. As a result, participants noted increased interest in topics like common barriers to internet and technology access, including energy infrastructure, internet infrastructure, and affordable devices. These issues also became more prominent on the service provision side. For example, one clinician who serviced rural and remote communities with the aid of virtual care technologies before the pandemic explained that COVID-19 forced many of their colleagues to use and thereby experience the shortcomings of health tech and telehealth for the first time. All participants agreed that speed is imperative in addressing these technology and infrastructure-related care gaps.

"We have to get those fibre optic lines up and running and as fast as we can. And the pandemic luckily has kicked us into gear. But we're still not there. There are so many communities that are lacking.”

Despite this attention, while smart health and wellbeing adoption increased *overall* during the pandemic,[8] this increase did not mitigate the care gap between rural and remote residents and their urban counterparts. According to a report released in late 2021, the rate of telehealth use for rural patients in Ontario, for example, did increase but not as steeply as the rate of their urban counterparts.[9] It follows that most participants in the private sector, for instance, noted that their business had increased since the start of the pandemic (see *Figure 1 and 2*),[10] and a service practitioner said that many virtual care tools had been introduced. As participants noted, this uptick in smart health and wellbeing adoption is likely due, in part, to barriers removed to facilitate care during the pandemic, such as a lack of specialized billing codes for virtual care. Despite these positive changes, experts suggest that “higher rates of urban telemedicine use during the pandemic coincide with generally higher rates of urban health care use as telemedicine became ubiquitous.”[11] So while adoption increased, it seems virtual care has not mitigated the care imbalance between rural communities and their urban counterparts.

How has the pandemic impacted technology adoption in rural and remote communities?

Pandemic highlighted the need for increased adoption in URBAN centres, let alone in rural communities.

Important to be able to transmit patient info or patient examinations to a doctor in another location for review

Technology has significantly increased accessibility for some individuals in rural and remote communities, but highlighted significant service gaps as well

Internet is a must, connecting all remote and major cities together as most of the experience exists in the cities.

Increased attention paid to adoption barriers in rural and remote communities.

increased realization that some currently adopted technologies are inadequate and fall short (example OTN) health outpost stations

Internet as a key component for many tele-health, mental health etc solutions

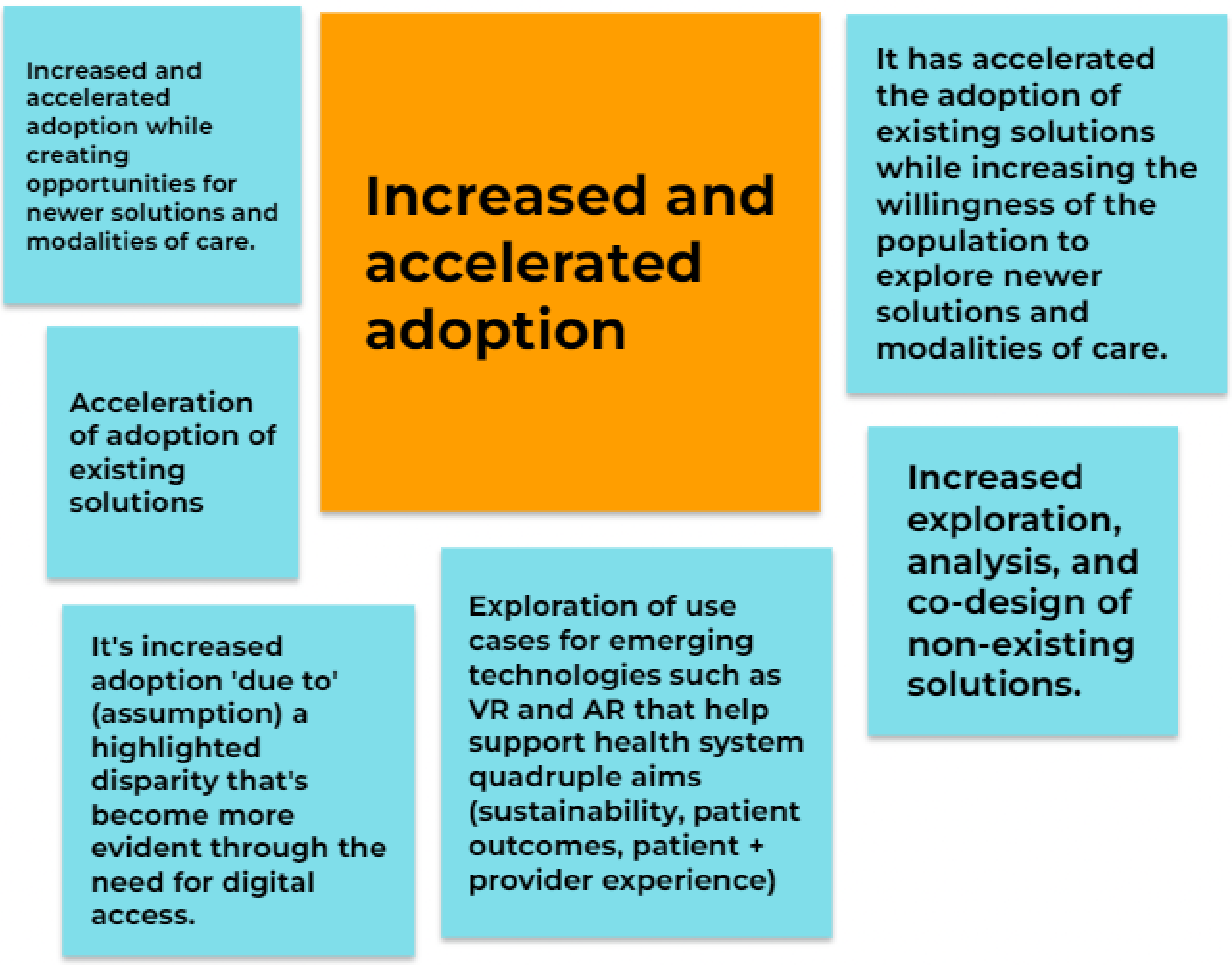
Increase in identification and discussion of the access constraints as they relate to technology adoption; ie. access to power, internet, affordable devices

During the pandemic remote was next door

The pandemic has highlighted the disconnectedness of health technologies that hinders adoption in some cases

Figure 1. COVID-19 impact on tech development in rural and remote communities (part 1 of 2).

How has the pandemic impacted technology adoption in rural and remote communities?



Increased and accelerated adoption

Increased and accelerated adoption while creating opportunities for newer solutions and modalities of care.

Acceleration of adoption of existing solutions

It has accelerated the adoption of existing solutions while increasing the willingness of the population to explore newer solutions and modalities of care.

Increased exploration, analysis, and co-design of non-existing solutions.

It's increased adoption 'due to' (assumption) a highlighted disparity that's become more evident through the need for digital access.

Exploration of use cases for emerging technologies such as VR and AR that help support health system quadruple aims (sustainability, patient outcomes, patient + provider experience)

Figure 2. COVID-19 impact on tech development in rural and remote communities *(part 2 of 2).*

Tech Development Challenges and Community Needs

To address community needs and develop products that centre on cultural wellness, participants suggested weaving community collaboration into the technology development process through methods including co-design and co-creation. Co-design and co-creation “build on participatory research methods that recognize power imbalances brought about by social inequities” by centring user experience in the product development process.[12] Tech companies who genuinely engage in the co-design process can produce products that reduce risks to vulnerable communities and promote accessibility.[13] Through this attention to usability, accessibility, and trust, research shows that co-design can help mitigate adoption barriers for health tech in rural Canadian communities.[14] In addition, recent research has shown that co-design can be particularly beneficial for rural and remote Indigenous communities based in Canada.[15] Because designing for specific community needs is essential to encouraging adoption, creating technologies “with, rather than for” Indigenous communities can help mitigate common barriers to adoption, including “concerns about privacy to maintain cultural safety.”[16] It follows that lack of co-design can have an adverse impact on adoption. One participant, for example, noted that the lack of community consultation led them to develop their app without an offline mode, leaving many rural and remote participants without access to their product.

While all participants agreed that co-design and other forms of community consultation mitigate disconnects between design and the intended population, a significant portion did not have the capacity or funds to support comprehensive collaboration. Indeed, several industry participants voiced their frustration that they often made assumptions about their target audience because of challenges with collaboration due to the inability to travel to meetings because of the pandemic, difficulty building trust with vulnerable communities over virtual co-design sessions, and financial limitations.

“There are so many assumptions that you're making about product development that aren't validated by community members and the end users. You have very little access to understanding their constraints in their context. Absolutely, collaboration is needed.”

“Let’s go to the community as the trusted source of how we can make this work and build the skill sets and knowledge right within the community. And they can be the go-to for other community members. They need to be the most important person at the table. There's an opportunity. If we start there, it will speed things up because we'll have a shared goal.”

“If we see a greater push for technology, I'm hoping that we'll see a greater push to consult with experts in the field and the technology around their needs.”

Participants noted that collaboration would be particularly helpful when addressing linguistic differences. One participant detailed how simple terminology differences in mental health discussions can easily be misinterpreted by someone without specific knowledge of the culture and language in question. The same term, for example, can be interpreted as suicidal ideation in one language or for one community, when the term is actually a common turn of phrase to express anxiety or depression in another language or community. Without community consultation, these linguistic differences could easily be translated into algorithmic bias in mental health apps that use artificial intelligence (AI) for natural language processing. Recent studies support the use of “ethically aligned co-design methodology [to ensure] trustworthiness in the early design phase of an AI system component for healthcare.”[17]

These language processing technologies and biases are particularly relevant for rural and remote communities. As the same participant noted, because internet connections often fail to support video calling in rural and remote areas, practitioners rely more heavily on automated transcription services and/or cues from natural language processing technologies when making their diagnoses. With fewer visual and verbal cues, the potential for misdiagnosis increases. A participant working on text-based coaching services noted they face similar issues both for language barriers and language-use. For instance, the participant explained that young people tend to use high-risk words and phrases, regarding self-harm or harm to others, more than their older counterparts. Community consultation combined with other processes, including market research, could help industry overcome these issues.

"If audio is the only thing you can capture—because sometimes we're providing care in rural areas—this creates barriers to accessing technology. There are challenges with knowing how to access technology and how to create a profile and different things like that. So, we have to be willing to work around those specific obstacles and then leverage data in a way that helps practitioners still provide the same level of care that they would if there in person."

"When we're developing smart applications that involve a lot of back-end processing for what's really going on in these services—text based, video based or otherwise—I think that there's a need to create systems or follow safe systems that are built to understand how other [different populations] speak or share information."

Addressing Key Challenges with Infrastructure, Funding, and Training

To solve these adoption and development challenges for smart health and wellbeing in rural and remote communities, the number one recommendation was increasing the range and quality of internet infrastructure. As one participant put it, to mitigate adoption issues, *"governments should be making sure that rural areas can have connection so they can invest in products or devices that could be used by a rural community for their therapy sessions."* Indeed, when asked what the most pressing barrier to technology is for rural and remote communities today, just almost half of the sticky notes on Jamboard related to calls for increased connectivity (see *Figure 3*). Participants also stressed that increasing the quality and quantity of infrastructure alone will not suffice. Internet connections must also be affordable for low-income rural residents and residents without high levels of tech literacy.

What are the most pressing barriers to developing tech for and adopting healthtech in rural and remote communities?

DEVELOP

Lack of incentive for independent service providers to create needed tech infrastructure

There is an up front cost and time to develop and implement

Barriers to co-design created by lack of opportunities for in-person collaboration.

Developing software that translates or understands translation/meaning of different languages and cultures

Emphasis on the dollar and cents as opposed to quality solutions informed by industry experts.

Underinvested and Underfunded; Canadian companies that have proven products, early ROI, still cannot access capital as easily as their US counterparts. This limits innovation and development.

Remote/rural communities need time and resources and capacity to CO-CREATE tech and digital/virtual tools and resources-this was not possible before the pandemic and still isn't

ADOPT

Access to affordable and consistent connectivity in rural and remote areas for digital health solutions

critical infrastructure is still needed. fast reliable, high speed internet, even phone service

If internet is not available is cell service as this would allow a start to some of the not serviced areas

Limited/constrained ability to demo and evaluate new innovative products by stakeholders in person due to pandemic gathering constraints.

lack of access to internet connection or devices

Lack of reliable connection to internet, when most technologies (video, cloud based, etc) require a connection. This is a high-cost infrastructure development

[For online] - Improve internet connection, reduce demands on bandwidth

Updating existing internet infrastructure can be cost-prohibitive

Health system priorities focused on Covid-19 response creates challenges for and slows adoption for solutions not relevant to the pandemic.

Lack of culturally-adapted and appropriate approaches to healthcare

There is a cost to implement and train end users and also a need to set up the responses at a major city to review the patient info

rural and remote Indigenous communities need digital programs that are culturally and contextually appropriate (and co-created)

Access to training or support in terms of feeling comfortable with technology options, make it "Easy"

Although perceived security around data within tech solutions has increased, with the number of incidents rising around data breaches, we will inevitably encounter challenges with adoption.

Figure 3. Pressing barriers to smart health and wellbeing solution adoption.

It is important to note that since the onset of the pandemic, the federal government has made several commitments to improve internet access and quality for rural and remote communities, including investing $2 billion for underserved communities as part of the Canadian Infrastructure Bank Growth Plan and an extra $1 billion over six years for the Universal Broadband Fund.[18]

In terms of smart health and wellbeing development, participants identified financial support for industry consultation with the communities in question as key to creating technology that responds to the specific cultural and structural needs of rural and remote communities. While all industry participants noted that they want to integrate co-design and other collaborative practices into their tech development process, many noted that they could not take on the financial burden. Several participants stressed that this financial burden was particularly difficult for small businesses.

“Everybody here is a busines. You're trying to make a living and you're trying to pay bills. And it can be quite a significant cost to say, ‘I'm going to go up [North] and develop relationships.’ That's a cost that's really hard for small business to bear.”

Even with more fiscal incentives, however, there are still many barriers to tech businesses that want to engage with the co-design process. Some participants noted, for example, that small companies often do not have the capacity to take on the additional work involved with community collaboration. Another potential barrier to successful co-design for companies identified in 2021 report from the World Economic Forum is the lack of established checks to ensure that “a company is indeed invested in the rights and liberties of its everyday users.”[19] Increased government funding, then, will only be effective if applied in concert with evidence-based methodologies that ensure power, inclusion, and justice are at the core of community collaboration.[20]

Another recommendation from a roundtable participant was to increase technology training opportunities and cultural training for practitioners servicing rural and remote communities. One practitioner noted that there is a lack of training on how to connect with people in different environments and communities. This lack of training extends to the technologies that practitioners use to facilitate service to these communities, including therapy tech, counselling tech, coaching on the phone, and teleconferencing or video conferencing for medical appointments. As an industry expert noted, technology adds another layer of difficulty if the patient is hard of hearing, doesn’t speak English, or does not trust the medical system.

“There's a gap in what we can assess and what we can learn in diagnosis [in rural and remote communities], but also from our learning, there's a there's a lot of gaps that need to be filled in our education.”

“We also need to [integrate tech] into how we're trained as practitioners, and look at how you develop rapport from a distance. What nuances do you look for? …How do we use technology with facial recognition software that also looks at your intonation? There is a lot coming on the horizon, and I think it needs to be developed responsibly.”

Breakout Room #2: Technology, Aging, and Wellness

Just over 10 roundtable participants joined the Solutions for Aging and Wellness Concerns breakout room. Participants were selected based on their expertise, which varied, and included the private sector, healthcare providers, and groups that support the needs of seniors. A facilitator from ICTC guided the session by working their way through a list of discussion topics, which were identified in a preliminary literature review. The details of the discussions are described in this section.

To determine first how roundtable participants felt about agetech, ICTC asked participants what comes to mind with the terms “aging,” “wellness,” and “agetech.” Several participants brought up specific technologies, such as fall detection, which is provided by Apple and other tech companies through smart watches like the Apple Watch. Fall detection technology senses when a person has fallen and will automatically send an alert. The alert must be cancelled within a certain timeframe, or the watch will contact 911 and/or call the individual’s emergency contact.[21] One participant stressed the importance of normalizing fall detection and expanding education about fall detection, not just among individuals aged 90 or older, but also among younger adults. This led to an important discussion about barriers to adoption for agetech solutions.

Barriers to Adoption for Agetech Solutions

Barriers to adoption for agetech solutions was a key theme during the breakout room discussion. Participants noted how certain barriers impact agetech adoption rates and felt that these barriers are important to research, discuss, and find solutions to. For instance, participants brought up the need to address the digital divide: when it comes to agetech, iPads, wearables, smart phones are great tools for enabling technological advances, however, we cannot assume that everyone is able to perform critical tasks, such as downloading an app. Digital skills development and community-based technology support programs are an important solution to this barrier.

Another prominent barrier to adoption is friction resistance, which roundtable participants noted is closely related to design. Poor, unfriendly, or discriminatory design is an underlying barrier that in turn impacts adoption and resistance to technology. According to one participant, “the biggest barrier is…the design of the technology,” and so, “making things easy to use will drive adoption.” Whether a technology is easy to use is highly subjective, as different user groups tend to have different technology backgrounds and are accustomed to different norms. Moreover, participants noted a possible disconnect between more senior user groups and software developers, who tend to be younger adults.

One participant brought up a real-life example of a design barrier that creates confusion and frustration among older users: when entering a phone number on many websites, a wrongly formatted phone number may yield an error, for instance, if the area code is missing, if the phone number includes spaces or dashes where it should not. A lack of standardization further complicates this issue. While an easy fix for engineers, coders, and designers, many websites continue to require specific formats for things like telephone numbers or addresses. The participant noted that this example is part of a larger, “underlying attitude in software design” that makes software “completely inaccessible” to more senior users.

According to another participant, this problem stems from the lack of accessible design skills in the information and communications technology workforce, since accessible design is not something that is taught in most schools and programs. Accessible design skills are not part of most curriculums, meaning younger people who take those programs are not necessarily able to design accessibly for different age groups. The participant further highlighted the importance of senior support organizations, which develop expertise and industry knowledge about accessible design for older age groups. Finally, they noted that these groups need to become more involved in education and design processes “to try to embed accessible design into education.”

While that may be one solution, another that arose during the discussion was co-design, whereby technologists and designers work collaboratively with users and/or subject matter experts, such as physicians, nurses, clinicians, researchers, innovation team, and patients, to design tech products and services. Co-design helps ensure that there is sufficient feedback from diverse users, and particularly from end users, and in this case, patients.

Finally, participants noted that in addition to health literacy, it is important for companies and healthcare providers to be able to explain the value of using a product or service to a patient. On top of making technology easy to use, improved communication of technology’s benefits would help increase adoption rates.

In a broader sense, closing the digital divide will also enable more of the aging population to develop and use technologies for their health. As one participant mentioned, there is a growing group of adults who are interested in adopting technologies and are ready to learn about technology for health. Nonetheless, it is important to ensure that aging is part of the conversation of inclusivity and diversity, and that more companies are open to integrate age-friendly design into their processes.

Breakout Room #3: Health Data

The roundtable's third breakout room, which included seven participants from different healthcare backgrounds, discussed health data. Based on themes from ICTC's *Digital Transformation: The Next Big Leap in Healthcare* report,[22] participants were asked six questions about the pandemic's effect on health data. How has what we consider health data changed during the pandemic? How has access to health data changed during the pandemic? How has the use of health date changed? Which of these changes are temporary and which are permanent? Which of these changes have had positive impacts and which had negative? Going forward, and thinking about these trends, what should key priorities for health data be? These and other follow-up questions were used by the facilitator to generate a broader discussion about health data, and from this discussion, four themes emerged:

- When healthcare service delivery changes, it can impact how health data is collected and who has access to that data.
- As the number of health technology companies increases, and more patients engage with health technology companies, there is a greater need for health data literacy.
- The number of technology-based therapies is also increasing, creating a need for data about the effectiveness of these therapies.
- There is an evident need for stakeholders involved in population health data collection to standardize certain types of data, such as demographic data.

These four themes are discussed in more detail in the sections below.

Healthcare Trends, Health Data Silos, and Patient-Centric Data

Changes to healthcare service delivery can also change how health data is collected and who has access to it. Roundtable participants discussed two trends in healthcare service delivery that impact who collects and has access to health data. For one, there has been increased use of telehealth services since the onset of the pandemic. Telehealth services, or telemedicine, are an alternative to in-person consultations with healthcare professionals, delivered via electronic communications, such as telephone, audio, video call, or text. While many telehealth services are an extension of Canada's public healthcare system, there is a growing number of private sector options. Companies like Maple, Babylon, Felix, and Dialogue, for example, are providing telehealth services to patients on a fee-for-service basis or by integrating with private insurance companies or employer benefits packages. Still others are multinational companies that provide a near endless number of services to Canadians over the internet.

Increased adoption of these services during the pandemic is evidenced by company growth rates and market caps. Since the onset of the pandemic, the number of patients Maple sees on a busy day has increased 400% while Dialogue's patients increased tenfold.[23] A report published by Health Canada in July 2021 notes that "digital health in Canada is now a full mature industry," with the largest Canadian players having market capitalizations larger than all but four provincial total budgets.[24] Moreover, the total capitalization of Canada's digital health market is now "somewhere between $15 and $20 billion," or "approximately twice as much as all the money [Canada Health] Infoway and the [provinces and territories] have invested since 2001."[25]

A second trend discussed by roundtable participants was patient choice in healthcare providers. In addition to having more providers to choose from, patients have better access to more comprehensive information about traditional healthcare providers, including online reviews, convenience, competitive wait times, or pricing. Why patients choose one provider over another may be based on any number of factors and may even differ across healthcare services. For instance, a 2019 survey by Accenture found that Gen Z and Millennial patients in the United States want healthcare to be more convenient, affordable, and higher quality, and are more likely to opt for services like virtual care and walk in clinics.[26] Further, younger patients are less satisfied with the status quo of traditional healthcare and are most likely to seek out complementary and alternative medicine, such as yoga, massage therapy, acupuncture, or naturopathy.[27] Interestingly, longitudinal studies and surveys find that use of complementary and alternative medicine has grown in Canada, reflecting a possible "diversification of preferences for different types of healthcare services."[28] One roundtable participant further discussed the relationship between patient choice and health data:

"Something tangential to a lot of what we're talking about is the idea of patients as decision-makers for their providers…there is research that shows that more and more people, especially in younger generations, are prioritizing how they choose to get healthcare services differently, which then affects where the data goes. Like when it comes to choosing a physician for a specific problem, patients are much more likely to prioritize a physician that is available immediately or close to them over their family physician."

Similar comments were made in a recent Health Canada report, which noted that “some observers see the pandemic as having unleashed consumer forces in healthcare,” with “more modern virtual care technology [being] a big winner.”[29] The report continues to say that patients, viewing themselves as “consumers” or “clients,” demanded more convenient, modern services and, where publicly funded tech was not available, switched en masse to privately funded tech.[30] While such trends are heavily debated, as noted by two physicians in the Canadian Medical Journal, “the private market is not waiting around for the question to resolve itself.”[31] Private sector spending accounts for approximately 30% of all healthcare spending in Canada and includes both private telehealth services and complementary and alternative medicine.[32] Similarly, a 2020 survey by the Competition Bureau of Canada found that 7% of respondents received virtual care from a private sector service provider, 30% from a provider of complementary and alternative medicine, and 14% from an “other” type provider.[33]

Roundtable participants noted that the growing number of private healthcare providers creates many new data opportunities but may also make health data more fragmented or siloed (see below quotes). Again, similar comments were made in a recent Health Canada publication, which noted that, the expansion of “borderless vendors and multinational corporations” into Canada risks further fragmenting Canada’s health data.[34]

“Especially in the digital healthcare delivery space, there's been a huge proliferation of health tech startups that are offering similar services, and so, a lot of new data is coming about, but all fragmented. We would be able to conduct interesting research about healthcare access and outcomes much quicker if we could bring together some of those data sources, or even just make them available outside of the private companies that collect them.”

“I think we have created a new dynamic where we are creating digital data at an increased and accelerated rate. If we continue to operate as we did before, then we will be worse off than we were before, so far as silos are concerned.”

Health data silos can negatively impact health research, treatments, administration, and decision-making. Today, if you are part of the healthcare system, whether as a long-term care provider, hospital, primary care research network, insurance provider, or pharmacy, you may have access to some data. Similarly, if you are a health technology startup and have gained a significant number of users, you may start to accumulate your own patient data. However, data sharing between these actors is scarce and actors tend to be protective of their data.[35] According to roundtable participants, data silos “squash creativity,” “limit the type of care and solutions that are available,” and “make it difficult to respond to public health emergencies like the pandemic.” As one participant noted, data silos reveal a marked “disconnect between health data being used for the public interest to address a problem, and the way it is currently set up and flows between different partners.” Currently, there is no overarching policy that assigns data custodians the duty to share their data for the public good; instead, the status quo is a lack of collaboration and pervasive disincentives to data sharing.[36]

One way to solve this challenge is recognizing the patient as a central access point for their data and empowering patients to understand, own, and use their data to enact positive outcomes.

“There is a trend whereby the patient is the only central access point for their data, and that’s something that’s emerging and will probably continue. If I go to five different providers, some of whom are private, that data only exists within my grasp as the owner of my health data—even though I may not know it… because of that, we need better frameworks and infrastructure to support patients in [understanding,] owning, and travelling with their data.”

Patient-centred data was also a theme in ICTC’s digital health study. According to interviewees in the study, while it was once debated whether health data should be made available to patients, “it is now acknowledged and recognized that citizens should have access to their personal information.” In provinces like Ontario, patients now have a legal right to access their personal health information record in an electronic format. Despite this progress, patient control over health data is still limited in many provinces. According to several interviewees, the next big stride in patient health information will be ensuring that patients own and have full control of their data, however, the exact technical solution is unclear. One possible approach is self-sovereign identity (SSI), a class of identity management where “the user, and only the user, has full control over their data.” SII counters provider-centric identity management, which is the status quo, causing individuals to have many scattered identities with different service providers.[37] Interviewees in ICTC’s digital health study and the roundtable participants made similar comments with respect to patient-centred data:

“I would go so far as to say that patients should own and be able to enable [third-party] access of their personal health information—not just the ability to see your values on a screen, but actually hold your own data, move it around, donate it for research purposes,

and be able to see how people are using your personal health information. I think really that's where it's going."

"What I'd like to see is every Canadian having their own portable electronic health record, so that no matter where they seek healthcare, whether it's public or privately funded, they can get their information: assessments, tests, diagnostic results would all be in one electronic health record that the patient would not only be able to access but contribute to as well."

Shortly after the roundtable took place, the Government of Canada's Expert Advisory Group on the Pan-Canadian Health Data Strategy published its second report on the future of health data in Canada. The report outlines a shared vision and principles for Canadian health data and makes several key policy recommendations.[38] Notably, the report advocates for a health data future that is "person-centric," whereby "all personal health information is collected in a single patient chart for use by healthcare providers on a need-to-know basis."[39] Whether or not this health data future materializes, empowering patients to be centralized access points for their health data and enabling them to use their health data for beneficial purposes will require new data sharing solutions and increased data literacy. These topics are discussed in more detail in the following section.

Data Governance and Health Data Literacy

For a patient-centred approach to health data to work, roundtable participants identified a need for increased health data literacy among patients and companies and new approaches to data governance. Nearly four in 10 Canadians do not understand their health information well enough to use health technology,[40] and according to participants, many patients are not familiar with health-sector-data challenges either. One participant noted that there is "a huge education issue" and that "one of the key priorities with respect to health data coming out of the pandemic has to be letting the public know that [data challenges] exist." For instance, many patients do not know the answers to key questions like: What health data exists? Who owns it? Where does it go? Who has access to it? What does my primary care physician have access to? Another participant, a practicing physician, said that many patients think physicians can access every interaction patients have with the healthcare system, such as receiving a vaccine, seeing a specialist, or being admitted to an urgent care clinic, but the reality is they often cannot. Patients being aware of such challenges could help decrease the impact of data silos.

Participants also noted that patients need to better understand how health data can be used for beneficial outcomes, not just at the individual level, but at the population level as well. According to one participant, the pandemic has given the healthcare sector a new and very tangible way to talk about opportunities afforded by population-level data: patients have witnessed during the pandemic that health data sharing “doesn’t just benefit them, but the entire population,” and “not at a detriment to their own use of their own personal data.” Health data literacy was another key, topic in the Expert Advisory Group on the Pan-Canadian Health Data Strategy’s most recent report. Specifically, the advisory group cautioned that the success of health data literacy initiatives depends on common and universally understood health data terms.[41] Several such initiatives exist across Canada, such as Infoway’s Digital Health Learning Program, which helps patients familiarize themselves with health data and gain better understand what digital solutions are available.[42] According to the advisory group, without common or universal health data terms, these initiatives “compete, rather than collaborate, toward a common outcome” and “may lead to mistrust and confusion among learners.”[43] As such, the advisory group recommends establishing a common language to inform health data literacy initiatives.

Finally, sustainable health data sharing relies on health data literacy among companies. One participant highlighted that fear is a major barrier to personal health data being used for the public good: for instance, patients might fear their data being misused, used nefariously by a for-profit entity, or not being used in way that generates returns for the public. As discussed by two roundtable participants, health data literacy among health technology companies can help establish trust between companies and their users:

“I can tell you that when I launched my first company, we were compliant, but we lacked experience and could have been breaking 20 different violations without knowing it. We did our due diligence, but it took us maybe three years to learn an effective way to communicate our privacy policy, make sure our users understood what we were and were not doing, and have them trust us enough to use our app—let alone let us use their data.”

“If you’re an advanced-complexity type two diabetic and on diabetes medication, and your insurer asks whether you approve of them using your claims information to either recommend enhanced clinical solutions to improve your outcomes or share cost savings with you by way of premium reductions, your answer is going to be very different than if they asked to access your health data to do research.”

According to these participants, in addition to health data literacy, companies need the ability to communicate about health data to their users. One important step in that direction is making it easier for new companies to not only comply with minimum health data standards, but actually excel in health data. Companies with better health data literacy will be more successful, as more consumers will feel a sense of comfort and trust in volunteering their data. Notably, the most recent Sanofi Canada Healthcare Survey found a significant discrepancy between how plan sponsors (e.g., companies) and plan members (e.g., patients) perceive issues like data privacy.[44] Sanofi concludes that the “growing gap” between plan members and plan sponsors is a “cause for concern” and notes that benefits providers and plan sponsors can “step up communications on how privacy will be protected” and how data can be used to manage chronic conditions, diseases, and overall health.[45]

Despite these challenges, some participants had experienced a noticeable shift in patient attitudes toward health data sharing in recent years, perhaps due to increased familiarity with health data products and services or increased use of technology during the pandemic. Participants referenced public surveys and consultations such as the Sanofi Canada Healthcare Survey[46] and the Canada Health Infoway’s A Healthy Dialogue Consultation,[47] which find that patient use of and attitudes toward digital health and data sharing are generally changing. Some quantitative benchmarks from these and other consultations are included below.

Canada Health Infoway’s A Healthy Dialogue Consultation[48]

- 90% of Canadians want tech that puts them in greater control of their health
- 92% of Canadians want tech that makes healthcare as convenient as other aspects of their lives
- 84% of Canadians say they would use tech tools to help manage their health
- 86% of Canadians agree that tech can solve many of the issues with our healthcare system
- Concerns about the privacy of personal health information declined during the pandemic
- 90% of Canadians say the pandemic has demonstrated that virtual care tools can be an important alternative

Competition Bureau of Canada’s Digital Health Services Survey[49]

- Only 12% of respondents identified concerns about data security or privacy as a barrier to using digital health services
- 24% of respondents said better security would increase their use of digital health services
- 22% of respondents said better privacy would increase their use of digital health services

Sanofi Canada Healthcare Survey[50]

- 53% of plan members used at least one digital device or mobile app to achieve personal health or fitness goals in the last year, up from 32% in 2015
- 70% of plan members aged 18 to 34 use a device or app, compared with 31% of plan members aged 55 and older
- 62% of plan members would consent to receive personalized health-related information based on their benefits use
- 74% of plan members who are confident their data will be kept confidential would consent to receive personalized health-related information, compared with 38% of those who are not
- 66% of plan members are confident their insurance company will protect their privacy when sending targeted health information
- 71% of plan members are willing to use virtual care tools to receive healthcare services

“A lot of good research has been done on what the public is interested in, and most of the public really does support the use of their data for the public good. So now the question is what would solutions look like?”

Several participants felt that growing public acceptance of digital health tools necessitates new data governance solutions, such as community-based governance models or data trusts. Data trusts involve ongoing and iterative governance by specific communities or the public over datasets in which they have an interest. Their use could overcome silos by permitting data to be brought together and made accessible to different parties with a clear intent behind its use. On this topic, one participant noted that “an enormous amount could be learned from Indigenous data governance and data sovereignty principles.”

Data-Driven Health Tech Procurement

A third theme discussed by participants relates to data-driven health tech procurement. Participants noted that the number of technology-based therapies has increased substantially in recent years and that during the pandemic, governments began covering new therapies at a record rate. For example, Ontario, internet-based cognitive behavioural therapy (CBT) is now covered by the province, with cognitive therapy services being provided by MindBeacon and AbilitiCBT by Morneau Shepell.[51] Some participants were concerned about how quickly governments have adopted technology-based therapies and were unsure whether appropriate oversight or reporting on the effectiveness of these solutions takes place. One participant noted that they were unsure whether appropriate benchmarking data exists because many of these therapies approach treatment in an entirely new way, such as delivering CBT through an app. Further, for some technology-based therapies, “much of the data that does exist comes either in part or in whole out of the companies who produce them.” Emerging from the pandemic, participants saw benchmarking new technology-based therapies as an important priority. This would help ensure governments are spending public money well while encouraging the best outcomes for patients. As recommended in a recent Health Canada report, all treatments “need to be continually evaluated… to ensure they are enhancing patient experience, improving population health, reducing cost, and improving the work life of healthcare providers.”[52]

“My space is mental health, so I'll speak to that effectiveness of digital CBT—the most relevant studies with the biggest datasets are coming from the companies that deliver online CBT… I think we need to find ways of effectively benchmarking these technologies without relying on the data of the companies that produce them.”

“Mass adoption happened almost overnight… and I don’t see evidence that there's a ton of oversight. When we look at this in an audit fashion, a little bit down the road, I think we're going to find very scary things.”

Standardized Data Collection

Finally, participants discussed opportunities to standardize data collection, particularly where the type of data being collected is new to the health sector or difficult to define. For example, the Government of Ontario published a report in August 2021 about the absence of standardized race-based data to inform the province's pandemic response.[53] Many provinces lack a systematic, region-wide approach to collecting socio-demographic data and, during the pandemic, were forced to rely on neighbourhood-level demographic data from other available sources. According to the Government of Ontario report, "experts in health equity in Ontario and Canada have long called for broadening the collection of socio-demographic data at the individual level, beyond age, sex, and postal code, to include language, race, ethnicity, and income."[54] Socio-demographic data would help researchers and the healthcare sector identify poorly served populations and other health inequities: for instance, jurisdictions that *did* collect socio-demographic data prior to or early on during the pandemic were able to identify a higher burden of illness and death among racial and ethnic minority groups.[55] Roundtable participants unanimously supported the continued collection of demographic data to support such research:

"Race has come up in so many social issues throughout the pandemic, emphasizing why collecting race-based data would be important… so, I'm hopeful that this is a permanent decision."

"I don't know how it will measure up or how long it will take, but I hope [race-based data] continues to be a priority moving forward. The challenge is finding mechanisms to easily collect that data."

"I think we need to see a lot more of that kind of social determinants of health insight in healthcare.... The proof is there that we need to be collecting that kind of data, but from my experience, at least, that data is still quite hard to integrate effectively."

The Expert Advisory Group on the Pan-Canadian Health Data Strategy included socio-demographic data in its vision for Canada's health data future. Specifically, the advisory group envisioned the adoption of a broader view of health data, inclusive of socio-demographic factors.[56] Statistics Canada, too, has identified intersectional research as a key priority under its multi-year plan: according to the plan, the agency's Analytical Studies and Modelling Branch will examine intersectional issues and the influence of socio-demographic characteristics on health.[57] In addition to a series of Census-to-

Vital Statistics linked datasets, new General Social Survey data on social identity, the Labour Force survey, and linked administrative data will make it possible to examine health inequities among Indigenous Peoples, visible minorities, and immigrants.

One of the challenges with socio-demographic data is that individual data sources can be difficult or impossible to aggregate if they employ different definitions or approaches to data collection. In May 2020, in response to urgent demand for socio-demographic data, the Canadian Institute for Health Information released an interim pan-Canadian standard for the collection of race-based and Indigenous identity data in health systems.[58] A follow-up standard was proposed in July but has not yet been adopted.[59]

Conclusion

The past few years have brought transformative change to Canada's smart health and wellbeing ecosystem, accelerated by the onset of COVID-19. While care gaps and digital divides remain, tech adoption increased for both rural and urban communities and for both older and younger patients, particularly in the use of telehealth services. Technology-based therapies also saw significant growth during the pandemic. These increases in virtual technologies and access to comprehensive information about traditional healthcare providers—including online reviews, convenience, competitive wait times, or pricing—have resulted in a patient-as-consumer system where patients demand more convenient, modern services. Changes to outdated government billing codes and coverage norms facilitated these upticks in tech adoption and created the conditions for rapid innovation.

To maintain momentum, it is imperative that policymakers and industry continue to work together and create a more inclusive ecosystem. Increased range and quality of internet infrastructure and targeted funding and other supports to facilitate community co-design for businesses, along with expanded practitioner training and education curriculum will help ensure community health and wellbeing needs are met for rural and remote communities. For Canada's seniors, key actions include developing community programs that support digital skill development, tech literacy, and industry-driven age-friendly designs. Finally, it is essential that rising quantities of data do not result in fragmented or siloed data, which could restrict health research, treatments, administration, and decision-making. Instead, new approaches to health data governance and higher levels of data standardization are needed. Canada is on the right track, but more change is needed to ensure a healthy future for the country's smart data and wellbeing ecosystem.

ICTC's fifth roundtable in a series of six Smart City Policy Roundtables took place in October 2021. Thought leaders from across Canada were engaged on the topic of Smart Health and Wellbeing to produce this brief. The next and final of ICTC's Smart City Policy Roundtable will take place in early 2022, focusing on the theme of Smart Regulation.

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The Information and Communications Technology Council is a not-for-profit, national centre of expertise for strengthening Canada's digital advantage in a global economy. Through trusted research, practical policy advice, and creative capacity-building programs, ICTC fosters globally competitive Canadian industries enabled by innovative and diverse digital talent. In partnership with an expansive network of industry leaders, academic partners, and policy makers from across Canada, ICTC has empowered a robust and inclusive digital economy for over 25 years.

About the Smart Cities project

ICTC is leading a multi-year national research initiative on smart cities. Under this project, ICTC investigates the development of smart cities across Canada and internationally, with the ultimate goal of understanding the labour, technology and societal needs and opportunities of Canada's future communities. To guide and shape this research, ICTC has chosen the following areas of focus: Smart Infrastructure, Smart Mobility, Smart Energy & Environment, Smart Health & Wellbeing, Smart Government, and Smart Regulation. During the course of this study, ICTC is hosting policy roundtables on each of these pillars. The first roundtable was on Smart Infrastructure and took place in November 2019. These roundtables engage a variety of stakeholders across Canada to uncover specific policy needs and put forward recommendations that can support a smart future for our cities.