The Digitally Empowered Patient

A Digital Health Canada Community of Action Report

May 2020

Digital Health CANADA

Acknowledgments

The Digitally Empowered Patient Community of Action Working Group


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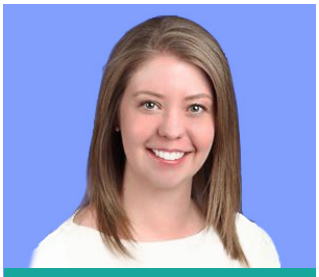
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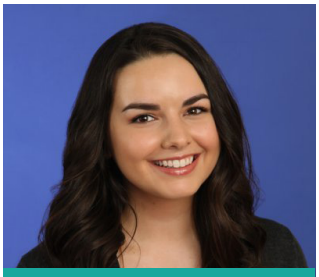
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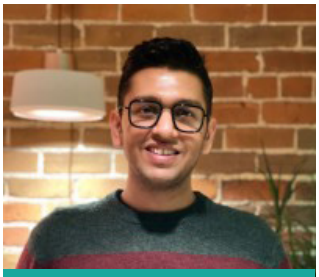
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Executive Summary

A digitally empowered patient uses technology to take an active role in effectively managing and advocating for their health and care. While the healthcare sector has yet to fully adapt to the digital world, patients' desire for access to digital health information and services is palpable. To this end, the Digitally Empowered Patient Community of Action was created to meet the following objectives:

- Identify programs and approaches that are breaking through the barriers to change
- Incent change by providing actionable advice for patients, providers, and all other stakeholders

We engaged patients, healthcare providers, system leaders and vendors across Canada to gain a diverse perspective on the barriers to widespread access and adoption of digital health tools and services. We supplemented these interviews with a literature and marketplace review, a conference presentation, and a web-based survey.

Our findings have been summarized into five themes:

1. **Awareness and use of digital health services:** Awareness leads to adoption for both patients and providers. With only 48% of respondents indicating they are familiar with available digital health tools, more targeted efforts are needed to promote these solutions.

2. **Streamlined access to digital health tools:** Lab results and appointment bookings are the most frequent uses of digital health tools. Yet data silos continue to hold back innovative new solutions. Improved integrations between digital health solutions are needed to drive equitable and streamlined access to patient health information.

3. **Contextualization of health data:** The fear of providing uncontextualized health information to patients is not justified. 54% of patients want immediate access to all their health data without exception. Providers should give patients their data and let them decide how to experience it.

4. **Privacy and security:** Canada is in the midst of a cultural shift in attitudes toward data sharing. As privacy legislation evolves, patients need more information and education about how data is used and safeguarded.

5. **Driving adoption of digital health tools:** A token patient representative will not drive adoption of digital health tools. In order for patients to be empowered in the management of their own health, all stakeholders must be held accountable for embedding the patient experience in every facet of digital health services.

Patients, clinicians, administrators, vendors, and governments all share accountability in creating a critical mass of Digitally Empowered Patients. We must move forward today to collectively demand and inspire systemic change.

Introduction

Access to digital health information will give patients and their advocates the **ability to proactively manage** their own health, wellbeing, and care. In today's digitally-enabled world, we have **access to tools and services** that help manage some of our most **valuable assets**; when these tools and services are effective, it can **change lives for the better**.

While the healthcare sector has historically taken longer than other industries to adapt to the digital world, **patients' desire for access** to their digital health information **is both real and palpable**. Patients are asking for their data: they want it in a digestible format and in a timely manner, so that they may be enabled and empowered to care for themselves and their loved ones.

Digital tools and services can, through proactive health management, **help address patient concerns such as limited access to healthcare and lack of coordinated care**, while also reducing the need for reactive access. When access is available, **digital technologies dramatically alter the manner in which patients can manage their care for the better**. Thus, hospitals, governments, and provider organizations have an **obligation to step up** and provide patients with digital health information. In today's environment, and with the current reality of COVID-19, digital health tools such as **virtual care solutions and remote monitoring can help to proactively keep** the Canadian population safe and healthy.

There are still significant barriers to patients accessing their data, knowledge, and digital health information but there are also organizations making significant strides to break down those barriers. This document will explore the five main themes discovered and will share tools to dissolve these barriers.

The Digital Empowered Patient Community of Action

The Digitally Empowered Patient Community of Action was created to identify opportunities that **enable better access** to digital health information, tools, and services, particularly for **"high frequency" system users**, such as individuals with chronic diseases. We adopted a **future-focused approach** to identify where our system currently is at in terms of **access**, the **challenges associated** with widespread access and adoption, and the **means to overcome these challenges**, in order to improve access. We engaged with patients, healthcare providers, system leaders, and vendors to gain a well-rounded perspective on these issues, and as a result **gained perspective on many innovative programs and approaches** that are breaking through the barriers to usher change, and improve lives.

We have summarized these findings within this report, and provided **practical, tactical, and actionable advice** for patients and providers on methods to move the dial in terms of improving digital access to health information. We hope this report serves as a **catalyst for change**, and help spread **innovative concepts** to anyone seeking to improve access to digital health information for patients.

> "Patients change the conversation when they're in the room and can drive the conversation and shape the future of healthcare."
>
> — SHELAGH MALONEY, CANADA HEALTH INFOWAY

Our advice to everyone reading this report is to **just move forward.**

Patients and family members – you have the power to inspire change when you use your voice. Solutions will begin to arise as you demand them - they already have. Solutions will continue to develop and become more user friendly as you provide feedback. You are the owner of your information – you should feel empowered to ask for what is yours, and demand change so that your needs can be better served. We sincerely hope you find this report inspiring and helpful in terms of what you can do to move towards complete access to what is yours - your digital healthcare information.

Healthcare providers, administrators, and vendors – we are aware that there are many challenges accessing digital health information that require systemic changes, including securing funding, changing regulation, and addressing privacy and security challenges. However, what is in your control is the ability to embed a culture of patient-driven change to lay a successful foundation. It is your role as leaders in this healthcare system to challenge the status quo, and push the boundaries. Set your organization up - from its roots to the executive boardrooms - to facilitate meaningful opportunities for patients to drive change. Engage with the critical mass of patients demanding access. Give them the confidence to manage their own care. Let patients know they can ask for their information, and let them know HOW to ask for it. We know that while there are still technological and policy barriers, there are also organizations making great strides to overcome them - and we encourage you to join the change-makers at this pivotal point in time.

Before we get started...

Throughout this report, we will reference a few terms to ground this conversation. Given that these terms are often employed in different contexts, we want to provide a few clarifying definitions.

Canada Health Infoway defines **digital health** as "the use of information technology/electronic communication tools, services and processes to deliver health care services or to facilitate better health."[1]

Within the Community of Action, we have developed the following definition for **the digitally empowered patient**: A Digitally Empowered Patient (or advocate for that patient) uses technology to take an active role in effectively managing and advocating for their health and care. This patient has access to an ecosystem of digital tools that provide timely access to actionable information to enable self-care, as well as connect to their care team and appropriate services.

[1] What is digital health. (n.d.). Digital Health in Canada | Canada Health Infoway. https://www.infoway-inforoute.ca/en/what-we-do/benefits-of-digital-health/what-is-digital-health

How we did it

United by our interest in patient advocacy, our pan-Canadian Community of Action membership contained representation from across the healthcare landscape, including patients, healthcare consultants, health informatics researchers, healthcare administrators, and healthcare students.

Our methods included:

- A literature and marketplace review: we conducted a scan of provincial, Canadian, and international leading practices and innovations which enable broader digital health access;
- Conference presentations: we attended various conferences specifically aimed at soliciting feedback, insights, opinions and knowledge from the audiences in attendance;
- Development and deployment of a web-based survey: to understand the current state of awareness and access to digital health tools and services, we surveyed perspectives on the current state of digital health access to explore how to improve digital health innovation within Canada, and;
- Key informant interviews (including patients, healthcare providers, researchers, government agency employees, and healthcare administrators): we gathered perspectives and insights on current state barriers and future state recommendations for making the digitally empowered patient a reality in Canada.

Our survey participants (**232** participants in total), included patients, family members/caregivers, public and private industry employees, hospital administrators, government agency employees, and researchers. Respondents to our survey ranged in age from **20 to 85**, with the mean age being **45.2** years.

232
survey participants

20-85
age range

45.2
mean age

Our survey was distributed through our pan-Canadian networks, and we received responses from coast-to-coast. A majority of responses **(>87%)** were from Ontario. We found that **64%** of patients and family members we spoke to were either living with a chronic illness or caring for someone who does (n=155), thus it is evident that chronic illnesses are common, and the need for delivering complex care is higher than ever.

A full overview of our methods can be found in Appendix A.

A breakdown of the survey respondents is available in Appendix B and Appendix C.

In consolidating both the responses received from our survey and key informant interviews with findings from our jurisdictional scan, a number of themes emerged as major drivers of digital empowerment:

THEME 1
Awareness and use of digital health services

THEME 2
Streamlined access to digital health services

THEME 3
Contextualization of digital health data

THEME 4
Privacy and security

THEME 5
Driving adoption of digital health tools

THEME 1

Awareness and use of digital health services

Despite the number of services available, patients (and providers) may not know about them. If they do, it can be overwhelming and confusing to determine which tools and services they should use to help manage their care

There must be awareness of the available digital health tools and services in order for a patient to become digitally empowered. With thousands of digital health services available across Canada, there is no shortage of options: **90+** patient portals exist in Ontario alone, along with a wide array of virtual clinics, e-referral services, and mobile apps. Emerging innovations are also continuing to be developed that harness digital concepts such as artificial intelligence, remote monitoring, and advanced analytics.

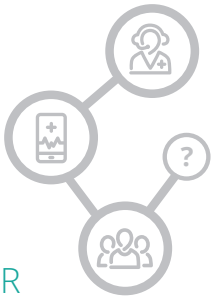
Even among individuals who are aware of these services or have tools and services in mind which they would like to use, there are barriers to meaningful access. Lack of public funding, poor usability, and/or a lack of integration limit the patient's ability to access their own digital health information. Addressing these challenges is a critical step towards enabling the Digitally Empowered Patient.

Patients, family members, and caregivers reported variable familiarity with digital health tools and services (including virtual care, mobile apps, and personal digital health records)

Patients and family members reported that a lack of awareness concerning the various digital health services, along with confusion about choosing a service among the many available options, limits their confidence in using these services to digitally manage their health. **48%** indicated they are familiar with the digital health tools and services, and **38%** indicated they were unfamiliar.

48%
FAMILIAR

38%
UNFAMILIAR



Key Takeaway: Adoption follows awareness. Patients and providers need to work together to understand which offerings are best suited to their personal health management, both through understanding their provider's current suite of offerings (if any) and knowing what additional services they might employ to augment their care.

While there are pockets of innovative tools and services across Canada, it's clear that more targeted efforts are needed to promote these solutions in order to scale them up to a larger audience - to providers as well as directly to patients. App developers and vendors should work closely with healthcare organizations and providers to provide applications that are meaningful and educate patients about the available services. Barriers limiting access and adoption - including funding and integration - must be removed with the ultimate goal of improving patient outcomes.

THEME 2

Streamlined access to digital health services

Create equitable and streamlined access to digital health tools and services

Awareness of, and access to, digital health services are intertwined. Irrespective of social status or health literacy level, patients should have access to high-quality, coordinated care; burgeoning structures such as the Ontario Health Team model demonstrate that this is a system priority as well. Digital health services can enable a broader reach for populations that are difficult to access, such as underserved populations and those that are rural/remote. Access to digital health tools and services has been a topic of interest for many governments: for example, Ontario's Digital First for Health Strategy specifically focuses on providing expanded access to services such as appointment booking and virtual care.

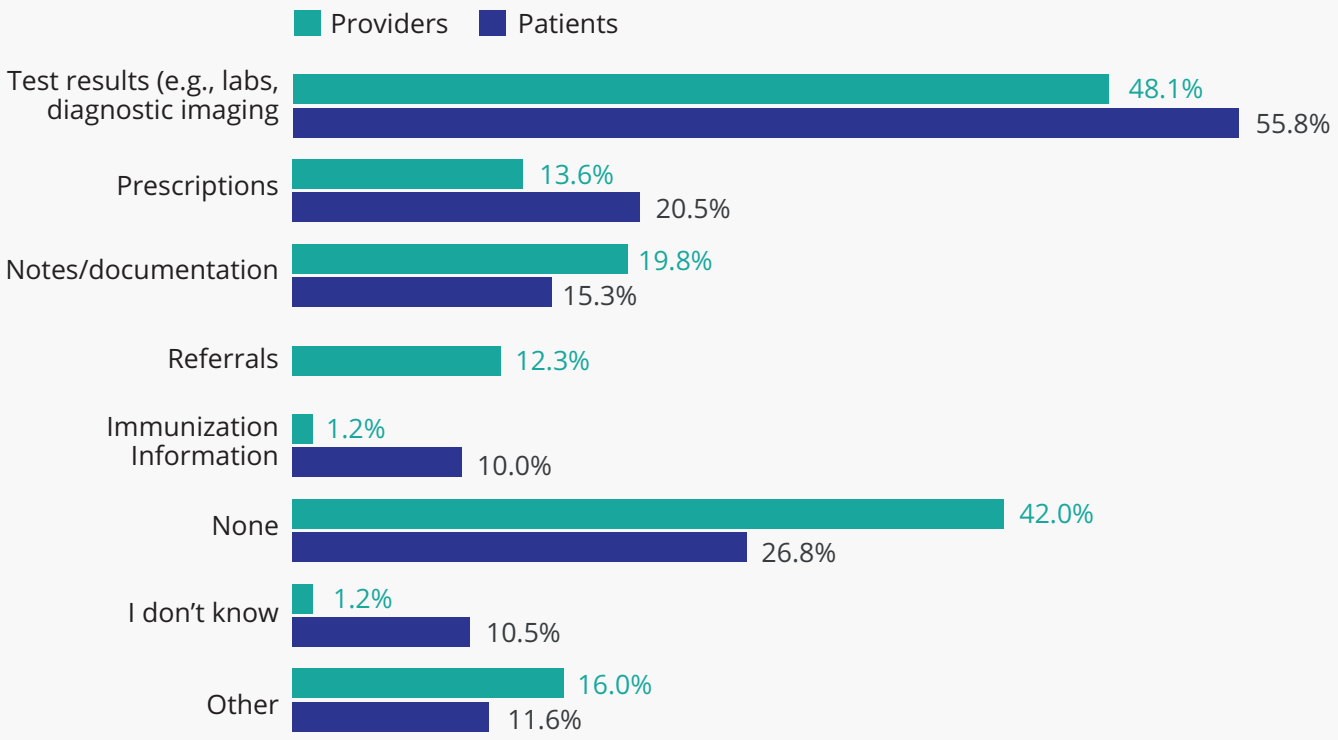
Of the patients and family members surveyed, **65%** use some form of digital health technology. Mobile apps (e.g. Apple Health or Samsung Health) and wearables (e.g. FitBit) were most commonly cited, along with digital health services that allow patients and family members to access their own electronic personal health records (using Web-based portals and systems such as MyHealth Record, MyChart, and DotHealth).

Patients and providers both report that lab results are the most accessed digital form of personal data

The majority of patients, family members, and caregivers reported accessing at least some personal data online, whether this data is available as a stand-alone output (e.g. lab results), or as an input within a service (e.g. electronic health record or app). When we asked providers what digital health services they offer, **58%** of providers shared that they offer some form of digital health information to patients. Lab results led the way in terms of digital access, with **48%** of providers reporting that they provide digital access to lab results.

> "We need to recognize that some patients will not be able to use [Digital Health] tools to access information. We don't want to miss out on that equity lens. We do have to be mindful of supporting people who wouldn't be able to use or adopt these tools, who don't have digital literacy yet as well."
>
> — LAURA WILLIAMS, UNIVERSITY HEALTH NETWORK

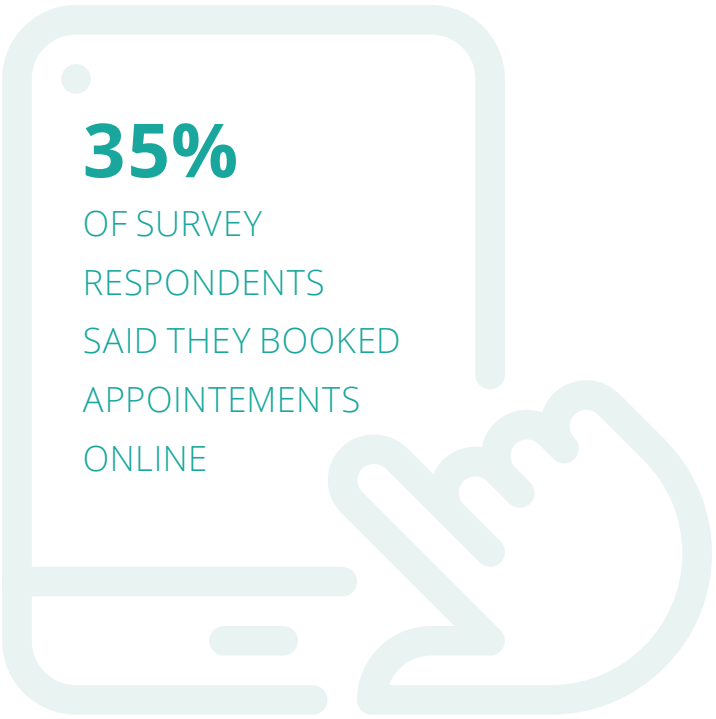
We asked patients, family members, and providers/enablers of services, do you currently **access/offer access to** any of the following digital health information?



Sample size: 190 patients, 85 providers

Online appointment booking is the most frequently used digital health service of the available options

Over half of the patients we surveyed did not currently access any of their health services online, and those who did shared that it was mostly to book appointments **(35%)**. Provider responses indicated that more digital health service options may be available than patients realize; however, given that some digital services are provider-facing, some gaps between patient and provider access are to be expected. For example, **24%** of providers offered virtual visits (versus **8%** of patients who reported accessing them), and **20%** of providers offered digital referrals (versus **5%** accessed by patients).



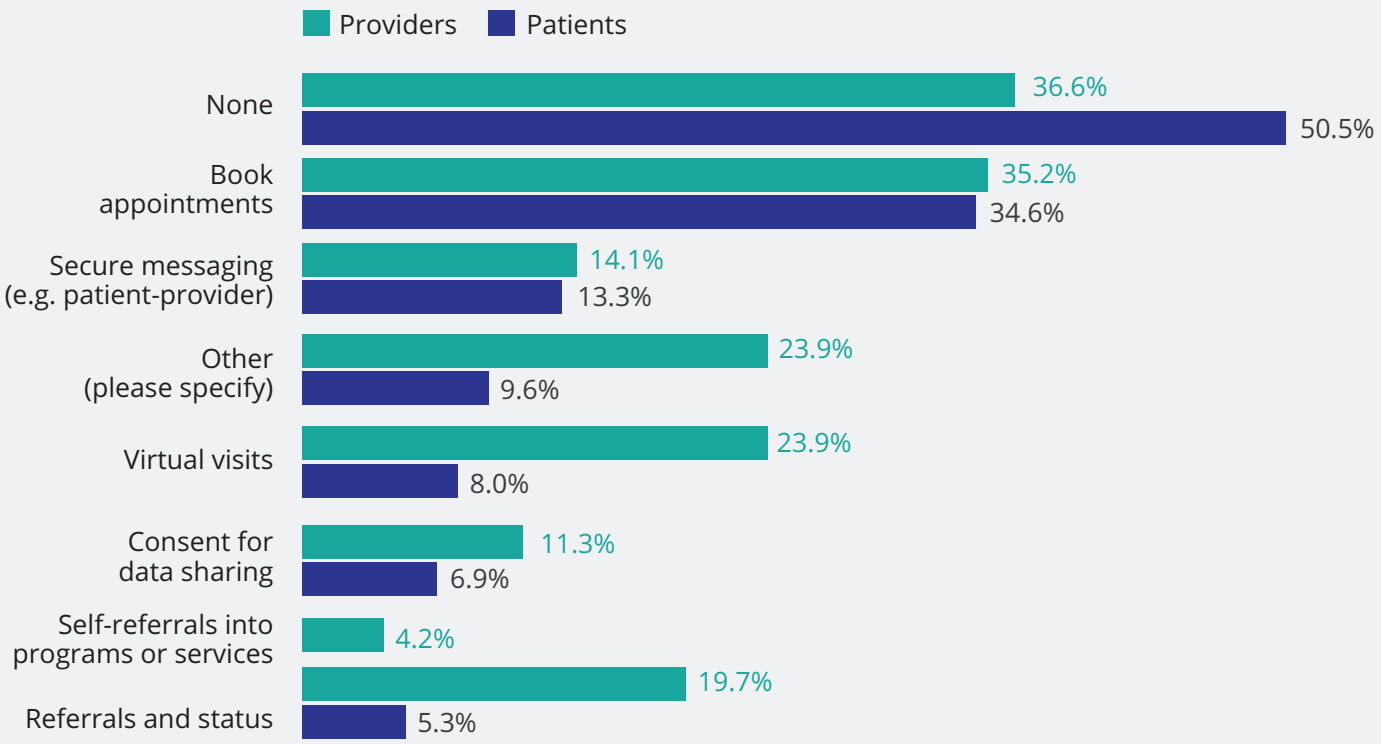
35%

OF SURVEY RESPONDENTS SAID THEY BOOKED APPOINTEMENTS ONLINE

"By not making it [healthcare data] available, we hold back opportunities in terms of healthcare and innovations. Making data available dramatically reduces silos so that information can be passed along between providers. More access means fewer barriers."

— RYAN DOHERTY, IAMSICK.CA

We asked patients, family members, and providers/enablers of services, do you currently **use/offer** any of the following digital services?



Sample size: 188 patients, 44 providers

Integration can be a barrier to access

About two-thirds of healthcare providers reported concern about the lack of data integration in digital health services within existing hospital and healthcare organization-wide information systems.

Even with these technological barriers, provincial governments and organizations like University Health Network (UHN) are driving innovative change through improved access and cultural shifts towards actively focusing on providing patients with the information that they want (e.g. real-time data). For example, as soon as lab results are made available by the community or public health lab, they are made available in the Ontario Laboratory Information System (OLIS), enabling patients to have real-time, secure access to lab results. UHN's program SPARK leverages this real-time information to create a patient-facing ecosystem which connects innovative digital health technologies to data from provincial digital health assets, including labs, immunization, and drugs.

Consumer data is not yet viewed as part of a patient's digital health record

57% of patients feel that their healthcare providers may not be willing and/or able to use their health data from digital health apps; however, **52%** of providers felt the same way about patients and their family members possibly not being willing and/or able to use the data available through digital health services. To address this, companies like Apple are exploring ways to encourage and promote the usability of consumer data (e.g. through making data medical grade) within a patient's digital health record.

> "We need a framework through which patients have the ability to make actionable decisions and choices. Patient empowerment is not just about the data, but how they access and utilize the data."
>
> — RYAN DOHERTY, IAMSICK.CA

Key Takeaway: Beyond ensuring that patients have access to digital health services, these services must also be useful to both patients and providers, through ensuring clinical value and utility. They need to be integrated with other sources of patient information, and with the overall healthcare system. Such tools will be adopted to the extent that they help patients with their healthcare issues, and when access to them is both streamlined and easy to use. Making access to digital health services equitable is essential, so that it is available to as much of the population as possible (rather than just privileged parts of the population). This will require understanding the information requirements of different types of users, and an understanding of where they are in their health care journey.

THEME 3

Contextualization of digital health data

Patients want their data whether it is contextualized or not

Contextualization of digital health data means that a patient is provided with access to their data, along with supplemental information which may help them to interpret their data with confidence. By improving patients' health literacy and understanding of their health, contextualizing health data becomes an important method for empowering patients to self-manage and make informed decisions about their own care.

While contextualization can provide useful insight into how information is relevant to a patient, the desire to provide context has historically been a barrier to providing patients with access to their medical records. Our survey results clearly indicated that access to personal health information, regardless of context, is a key priority for patients. Patients want their data and would rather have it sooner than wait for context to be provided. Organizations such as UHN have heard the same sentiment from patients in their extensive patient engagement strategy. These findings influenced a change in the hearts and minds of leadership and clinicians, who may have previously worried about providing data without context.

In our survey, **54%** of patients indicated they wanted access to all of their health information without exceptions. Many providers felt that context was important, but results were mixed: **44%** of surveyed providers felt that only contextualized information should be shared with patients, while **33%** shared that all results should be provided, regardless of context.

"Instead of us deciding it needs to be contextualized, let's let the client decide what the experience needs to be."

— ZAYNA KHAYAT,
SE HEALTH

54%

OF PATIENTS INDICATED THEY WANTED ACCESS TO ALL OF THEIR HEALTH INFORMATION WITHOUT EXCEPTIONS

With similar results, Canada Health Infoway's Digital Health Myth series found that **76%** of patients who first saw their lab results online were confident that they understood the results and were no more anxious than those who waited to gain context about their results in person[2]. These results are further evidenced by systematic reviews that found the most prevalent positive impact of sharing information with patients, regardless of context, is improved patient-provider communication[3].

It is clear that the conversation about context needs to follow patients' primary goal of having digital access to their data, contextualized or not. Some would argue that having this access is a right: a report by the Virtual Care Task Force, composed of members from the Canadian Medical Association, Royal College of Physicians and Surgeons of Canada, and the College of Family Physicians of Canada, suggests the development of a national charter of patient information rights and responsibilities, along with national standards for information access[4].

> "I'm not aware of any case that has led to an adverse outcome when a patient received non-contextualized information. I'm not sure this fear is justified."
>
> — DR. MOHAMED ALARAKHIA, EHEALTH CENTRE OF EXCELLENCE

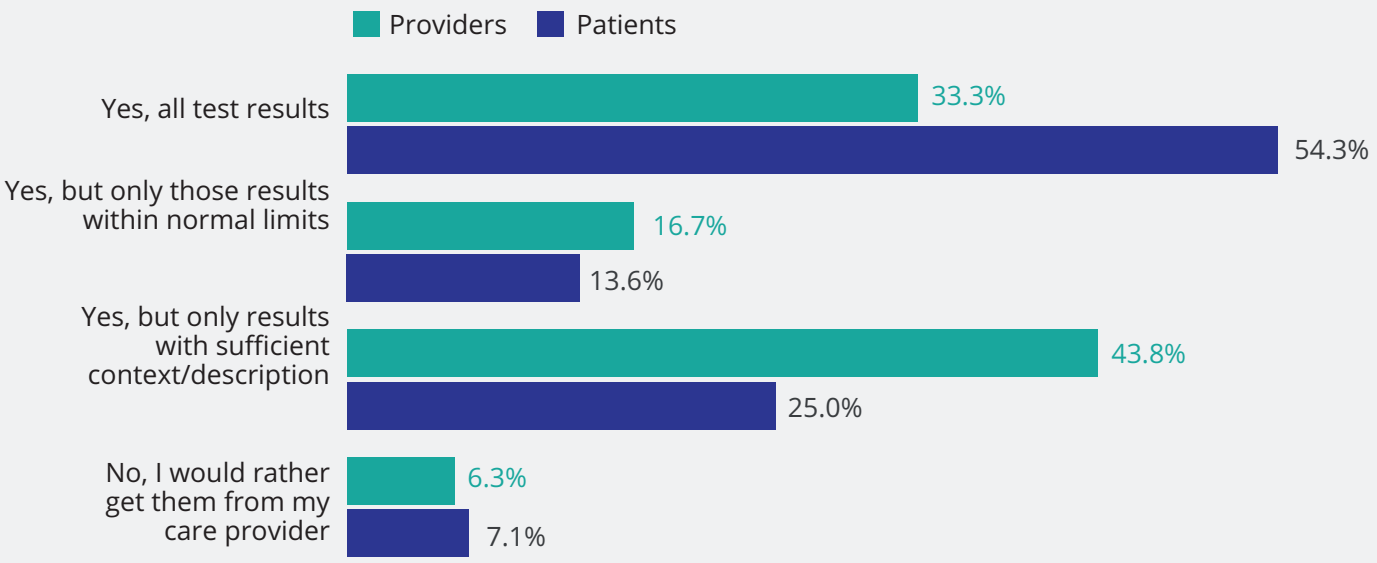
Key Takeaway: The fear of the unknown has been disproved as a factor in the debate over withholding data until it can be contextualized. Patients own their data; we should give it to them. Context matters, but not as much as providing immediate access to digital health information; everything else will follow.

[2] Nancy Marchioro Admin. (n.d.). Digital health myths. Digital Health in Canada | Canada Health Infoway. https://www.infoway-inforoute.ca/en/myths

[3] Patient and provider attitudes toward the use of patient portals for the management of chronic disease: A systematic review. (n.d.). PubMed Central (PMC). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4376181/

[4] Report of the virtual care taskforce. (n.d.). Canadian Medical Association. https://www.cma.ca/sites/default/files/pdf/virtual-care/ReportoftheVirtualCareTaskForce.pdf

We asked patients, family members, and providers/enablers of services, would you prefer to access/are you comfortable with them **accessing all test results online** regardless of severity or impact?



Sample size: 184 patients, 48 providers

THEME 4

Privacy and security

Provincial privacy and security regulations were written for healthcare custodians, not for patients managing their care using digital health tools and services

Established in 2004, Ontario's Personal Health Information Protection Act (PHIPA) is an example of a provincial privacy and security legislation[5]. The digitization of our lives and the active role that patients now play in their own care has resulted in current legislation and regulation being misaligned with the way patients interact with the healthcare system. Patients deserve unfettered and complete access to their digital health information, and legislation should be revised to support this.

Ontario is one of several provinces addressing this by amending PHIPA. Through the Digital First for Health Strategy, the province is planning to modernize the integration, access, use, and disclosure of personal health information in order to ensure broader access. There must be an open dialogue about how to strike a balance between the ability to share data, and the need to protect patient privacy. In doing so, preconceived notions about how patients think about healthcare data privacy need to be challenged.

From a privacy perspective, the top three patient concerns are identity theft, discrimination, and loss of employment opportunities

These concerns highlight the need to incorporate privacy as a key design element for services and systems. Users of these services should be made aware of who can see their data and how it can be leveraged by embedding iterative and "user-friendly" terms and conditions that enable patients to give informed consent to their data being shared.

Discrimination and employment concerns were further validated through patients expressing apprehension in sharing data with their employer **(83% disagreed or strongly disagreed)**, and insurance agencies **(58%).**

[5] Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A English View (March 25, 2020). Government of Ontario. https://www.ontario.ca/laws/statute/04p03

An understanding of how privacy legislation is changing to protect digital health data needs to be more broadly communicated

Though the majority of participants reported some level of awareness about privacy legislation, ensuring broader awareness is important. How patient data is protected and accessed needs to be communicated plainly by providers, vendors and organizations developing digital tools and services, and government agencies developing privacy legislation.

Respondents were asked whether they felt that existing legislation was a barrier or enabler to the deployment and adoption of digital tools. Results were divided: **38%** felt that current privacy laws are a barrier, and **44%** considered it to be neither a barrier nor an enabler. While privacy legislation revisions are being made to broaden access to personal health data, these survey responses underscore that policy change without a mindset change could result in a continuation of the status quo.

> "Privacy works for health information custodians—new frameworks have to be built [for patients}.
>
> — SHIRAN ISAACKSZ, UNIVERSITY HEALTH NETWORK (UHN)

Key Takeaway: Broader education about how patient data is used, and the policies in place to safeguard information, need to be shared by providers, organizations, vendors, and the system at-large, particularly as regulations like PHIPA are updated.

Canada is in the midst of a culture shift. Current boundaries around digital access to Personal Health Information (PHI) are changing, with the adoption of services like eReferral, eConsult, and virtual care. We are also seeing a shift in vendor responsiveness in terms of bilateral data sharing between vendors and providers. But the conversation is just starting. To accelerate the rate of change, patients need to vocalize their need for their health data to better manage care.

THEME 5

Driving adoption of digital health tools

As patients and providers look to technology to support the management of patient care, it is critical that both are empowered with tools and services to support patients' care goals

Tools available to patients need to be functional and practical. For example, an expensive app that can't be integrated with personal health records lacks both practicality and function. Finding ways to drive patient and provider adoption of tools ensures that these services and tools meet their needs and support the delivery of better care.

The most straightforward way to ensure adoption of digital tools and services by patients is to ask them what they want. While digital tools are developed for patients, they are much less often developed with patients, and this can lead to a disconnect between the digital tool's intended use and its real-life application and adoption.

In our survey, we asked patients and their family members how they might envision being engaged in the development of digital health innovations. Many respondents shared that they wanted to provide input on user-friendly design, such as having a consolidated, visual dashboard of their data, access to real-time results, and the ability to seamlessly integrate data from their wearables (such as their daily steps) into the tool/service. Having patients as key contributors to development of a tool or service ensures that the design works for the patient and provides an experience that enhances their care journey.

Create a culture of accountability when it comes to embedding the patient experience

Involving patients, family members, and caregivers changes the conversation because they provide a very different perspective on the healthcare system. Currently, many organizations involve patients on an ad-hoc basis, as opposed to truly embedding the patient voice in the culture of the organization. To further drive a culture of accountability, healthcare organizations should develop strategies which embed diverse patient experiences. Through incorporating patients in foundational structures, organizations can ensure that relevant strategies and projects will provide real benefits to patients.

Providers too need to be engaged through this process. To keep leaders and organizations accountable, a culture of accountability needs to be created. Organizations are starting to make strides to hold leaders accountable for driving patient engagement and partnership through expected Key Performance Indicators and documented strategic plans. Leaders need to be coached to create a culture of accountability that will filter through entire organizations.

Rather than engaging patients in specific initiatives, such as to drive adoption of digital tools and services, organizations should look to embed the patient voice throughout their work. Medical schools in Ontario, such as the University of Toronto and University of Ottawa, are introducing a curriculum on patient partnership and patient engagement. This engagement is based on a model from the University of Montreal that creates opportunities for physicians to learn about patient engagement and partnership, with the aim of fostering leadership and cultural change. Similarly, The Canadian Foundation for Healthcare Improvement (CFHI) has a long-standing executive leadership training program called EXTRA. The six-module EXTRA Training Program curriculum is currently being revised to embed patient engagement and patient partnership, including how to bring patient-generated information back into organizations (to drive adoption of digital tools and services), practical ways of doing this well, and driving and supporting cultural change.

> "The one thing that every leader agrees with is - none of this will happen until patients are activated and engaged in their own health."
>
> — ZAYNA KHAYAT, SE HEALTH

Key Takeaway: Adoption of digital health tools requires an iterative engagement strategy, ensuring participation, feedback, and support for both patients and providers every step of the way. Through addressing barriers to adoption, like embedding a culture of patient partnership, these digital tools and services can serve their intended purpose.

Call to Action

All stakeholders have a role in supporting the Digitally Empowered Patient.

From mobile apps to artificial intelligence, digital health tools and services of all types can improve access and quality of care, resulting in healthier, more informed, and more engaged patients and populations. In support of this, a number of themes emerged from our research which point towards areas for action to produce digitally empowered patients at the system, individual and practice level.

Take the necessary steps to demand or provide access to digital health information.

There is shared accountability to thoughtfully and meaningfully engage patients and healthcare providers to drive adoption. Patients, clinicians, government, and industry professionals need to work together to act as catalysts and motivators for change.

Patients: Ask for what you want, as loudly as you can, in as many places as you can. As momentum builds, change will follow. Adoption will take place when the tools and services are easy to access and use, and the information they provide is easy to understand, relevant, and cost-efficient.

Clinicians and Organizations: Create a patient-driven culture in your organization. If you're not doing it now, here is your opportunity to make it happen. When patients are invited to participate in the foundational decision-making structures of healthcare organizations, tools and services become easier to use and access. The patient voice will be embedded into the culture when leadership is held accountable for making this happen. At minimum, adoption requires leadership support and resources to gain and sustain momentum.

Vendors: Listen to what patients and providers are asking for. Action it. Co-design patient-driven solutions. Patients are very interested in co-design, and they are the best resource to ensure that the solutions in development serve their intended purpose. Partner with them in this process and engage with them regularly.

Federal and Provincial Governments: Design and support systems that better enable patient-driven care. Patients, providers, and healthcare organizations need to be supported in their push for change. Through disseminating "digital-first" strategies and legislation to support the availability and access to digital tools and services, and through promoting coordinated and digitally-driven care delivery models, Canadians will become equipped with the information they need to lead healthier lives.

Improving access is an iterative process, and that not all actions can be completed overnight. **Change takes time, but there is no better time than now to begin. We can all take action today.**

Collectively moving ahead and pushing the boundaries of what's possible in improving access to digital health information and digital service delivery will truly support, and create, **the Digitally Empowered Patient.**

APPENDIX A

Methodology

I. Community of Action composition

United by our interest in patient advocacy, our pan-Canadian Community of Action (CoA) consists of members representing the broad healthcare landscape, who are interested in / have a role in digital health including: patients, private healthcare consultants, health informatics researchers, and healthcare administrators.

Our methods included:

- A literature and marketplace review
- Development and deployment of a questionnaire
- Interviews with key stakeholders

II. Literature & marketplace review

We began our literature review by conducting a jurisdictional scan to identify case studies of innovative approaches to digital health access for patients. This preliminary research was conducted to inform the areas of focus for our survey based on best practices and gaps in design and access, among others. We reviewed 26 case studies across Ontario (n=10), Canada (n=10) and internationally (n=6). Innovations spanned a variety of digital health categories including patient portals, virtual care tools, health literacy tools, self-management apps, wearables, and tools to identity, access and authorize.

Common challenges that were present across jurisdictions included interoperability/integration, privacy and security challenges, accessibility of digital health data, change fatigue, and adoption and scalability. Following this, we conducted a poll as part of an interactive session at Digital Health Canada's Driving the Future of Digital Health Conference (October 2019) to gather what themes and challenges from our literature review resonated with attendees. Information from both of these sources was used to inform emerging themes for our research.

III. Instrument development

1. **Survey:** We developed a comprehensive survey (31 closed and open-ended questions) to gather data on the following five themes: (1) Awareness and use of available digital health services, (2) Streamlined access to digital health services, (3) Contextualization of digital health data, (4) Privacy and security, and (5) Driving adoption of digital health tools. Questions were workshopped with the entire CoA, following which we re-tested the survey with colleagues and our networks (n= 10) to get further feedback.
2. **a. Key informant interview guide:** This guide was developed through diving deeper into the survey questions, discussion in our CoA on other important themes to cover, and findings from the literature and jurisdictional scans.

   b. Key informant list: A list of those individuals who have worked within the Canadian digital health space was developed. This list was developed in consultation with colleagues and members of our CoA, as well as by reviewing important publications.

IV. Data collection

Ontario Nursing Informatics Group (ONIG)

Presentation: A presentation was delivered to ONIG members in November 2019, where we surveyed a smaller group of clinicians and/or patients with a more concise version of our survey (see Appendix).

Survey: The electronic survey was distributed via Digital Health Canada mailing list, social media (Facebook, Linked In, Twitter), and patient advocacy mailing lists.

Key informant interviews: 10 interviews were conducted between November 2019 - January 2020. Due to time and budget constraints, detailed transcripts were not produced. A minimum of one notetaker and one interviewer were present at all interviews.

IV. Data Analysis

Survey: Responses to three questions from the ONIG presentation were integrated into the larger survey. Descriptive analysis for all survey questions were carried out.

Key Informant interviews: Thematic analysis was carried out for all interview notes.

APPENDIX B

The Digitally Empowered Patient: Survey and Sample Size

Section 1: Demographics

1.	What kind of stakeholder are you?	217
2.	What is your age? (0-100)	217
3.	What province/territory/state are you from?	217
4.	Do you or someone you care for have a chronic condition?	155

Section 2: Awareness of available digital health services

5.	As a patient/ family member/ caregiver, do you currently have access to any of your digital health information?	190
6.	As a patient/ family member/ caregiver, do you currently use any of the following digital services?	188
7.	If you are a provider or enabler of any type of health services, do you currently offer digital services?	44
8.	As an owner or custodian of health information, do you currently provide patients with digital access to their health information?	85
9.	As a patient/ family member/ caregiver, I am familiar with the variety of digital health interventions available to me (including virtual health, mobile apps, access to EHR)	191

Section 3: Streamlined access to digital health services

10.	As a patient/ family member/ caregiver, I currently use mobile apps, wearable health and fitness devices, and/or online services to track or treat my health.	188
11.	Please list the mobile apps, wearable health and fitness devices, or services you use.	120
12.	Were any of them recommended to you by your healthcare provider?	146
13.	As a provider or enabler of any type of health services, I currently recommend mobile apps and/or online services to my patient's for tracking or treating their health.	51
14.	As a patient/ family member/ caregiver, what are the key concerns when it comes to using digital health data?	186
15.	As a provider or enabler of any type of health services, what are the key concerns when it comes to digital health data?	75

Section 4: Automating the contextualization of patient health information

16.	As a patient/ family member/ caregiver, would you prefer to find out all of your test results online without needing to see your provider, regardless of severity or impact?	184
17.	As a provider or enabler of any type of health services, are you comfortable that your patients see all test results regardless of severity and impact?	48
18.	Do you have any thoughts on how information should be personalized or contextualized to your (a patient's) information needs?	69

Section 5: Privacy and security regulations

19.	As a patient/ family member/ caregiver, I am willing to share information from my digital health information (from any source) with each of the following:	176
20.	As a patient/ family member/ caregiver I am asked for consent by institutions and/or health care providers prior to sharing my health data digitally	176
21.	Do you believe privacy legislation such as Personal Health Information Protection Act (PHIPA, i.e. Ontario's legislation) is a barrier or enabler to the deployment/adoption of digital tools?	176
22.	I am aware of the current privacy and security policies and measures that safeguard data. (e.g. PHIPA, secure staff logins, records accessible by care team or designated staff only).	174
23.	Do you worry about any of the following when it comes to privacy/security of the health information you access or input digitally?	176
24.	The following entities should be responsible for making patients aware of how their data is being processed and used (in collaboration with patients).	176

Section 6: Incentivizing providers & patients to adopt digital tools

25.	As a provider or enabler of any type of health services, how do you currently promote innovation in your digital health capabilities that enable patients to either access their health information, promote health literacy, or enable patients to self-manage their care?	62
26.	As a patient/ family member/ caregiver, how do you envision being engaged in digital health innovation?	110
27.	A change to current compensation models for providers is needed in order to promote adoption of digital health tools (e.g. how physicians are paid).	169
28.	Which stakeholder do you believe should be primarily funding efforts to integrate and/or manage data across different digital health systems?	169
29.	Patients who practice healthy behaviours should be financially incentivized (e.g. subsidized wearable devices for patients who meet their activity requirements, subsidized medication for those with high medication adherence).	169
30.	One of the main benefits of digital tools is to empower patients through improved access to information and services. How might we empower those with limited access to leverage these tools (e.g., those with limited access to technology, those who don't speak English, newcomers who are unfamiliar with our health system)?	105
31.	In your perspective, what should be the top priority for incentivizing systemic change to enable digital health solutions that empower patients? Please select one	169

APPENDIX C

The Digitally Empowered Patient: Survey to Ontario Nursing Informatics Group and Sample Size

1.	What kind of stakeholder are you?	37
2.	Do you think that access to your digital health information through various tools would help you better manage your health and care?	-
3.	Do you currently have access to your digital health information or provide patients with digital access to their health information? (multi-select)	17
4.	What percentage of the information that you are able to access digitally would you consider to be provided with context?	-
5.	Do you currently have access to (or offer) digital services for patients? (multi-select)	17
6.	What frustrates you the most about accessing digital health information or digital services? (single select)	-
7.	Do you think that patients have a right to access all of their health information digitally?	-
8.	Should patients have the ability to control how they would like to find out the results for each diagnostic test?	-
9.	What is the top priority that needs to take place now to incent change? (single select)	-

APPENDIX D

The Digitally Empowered Patient: Key Informant Interview Guide

(questions differed depending on the role of the key informant)

1. Can you please tell us some of the major initiatives around digital health at [organization]? Which in your mind is the most successful program and why?
2. What do you think is needed to scale programs across the province? Across the country?
3. From an integration standpoint, what do you think is required to make this all work together?
4. What types of digital health information and services do patients still not have access to? Patient perspective? Clinician perspective?
5. Do patients have enough of a voice?
6. What types of digital health information and services do patients still not have access to?
7. Do you have a roadmap to getting this information in the hands of patients?
8. What types of digital health information and services do patients still not have access to?
9. What barriers are you facing (e.g. funding, integration)?
10. Do you believe there should be limitations in what patients can access in terms of their digital health information?
11. How important do you think it is to have digital health information contextualized for patients? Why?
12. As a provider, what do you think needs to change in the Canadian health ecosystem to better digitally empower patients?
13. How does the Ministry of Health (MOH)'s announcement to expand the commitment for the Digital First for Health Strategy factor into Ontario's strategy and what are some of the key influencing factors?
14. Can you expand on Privacy and Security/PHIPA Modernization?
15. How do you define marginalized populations?
16. We've heard that some providers are hesitant to provide patients health information right as it's collected for fear of patients drawing incorrect conclusions without context. What are some additional complexities that marginalized populations face in this regard?
17. What patient empowerment projects have you worked on or are working on currently that have been successful? What made them successful?
18. As we look ahead to genomic sequencing etc.—grey areas in terms of what results actually mean—does this change his thinking in terms of what patients should have access to?

How do you incent action for more patient involvement/engagement/leadership etc.?
What is tokenism and how to spot it?
How do we do better around this concept of patient engagement?

20. What comes to mind when you hear "digitally empowered patients"?

APPENDIX E

Methodological Limitations

Our survey has the following limitations that the reader should be cognisant of while interpreting results:

- A large majority of respondents (> 87.5%) were based in Ontario. Data should not be generalized as a pan-Canadian perspective, but rather as an Ontario-leaning view of digital patient empowerment.
- For five questions (Q 1, 3, 5, 9), we combined data from two separate surveys, which each had a variation in questions and/or response options. This merging of data posed challenges in data interpretation.
- The survey was distributed in an electronic format and discussed themes around access to digital information and digital services. Having an electronic survey completion medium could pose challenges when trying to gauge responses from those individuals who have limited access to technology or are not well aware of certain types of technology.
- A slight bias may result from two large clinician groups (e.g. Ontario Nursing Informatics Group and Canadian National Informatics Association) being surveyed.
- 22 respondents completed only the demographics section of the survey (i.e. stakeholder type, age), and were excluded from the final analysis.

Digital Health Canada connects, inspires, and educates the digital health professionals creating the future of health in Canada. Our members are a diverse community of accomplished, influential professionals working to make a difference in advancing healthcare through information technology. Digital Health Canada fosters network growth and connection; brings together ideas from multiple segments for incubation and advocacy; supports members through professional development at the individual and organizational level; and advocates for the Canadian digital health industry.

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