Chapter 8
Connected Health and the Digital Patient

Shelagh Maloney and Simon Hagens

Abstract Technology has impacted every aspect of our lives, empowering us with more choice and more information upon which to make decisions. When it comes health care, most citizens want the same thing—they want to be empowered so they can take a more active role in managing their health. They want to understand their conditions and have access to digital tools to help manage their health and be involved in their care decisions.

This is important because the evidence is clear; when citizens are engaged in their health, they have better health outcomes. In Canada, there are many examples of how citizens have affected health policy and how they are using digital tools and services to empower them to play more active roles in their care. Telehomecare, which provides citizens with the ability to monitor their conditions while at home and patient portals, that provide citizens with access to their health information, are just two examples of how technology is changing the landscape of the health system by allowing citizens to become more engaged.

Digital health technology is also changing how clinicians deliver care. While progress has been relatively slower in health than in other industries and while Canada lacks behind other countries in some areas of digital health technology, we are making significant progress. The movement toward citizen-centred care and the digital patient is not without challenges and obstacles. Ensuring that personal health information is kept confidential and secure is a major concern for many. Similarly, we must be mindful of equity issues so that access to digital health and the benefits that accrue are available to all.

As the health professionals that are most accessible to patients, nurses can play a pivotal role in ensuring that they and their patients are equipped with the skills they need to be effective digital players in the health system.

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Connected care · Telemedicine · Patient portals · Privacy

Learning Objectives for the Chapter

1. Understand what is meant by citizen-centric health care and the factors that contributed to its popularity.
2. Become familiar with the benefits of patient participation in their care and provide examples of how technology has empowered the digital patient.
3. Understand the Canadian and international landscape around citizen centred care and Canada's position relative to its international peers.
4. Understand the evolution of digital health technology among clinicians and their perceptions of the benefits.
5. Become familiar with the issues that must be considered as we move toward citizen-centric care and the role of the nurse in this evolution.

8.1 Technology Has Impacted Every Aspect of Our Lives

It is hard to believe just how quickly and pervasively technology has impacted our lives. The way we work, play, shop, learn, communicate—it has all been significantly impacted by technology. The advent of the internet, for example, has led to the democratization of knowledge such that information is readily available to all. Much in the same way the printing press facilitated the spread of information uniformly among the masses in the eighteenth century, the internet has allowed for the availability and dissemination of information to reach unprecedented levels. Today, the availability of online content far outnumbers the information published in every kind of print form. This increased access to information empowers people to inform themselves and reduces their dependence on experts.

In terms of pervasiveness, 86% of Canadians reported owning a smartphone, according to a 2019 survey conducted by the Consumer Technology Association. These mobile devices have made it possible for technology to disrupt entire industries. With vast amounts of computing power and so many apps, it has never been easier to call for a ride, order food, check the weather or order a new coat.

A 2020 survey of Canadians provides a snapshot of the expanding impact of technology.[1] As per Fig. 8.1 below, online shopping, navigation, money management and scheduling are the most common ways by which citizens are embracing having key information at their fingertips and migrating transactions from face-to-face experiences to virtual.

Question: How often do you use the following pieces of technology? January 2020

[1] Survey of Canadian Citizens, Environics, March 2020, Commissioned by Canada Health Infoway.

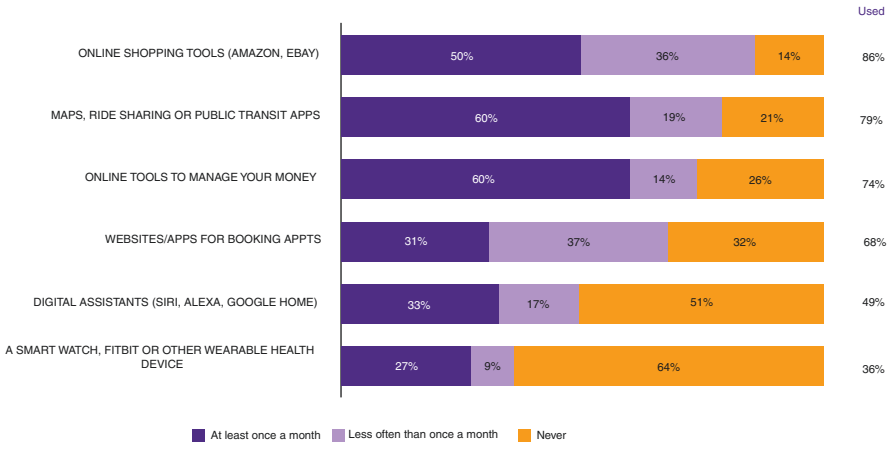


Fig. 8.1 Technology Use Among Canadians

8.1.1 Technology Has Changed the Experience and Expectations of Consumers

The primary benefits of technology are time savings and increased access to products and services.[2] Technology has changed the role and experience of the consumer. They now have choice, control and information.

Online shopping has literally 'opened the world' to consumers. Digital shopping has removed the analog constraints of time and distance. No longer limited to the bricks and mortar locations within a reasonable distance from their home, consumers now have access to products from around the globe. It is as convenient for them to see and access product details from large, global retailers as it is to check out the website of a small artisan. It is as convenient for them to shop for cheese at the local shop around the corner as it is to import cheese from France or Switzerland. This increased access to products and the ability to choose is a fundamental shift that has had a significant impact on how we shop.

Similarly, technology has given consumers more control and has put them in the driver's seat when it comes to making purchasing decisions. Consumers can now determine when they shop, no longer constrained by store hours. They are also no longer constrained by location—mobile devices make it possible to shop from home, while in transit, at a coffee shop or from a beach. If there is an internet connection, products and services can be purchased.

Finally, one of the biggest changes that consumers have seen is access to information that helps them make informed purchasing decisions. Information is usually available about the product as well as about the entire purchasing experience. While consumers contemplate their options, they can peruse detailed product specifications from the manufacturer, and they can read product reviews by other consumers like themselves. It is also worth noting that often consumer reviews include information beyond the quality of the product and address issues such as the ethical

[2] Survey of Canadian Citizens, Environics, March 2020, Commissioned by Canada Health Infoway.

scorecard of the seller, which expands the breadth of information upon which to base a decision.

Another important attribute about the digital consumer is their ability to rate their experience and share this information broadly. Because the digital age has vastly expanded consumer choice, the entire purchasing experience, not just the product, has become increasingly important. And consumers now have the power to share their experiences, positive and negative, with the digital world. This represents a significant power shift from sellers who controlled the message to consumers who are increasingly vocal about their experiences. And it matters; Northwestern University's Speigel Research Center reports that nearly 95% of shoppers read online reviews before making a purchase.

Why is this important? Consumers expectations have changed. They want the benefits of convenience, better access and improved decision making to extend to all aspects of their lives, including their interactions with the health system.

8.1.2 The Empowered Consumer as the Empowered Patient

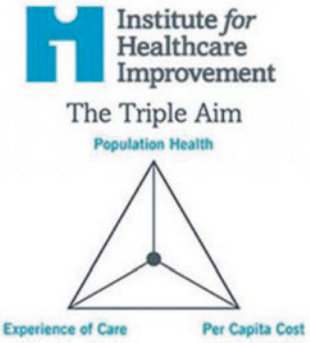
Broadly stated, patient engagement is a term used to describe patients' ability and desire to being active participants in their health journey and being equipped, enabled, and empowered to do so.[3]

In the same way that the last decade has seen a shift in the role of the digital consumer, there has been an evolution in the role of the patient in healthcare. From a system where patients often had limited knowledge and limited voice, there have been a series of efforts at improvement, both from within the system and from patients themselves.

As early as 1998, the term "nothing about me without me" was coined and used as a rallying cry in the activist patient community to describe a global effort to help patients become equipped and educated so that they can participate as full members of their care team.

The patient safety movement also brought patient issues to the forefront and patient stories to the ears of policy makers. The Institute for Healthcare Improvement in the U.S. introduced the Triple Aim in 2008, which asserted the experience of the patient as critically important:

[3] Ferguson T. E-patients: how they can help us heal healthcare. 2007. http://e-patients.net/e-Patients_White_Paper.pdf Accessed March 15, 2015.



Improving the U.S. health care system requires simultaneous pursuit of three aims: improving the experience of care, improving the health of populations, and reducing per capita costs of health care. Preconditions for this include the enrollment of an identified population, a commitment to universality for its members, and the existence of an organization (an "integrator") that accepts responsibility for all three aims for that population.

A growing awareness and commitment to understanding the patient experience has brought insights and revealed concrete opportunities to do better. Patient-centred care has become a centre piece of legislation, and influenced thinking throughout health systems. There were many drivers for this change, led by a common understanding that it was the right thing to do.

Across Canada, patients and their families have played pivotal roles in shaping health policy, research and technology. For example, most health organizations and agencies have established patient and family advisory councils who influence or develop policies and processes. In 2014, The Change Foundation, an independent health policy think tank in Ontario, published *Patient/Family Advisory Councils in Ontario Hospitals: AT WORK, IN PLAY Part 3: Examples: What the Councils Changed*.[4] The report lists numerous projects where councils have had an impact. The examples are listed under five broad categories:

- Changes to hospital policy and/or programs affected by policy
- Initiatives to support infrastructure planning, re-design, signage and wayfinding
- Initiatives dealing with food
- Initiatives in staff orientation and public education
- Initiatives to create/update hospital informational materials

The Canadian Institute for Health Research[5] (CIHR) is another example of an organization that is embracing patient-centred care and research. Wanting to include patients as proactive partners in health research rather than passive receptors, CIHR launched Strategy for Patient-Oriented Research (SPOR). Patient oriented research

[4] https://changefoundation.ca/wp-content/uploads/2016/05/PFAC-Part3-FINAL-web.pdf.

[5] https://cihr-irsc.gc.ca/e/41204.html.

is about engaging patients as partners in the research process. This engagement helps to ensure that studies focus on patient-identified priorities, which ultimately leads to better patient outcomes.

In addition to healthcare organizations initiating patient groups, patients themselves, along with their caregivers and family members have formed grassroots patient organizations as well. *IMAGINE—Citizen Collaborating for Health*,[6] based in Alberta, for example, is a coalition of Albertans whose vision is: **a health system that is designed, and care that is delivered, in partnership with citizens, achieving the best possible experience and outcomes for patients.** IMAGINE, like most similar organizations, has four areas of strategic focus. The first is around citizen participation; connecting with citizens to create a collective voice. The second area of focus is to ensure that the citizen perspective is communicated effectively and shared extensively. A third focus for most patient organizations is the development of partnerships; collaborating with the health system to drive change. Finally, many groups have an evaluation and research component to their work; they collect and share information about best practice and/or improved patient experience.

8.1.3 Empowered Patients Have Better Health Outcomes

Patient engagement matters because there is growing evidence to suggest that engaged, empowered patients have better health outcomes. This is good for the patient and it is good for health system resources. Patients with access to their personal health information report feeling more confident and involved in managing their health and report having a better relationship with their primary care provider.[7] There is a significant association between engaged patient status and the use of digital health services; specifically, electronic personal health records and electronic prescription renewals.[8] The importance of the relationship between patient engagement and better health outcomes is nicely summarized in a 2012 quote by Leonard Kish, a health IT strategy consultant, when he wrote: *"If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it"*.

Improving patient engagement and empowerment was the major driver in the global shift to providing citizens with access to their health information, according to a survey of member countries of the Global Digital Health Partnership (GDHP) (see Fig. 8.2). The GDHP is an international forum for global collaboration and sharing of evidence to guide the delivery of better digital health services within participant countries.

[6] https://imaginecitizens.ca/.

[7] https://infoway-inforoute.ca/en/what-we-do/blog/access-to-care/8439-meet-the-engaged-patients.

[8] https://infoway-inforoute.ca/en/what-we-do/blog/access-to-care/8439-meet-the-engaged-patients.

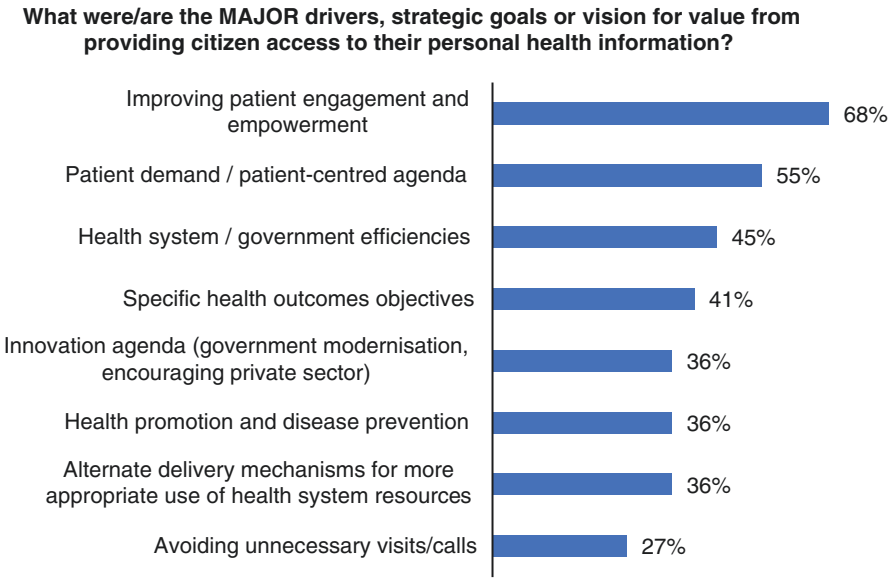


Fig. 8.2 Drivers for providing citizens with access to their personal health information

Several countries—such as Estonia, Portugal, Uruguay and the Netherlands—focused on the philosophy of citizen ownership of data and centrality. Access by people to their information was described as an opportunity to address the power imbalance that exists between patients and clinicians. A number of countries that approach it as "the right thing to do" have focused on liberating the data for citizens as their primary objective, with the understanding that empowering patients is the starting point for a range of improvements. In other countries, access to information for patients is more focused on specific use cases or clinical objectives, such as post discharge care or management of chronic disease.

Other drivers for providing people with access to their personal health information include: improving the quality of care and patient experience (for example, reduction in adverse events, better coordination of care, reduced wait times, improved patient outcomes); reduction in health costs (for example, reduced duplicate testing, better self-management by patients); providing equity in access to clinical information; and ensuring patients their constitutional rights.

8.1.4 Health Care Technology: Empowering Patients

Technology is a significant driver of patient engagement. It provides patients with greater access to their health information and to digital tools that empower them to become more active members of their care team. Figure 8.3 shows results from a 2019 survey, in which nine of ten Canadians said it was important to have

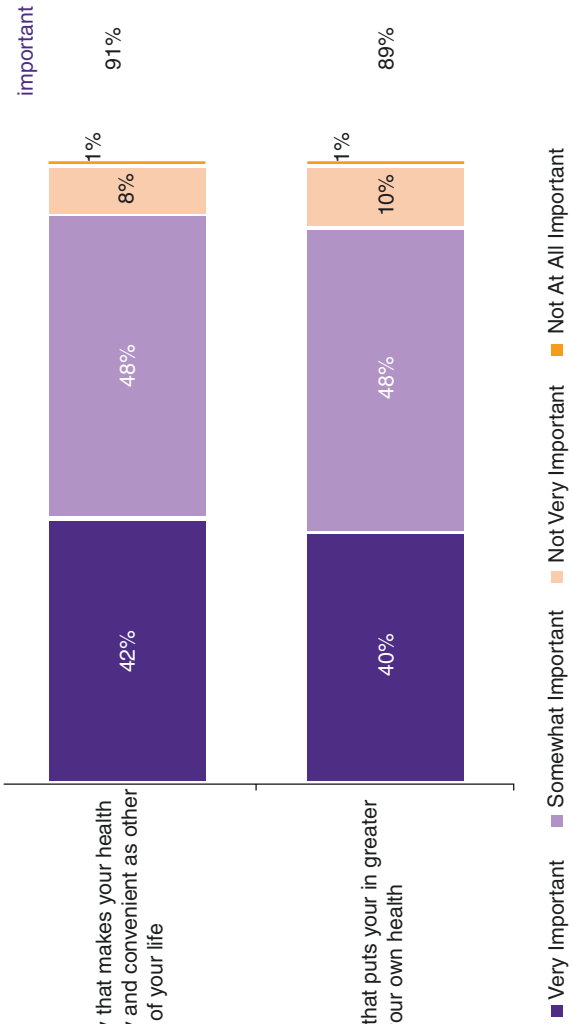


Fig. 8.3 Outcomes of digital health that are important to Canadians

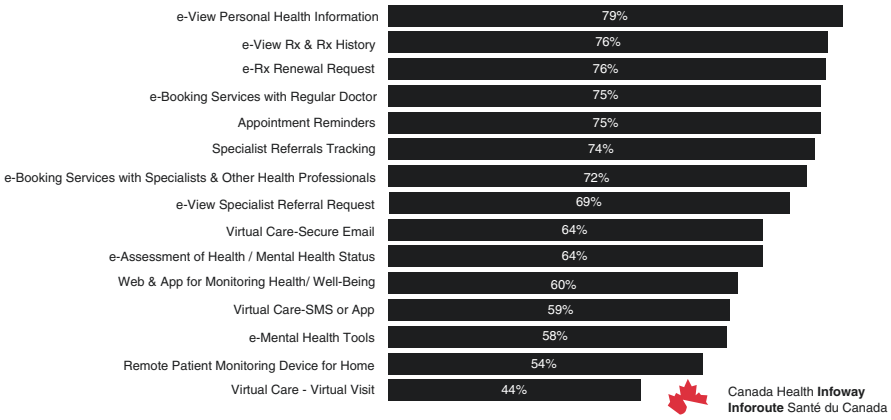


Fig. 8.4 Digital services of most interest to Canadians

technology that makes health care as convenient as other areas of their lives, and to have technology that puts them in greater control of their health (91 and 89%).[9]

Question: How important is it to you…? January 2020

Canada Health Infoway (Infoway) has been tracking Canadians' priorities and interests in digital health services for over a decade. The demand for digital health services has remained consistently high and the priorities that Canadians have identified as most important to them, are consistent over time and across geographies. Figure 8.4 below lists those digital tools and services most desired by Canadians. Not surprisingly, the benefits derived from the availability of the services listed reflect the same benefits listed by consumers: access to information, convenience (time savings), and control. Infoway has continued to test those market interests and trends and the demand remains strong for these top services, and when they are made available to them, Canadians will use them.

Question: Would you be interested in…?

8.1.5 Gap Between Desired Patient-Empowering Technology and Availability

In Canada, citizens are only beginning to experience digital health for themselves. In recent years, there has been great progress made in empowering patients with technology, however, there is a gap between the number of Canadians that want empowering technology that helps them manage their care and those that have it. In the Canadian context, "Understanding the gap between desire for and use of

[9] Survey of Canadian Citizens, Environics, March 2020, Commissioned by Canada Health Infoway.

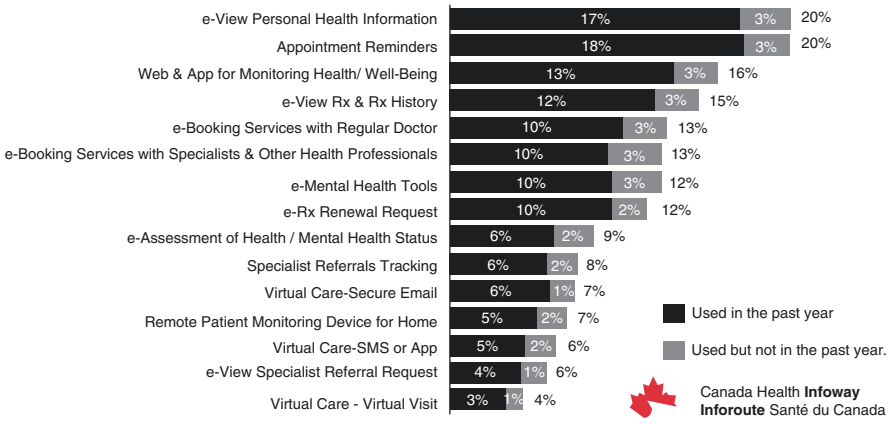


Fig. 8.5 Digital services most used by Canadians

consumer health solutions" published in 2014 presented this gap and reinforced the significant demand.[10]

A 2019 survey demonstrated that, while 79% of Canadians were interested in accessing their health information, only 20% of Canadians had done so. Similarly, while 75% expressed interest in e-booking an appointment with their regular care provider, only 13% had done so. Similar gaps exist for most services including electronically renewing a prescription (76% interest vs 12% who did) and virtual visits through email (64% interest vs 7% actual use). Figure 8.5, lists citizen utilization for selected digital health services.

Question: In the past year, did you? Have you ever?

8.1.6 International Progress

Internationally, the Commonwealth Fund International Health Policy Surveys collect experiences and perspectives from citizens and primary care physicians on a rotating basis. The data provide a sense of how the landscape is evolving across the ten or so participating countries on topics such as access to care, coordination of patient care, and use of information technology. The 2019 Commonwealth fund survey polled primary care doctors in 11 countries, including more than 2500 Canadian primary care physicians. This survey found that on average 37% of respondents across countries reported that their patients can view test results online, while 26% can view patient summaries[11] (see Fig. 8.6 below). Electronic booking

[10] https://www.longwoods.com/content/23871/healthcarepapers/understanding-the-gap-between-desire-for-and-use-of-consumer-health-solutions.

[11] https://www.cihi.ca/en/commonwealth-fund-survey-2019.

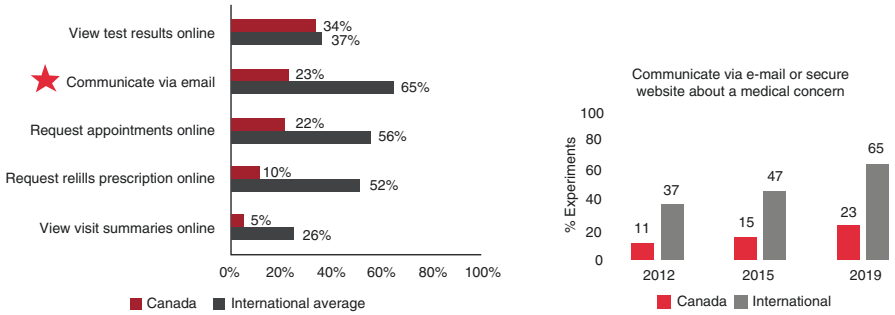


Fig. 8.6 Online services available to patients: comparison of Canada to international average

and prescription renewals are now becoming mainstream services, reportedly offered by more than half of respondents. These services are very popular because of the convenience they offer for patients; they also offer efficiencies for clinicians and administrative staff.[12]

The opportunity to communicate by email was the leading digital health tool that primary care physicians internationally report offering to their patients. For this metric, the question had been asked in previous waves of the survey, thus providing a snapshot of the rapid evolution of virtual visits. In 2012 it was a feature offered by 37% of respondents and by 2019 that number had increased to 65%. While this pace of change is slow in comparison to diffusion of many kinds of technology, health system change is demonstrably slower than in many other sectors. A closer examination of the simple exchange of messaging between patients and their care providers reveals the complexity of this change.

Availability of technology at both the patient and provider end is a necessity, but requires a higher bar for authentication, privacy and security than most electronic communications. The email citizens and providers use in day to day life is often not sufficient for the purpose. More importantly, clinical communication represents a very different approach to the processes by which clinicians assess health problems, arrive at diagnoses, determine treatment plans and work with patients to action those plans. Email is clearly appropriate only in some situations, and the evidence continues to evolve about how this kind of communication can be best used. Through this lens, the progress from 37% in 2012 to 65% internationally over 7 years should be viewed as a dramatic shift in healthcare delivery.

As per Fig. 8.6 below, Canada lags behind our international peers in making online services available for patients. While there are many reasons that have contributed to a slower uptake in Canada, clinician reimbursement for digital services for patients has been a challenge, with many physicians still paid based on the

[12] Doty, Michelle M., et al. "Primary Care Physicians' Role In Coordinating Medical And Health-Related Social Needs In Eleven Countries: Results from a 2019 survey of primary care physicians in eleven high-income countries about their ability to coordinate patients' medical care and with social service providers." Health Affairs 39.1 (2020): 115–123.

Fig. 8.7 Reported Citizen Adoption Rates for Selected GDHP Countries

delivery of discrete in-person services. Health system payers seeking to ensure that funds are spent as efficiently as possible have been reluctant to provide billing codes for online services which are harder to define and value. Newer models of primary care organizations, with innovations like team-based primary care and capitation for rostered patients have been helping to address some of these reimbursement challenges.

Question: Please indicate whether your practice offers your patients the option to communicate with your practice via email or a secure website about a medical question or concern? Request appointments online? Request refills/renewals for prescriptions online? View test results online? View patient visit summaries online?

Commonwealth Fund 2019 International Health Policy Survey of Primary Care Physicians in 11 Countries

Similar adoption rates were reported by those member countries of the GDHP (see Fig. 8.7).

8.1.7 Examples of Patient Empowering Technologies

There are many digital health examples, such as telehomecare (also know as Home Telehealth, Remote Patient Monitoring (RPM)) and patient portals. This section will provide evidence that these digital health tools can empower patients and provide tangible value for the health system as well as a compelling return on investment.

Telehomecare interventions have been used in various forms for decades. The literature includes many studies across a range of technologies that support people with chronic conditions to better manage their health at home with the support of clinical guidance and monitoring. The variability has made these hard to

characterize as a whole, finding largely positive effects and great variability in efficacy and adverse effects.[13,14]

In Canada, a 2014 report, "Connecting Patients with Providers: A Pan-Canadian Study on Remote Patient Monitoring", helped Canada focus on the most promising interventions.[15] The report defined four streams of activity:

1. Enabling Information: The provision of information relating to a patient's condition through websites, patient portals and mobile applications. Enabling information may exist as a component of RPM programs, but is limited to the provision of information about a patient's condition, such as their care plan and medication regime.
2. Self-Monitoring: Programs in which patients report their health information through an enabling technology at regular intervals to a care provider. Interventions are triggered when thresholds aligned to a patient's health status are surpassed.
3. Assisted Monitoring: Programs involving patient monitoring or coaching at prescribed intervals, through the direct use of community care professionals, when complex patients are discharged into the community.
4. Environmental Monitoring: Programs designed for highly complex patients (e.g., those with a functional disability and/or multiple, complex comorbidities) involving the use of installed devices that monitor their ability to live independently. Self-monitoring is not typically a component of these programs.

With costs and health system complexity increasing dramatically across these streams, the report included a framework to help system planners consider the most appropriate interventions for different patient groups (see Fig. 8.8).

In Canada, the results of early pilots in telehomecare demonstrated strong efficacy and patient satisfaction for moderately complex patients with Congestive Heart Failure (CHF) and Chronic Obstructive Pulmonary Disease (COPD). This led to accelerated deployment in many provinces, reaching over 50,000 Canadians by 2020. Evaluations from these projects demonstrated significant reductions in utilization of health system resources consistently across the country, and despite the high cost of these intensive interventions represented a return on investment of $4 in worth of system capacity for every 1$ invested.[16]

As the expansion of telehomecare and the vast range of other monitoring technology continues to expand, the critical success factors identified in "Connecting Patients with Providers" offers guidance for system planners trying to ensure the best outcomes and value for money:

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[13] https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2753.2010.01536.x.

[14] https://journals.sagepub.com/doi/abs/10.1258/jtt.2009.090812.

[15] https://www.infoway-inforoute.ca/en/component/edocman/1918-rpm-benefits-evaluation-study-full-report-final/view-document?Itemid=0.

[16] https://www.infoway-inforoute.ca/en/what-we-do/blog/telehomecare/7846-telehomecare-receiving-high-marks-from-patients-while-providing-significant-value-for-the-health-care-system.

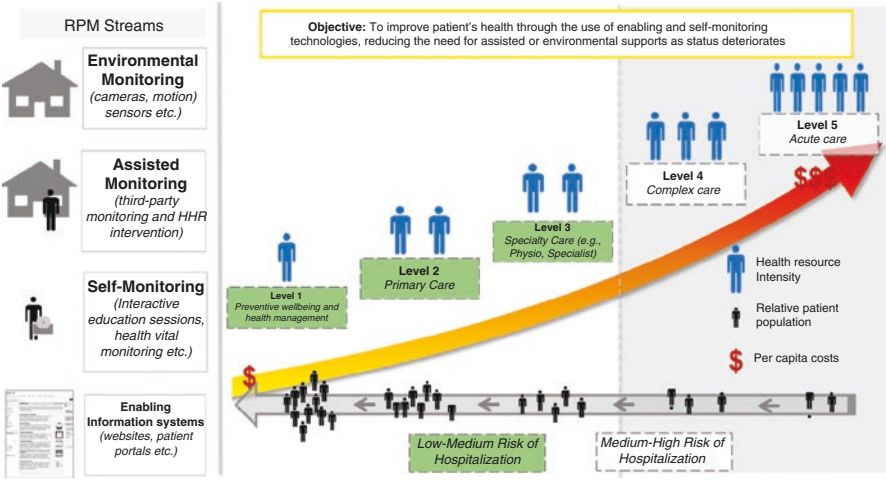

Fig. 8.8 Framework to illustrate the relationship between technological complexity and patient acuity

1. Engagement and collaboration. As clinicians are at the forefront of understanding the clinical complexity of patients, they should assist in designing an RPM program, along with the patient and/or caregiver, including the selection of appropriate technology that aligns with a patient's acuity and health care requirements. Clinicians are uniquely positioned to describe and deliver a compelling value proposition to potential patients, facilitating greater recruitment and retention.
2. Patient recruitment and retention. This is to ensure that providers identify patients that can benefit from the RPM program based on the complexity of the patient's condition, potential benefit from using the supporting technology and the actual technology involved. Appropriate recruitment and retention of patients relies on a consistent level of communication with patients regarding both the benefits of the program and the potential to track progress towards improving their health status throughout the duration of the program. The analysis also found that achieving a critical mass of patients is necessary to maximize benefits, recover program costs and return savings to the health system for reinvestment. This minimum number of patients was found to be highly variable and dependent on the scope and design of the program.
3. Benefits measurement. As RPM programs remain a relatively new care delivery enabler in Canada, determining likely benefits and consistently measuring those benefits will allow patients, clinicians and policymakers to understand the patient and system-level value RPM programs provide.

4. Integrated care and care-coordination. RPM should be integrated into a clinician's workflow through an assisted or environmental monitoring program, or coordinated across the care continuum through a self-management program to achieve the best patient benefit.

These programs, that are better for the health system as well as patients and their families, all have patient engagement in common. The derived value includes staying healthy and out of hospital and making judicious use of the health system, preserving capacity in stretched systems.

A Life Transformed

Since its launch, Eastern Health's Remote Patient Monitoring (RPM) program has been transforming patients' lives. It's been helping them stay at home instead of the hospital and it's helping them avoid trips to the emergency room. Joy Williams is one such patient. Since enrolling in the program, Joy has stopped using her blood pressure medication, left behind her walking stick and, best of all, is now able to spend more time with her energetic granddaughter.

That's because the program enabled Joy, who has diabetes, to monitor her condition using digital health tools and share the information electronically with a registered nurse in another community. Through the RPM (which is also known as telehomecare) program, she can access round-the-clock coaching, education and support that has enabled her to improve her condition.

Life was very different for Joy before enrolling in the program. She had been living with diabetes for two decades, and as a result, went on to develop hypertension and became insulin-dependent. "It seemed like no matter what I did, I just couldn't wrestle my diabetes symptoms under control," she says. "I was taking massive amounts of insulin and still not accomplishing the target levels that were suggested by my health care providers."

Joy's struggle with diabetes eventually led to osteoarthritis, forcing her to walk with a cane and rely on her two adult children to help complete everyday tasks. "It

felt like my entire world was shrinking and I was really helpless," she says. "It was a really awful feeling." Things changed when a friend handed Joy a brochure for the RPM program which she had come across at an Eastern Health fair.

Within a week of reaching out to the RPM team, Joy received a tablet, which she used to connect to a registered nurse who remotely monitored and coached her. "It was all really instrumental in teaching me how to recognize and treat my condition, and better yet, how to avoid having symptoms altogether," she says. "That was invaluable to me because I didn't know how to do that before." Just seven months later, Joy was able to get her diabetes under control, lose weight, decrease her medication consumption, lower her blood pressure and start walking without a cane.

Patient portals often offer patients access to their own personal health information in a secure setting, and can include other information resources and e-services. "Citizen Access to Data: An international review of country approaches to citizen access to health data", a white paper by the Global Digital Health Partnership explored the value of citizen access. The primary drivers identified by most countries was citizen demand and the belief that citizens should be more engaged and empowered. However, many also identified tangible benefits they expected, including health system efficiencies, improved health outcomes, better health promotion and disease prevention and avoided visits or calls by patients. Some countries who are further ahead in the journey report experiencing many of these benefits.

The peer-reviewed literature around patient access to information is still thin, as these technologies have rapidly expanded only in recent years. One recent systematic review found "Patient portals are increasingly available, but their impact on health outcomes has yet to be established. Previous systematic reviews found positive effects on patient engagement and satisfaction, but evidence on the effect of patient portal use on care processes and health outcomes is conflicting."[17]

Evidence from Canadian project evaluations suggests that impacts of patient access to information can vary substantially based upon the functionality, ease of use, complementary educational resources, etc. "Valuing Canadians' Access to their Health Information and Digital Health e-Services"[18] found that patient access to their own information has some significant value on its own, but when combined with the ability to visit with care providers virtually through video or messaging, and the ability to renew prescriptions electronically unlocks huge potential for citizens (Fig. 8.9) and the health system (Fig. 8.10).

[17] Fraccaroa P, Vigoc M, Balatsoukasb P, Buchana IE, Peeka N, van der Veerb SN. Patient portal adoption rates: a systematic literature review and meta-analysis. In MEDINFO 2017: Precision healthcare through informatics: proceedings of the 16th World Congress on Medical and Health Informatics 2018 Jan 31 (Vol. 245, p. 79). IOS Press.

[18] https://infoway-inforoute.ca/en/component/edocman/3552-valuing-canadians-secure-access-to-their-health-information-and-digital-health-eservices/view-document?Itemid=0.

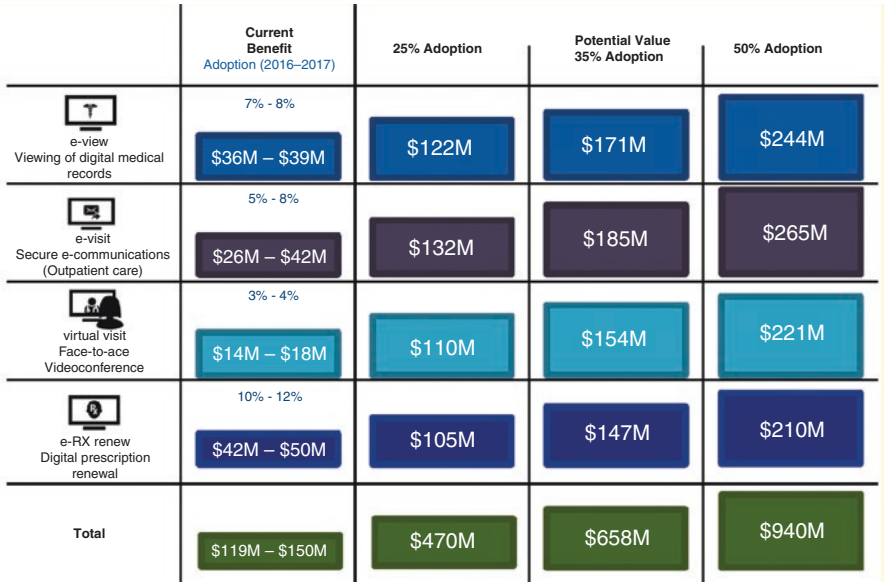

Fig. 8.9 Estimated Potential Value for Canadian **Citizens:** "Valuing Canadians' Access to their Health Information and Digital Health e-Services"

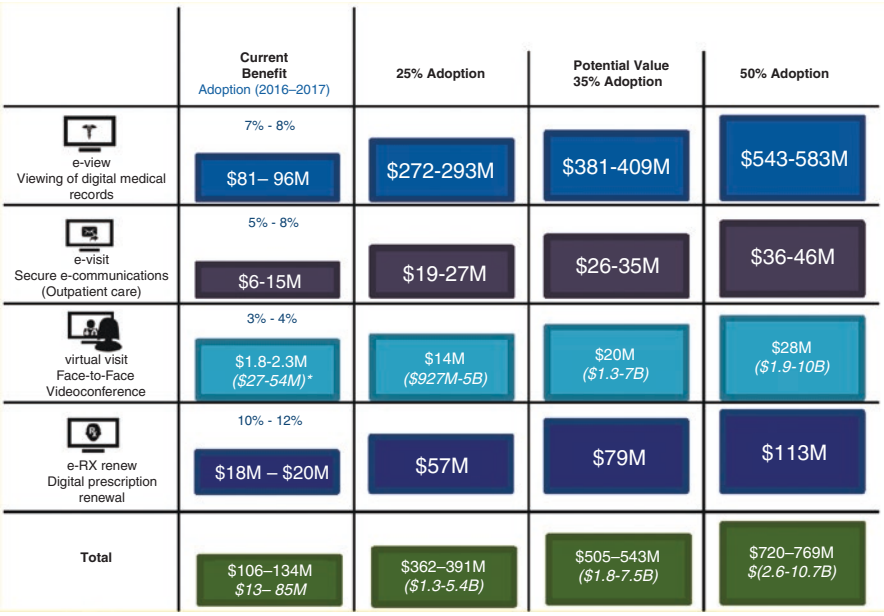

Fig. 8.10 Estimated Potential Value for Canadian **Health Systems:** "Valuing Canadians' Access to their Health Information and Digital Health e-Services"

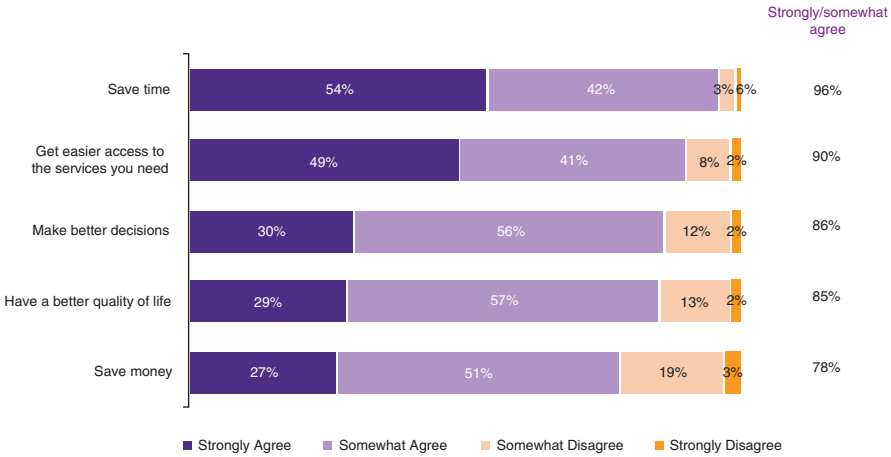

Fig. 8.11 Impacts of Digital Tools when Accessing for Common Services in Canada

This broad range of value is also evident from the feedback of citizen users of digital health tools, with saving time and improving access as leading benefits (Fig. 8.11).

Question: To what extent do you agree or disagree that these types of technology have helped you?

Mobile health apps and smart connected devices are also gaining popularity as mechanisms by which Canadians are empowering themselves to monitor their health. In 2017, researchers in Quebec published the first national study "The Diffusion of mobile health apps and smart connected devices in Canada", a study that examined Canadians' use and intentions for using mobile apps and smart devices to monitor health and well-being. It was the first national study of its kind in Canada, and the largest ever, worldwide.[19] The study found that two thirds (66%) of respondents regularly self-track one or more aspects of their health and one in four (25%) owned a wearable or smart medical device. Fitness trackers and smartwatches device made up the majority of these devices. Mobile apps and digital self-tracking devices were most commonly used for physical activity (51%), diet and nutrition (33%) and sleep (29%). Clinical tools were less common with some reporting functionality like monitoring cardiovascular and pulmonary biomarkers (13%), medication management (8%), and glucose monitoring (5%). Most users of connected care technologies are highly satisfied (83%) and many said they were able to maintain or improve their health condition (69%).

The results of the study show an opportunity to advance the health of Canadians through mobile apps and smart devices; and highlight important nuances to better understand key market segments and opportunities.

[19] Paré G, Leaver C, Bourget C, Diffusion of the Digital Health Self-Tracking Movement in Canada: Results of a National Survey, J Med Internet Res 2018;20(5):e177.

8.2 Health Information Technology and the Clinician

A discussion of the connected patient is not complete without a discussion of the evolution of health information technology for clinicians and for the system as a whole because citizens' experiences and relationships with the health system contribute to the development of their attitudes.[20]

In terms of medical technology in general, imaging, monitoring and interventional tools have always been a visible part of the healthcare landscape but health information technology has lagged. Many are familiar with the image of large paper charts unreliably following patients around institutions and the system.

To address this lag, the federal government funded the creation of Canada Health Infoway in 2001. Infoway is an independent, not-for-profit organization that works with its jurisdictional partners (provincial/territorial ministries/departments of health) and other stakeholders to improve the health of Canadians through digital health solutions. In the early years, the focus of Infoway investment was on the creation of electronic health records (EHRs). Moving information from paper to electronic/digital form greatly facilitated information sharing. Efforts in this regard were focused on lab information systems, drug information systems, diagnostic imaging and provider and patient registries. By 2019, much of this work was complete and approximately $30 Billion CAD in benefits with respect to improved quality (e.g. fewer drug interactions, better access to information for decision making), improved access to care (e.g. through telehealth initiatives) and greater system efficiency (e.g. fewer repeat lab tests) were generated.

Once the foundational building blocks were largely in place, focus shifted away from the infrastructure and to the clinician. Specifically, to the adoption of electronic medical records (EMRs). An EMR is a computer-based patient record specific to a single clinical practice, such as a family health team or group practice. In clinical settings where there are doctors, nurses, dietitians, pharmacists, and other health care professionals, EMRs improve communication between them and support productivity.

The adoption of EMRs in Canada, and internationally, was significant. The Commonwealth Fund, has conducted an international survey of primary care physicians on a roughly 3-year cycle since 2006.[21] In 2006, the average adoption of electronic medical records was at 64% in the relatively advanced group of countries included in the survey. By 2019, that number had risen to 93% and many other aspects of healthcare delivery had made similar gains, including a growing number of hospitals and health systems with advanced patient record systems which make possible analytics and other important opportunities for health system improvement (Fig. 8.12).

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[20] CARTER-LANGFORD, Abigail, and David WILJER. "The eHealth trust model: a patient privacy research framework." Improving Usability, Safety and Patient Outcomes with Health Information Technology: From Research to Practice 257 (2019): 382.

[21] Reference most recent.

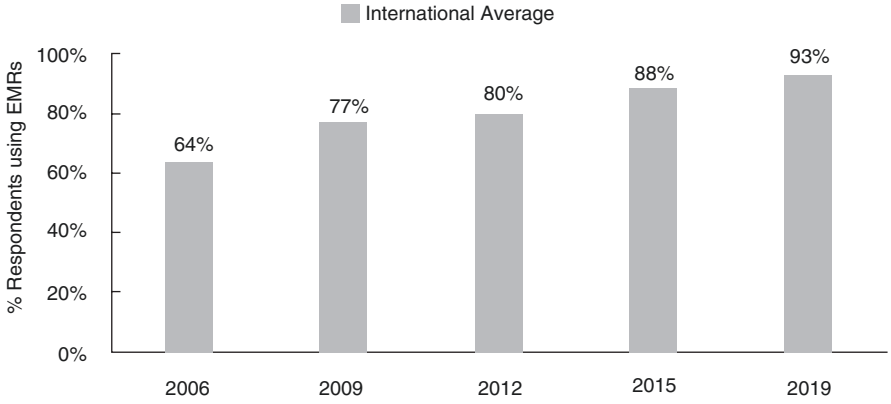

Fig. 8.12 Average Electronic Medical Record Adoption Rate for Countries Participating in the Commonwealth Fund International Survey of Primary Care Physicians

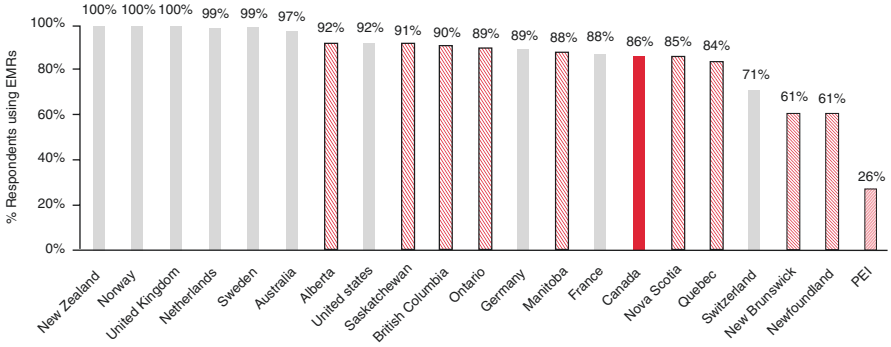

Fig. 8.13 2019 International and Canadian Provincial EMR Use Comparison

Question: Do you use electronic patient medical records in your practice (not including billing systems)?

In Canada, 86% of primary care physicians were using an EMR by 2019. It is worth noting, however, that there was substantial variability of adoption rates by jurisdiction (Fig. 8.13) and that growth in EMR use continues.

Question: Do you use electronic patient medical records in your practice (not including billing systems)?

8.3 Impact of Information Technology on Clinicians

For clinicians, the shift to EMRs has included a mix of improvements and positive impacts, as well as additional issues and stresses. In Canada, nurses, pharmacists and physicians were asked about impacts on productivity (see Table 8.1) and quality (see Table 8.2) revealing stories that are similar.

Table 8.1 Reported impact on productivity by Canadian clinicians

	Increased (%)	No change/Don't know (%)	Decreased (%)
Nurses with electronic records (2017)	50	27	23
Pharmacists with access to lab results (2016)	54	36	10
Physicians with electronic records (2013)	47	35	18

Table 8.2 Impact of electronic record keeping on quality of care

	Increased (%)	No change/Don't know (%)	Decreased (%)
Nurses with electronic records (2017)	56	34	10
Pharmacists with access to lab results (2016)	85	15	–
Physicians with electronic records (2013)	62	33	6

Productivity increases were experienced by about half in each group of respondents. Those experiencing increased productivity were more likely to be long term users of the solutions in question and more likely to work in a paperless environment. Some reported decreases in productivity by 10–23%, which is a substantive issue. Evidence points to the importance for change management, including workflow redesign to optimize productivity.

Quality increases were more commonly reported than productivity and reported decreases in quality were much rarer. These findings suggest that while the change introduces new risks overall, there are important gains increasingly being generated from digital health. More experience with digital health or use of more functionalities increases the likelihood of clinicians reporting quality of care improvements.

With such rapid change in digital health over the last decade, the peer-reviewed literature lags and many important research questions about the relationship between digital health and quality of care remain outstanding. However, findings are generally consistent with the sentiments identified in the clinician surveys. One systematic review from 2016 found that electronic health records "when properly implemented, can improve the quality of care, increasing time efficiency and guideline adherence and reducing medication errors and adverse drug events. Strategies for implementation should be therefore recommended and promoted."[22] Importantly, this study emphasized the potential value, but recognized that context and specifics of digital health initiatives can create a range of positive and negative outcomes.

Considering the variability of experiences with digital health, understanding the barriers or considerations for achieving value is important. While this topic is a

[22] https://academic.oup.com/eurpub/article/26/1/60/2467302.

complex one and increasingly a focus of study, clinician surveys again provide an early indication of where to focus.

Canadian nurses report a set of interconnected issues that generally relate to the range of disparate systems and processes they need to work with. Working across multiple systems, specifically having a mix of paper and electronic information is top of the list. For electronic solutions, login challenges are prevalent and closely relate to other concerns around workflows, equipment, etc. The multiple systems also create issues with fragmented patient information within healthcare organizations but more importantly when patients move between different parts of the health system.

It is important to recognize that patients will have different experiences, attitudes and perceptions about health information technology. It is equally important to understand that the same is true for clinicians. The availability of digital health solutions in different work settings, personal experiences with the technology and other factors all contribute to the clinicians' ability and desire to empower patients and help them use the available technology to better manage their health.

8.4 Considerations

There is no question that technology has had a positive impact on the way care is delivered. It has given clinicians access to more information upon which to base care decisions and has facilitated the sharing of information among the entire care team, including the patient. The use of wearable technology, sensors and other devices has provided us with more data upon which to make decisions, predict outcomes and effect change. In fact, 82% of Canadians surveyed in 2019 reported feeling that technology can help solve many of the issues within the health system.

It would be naive, however, to believe that technology is not without its challenges and that there are no important considerations that must be acknowledged and discussed if we are to ensure that the five tenets of the Canada Health Act are to be maintained and that all Canadians benefit from Canada's universal health system.

According to a 2019 Environics survey, concern about the privacy and security of their health data was the primary concern for Canadians with 78% stating that it was a significant barrier (39%) or somewhat of a barrier (39%). As per Fig. 8.14 below, other areas of concern included the cost of technology, health and technology literacy issues, perceived inability to navigate the system and lack of internet access.

Question: How much of a barrier, if at all, are the following to your own use digital health technology?

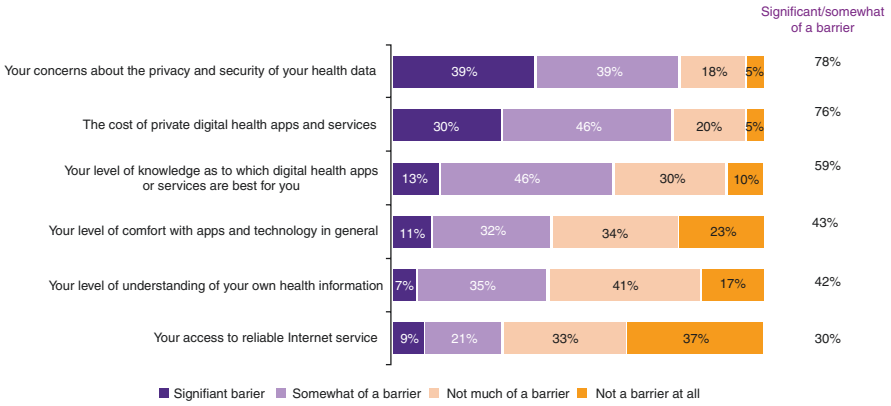

Fig. 8.14 Barriers to the Use of Digital Health Technology reported by Canadian Citizens

8.4.1 Privacy and Security

Concerns about privacy and security of their health information is consistently the most commonly cited barrier to digital health technology by Canadians. High profile data privacy breaches are a regular occurrence in Canada and while Canadians accept that technology associated with the financial sector has methods to help victims of privacy breaches when their data is compromised, they don't see how government and health care providers can offer similar protections and assurances about health information.

It is also important to note that Canadians have different thresholds of concerns, depending on the situation. For example, there is considerably less concern about sharing personal health information with a care provider. Approximately 75% of Canadians are willing to have their personal health data regularly observed by their doctor so they can be alerted if at risk for a serious health condition or share genetic information with their doctor so they can be informed about health risks. Willingness to share personal health data with private organizations decreases significantly, to 28%.

Similarly, Canadians are willing to share their anonymized health data to contribute to the 'greater good'. Most will share their data to help diagnose and treat other Canadians with conditions like theirs (82%), improve the performance of the health system (81%) and help advance scientific research (82%).

Furthermore, privacy and security concerns are more prevalent among different segments of the population. Older respondents, women, people born in Canada (rather than newcomers), and Indigenous peoples were more likely to report that "concerns about the privacy and security of your health data" is a barrier to use of digital health technology.

8.4.2 Technology as a Further Barrier or an Enabler for Underserved Populations?

Despite *accessibility* and *universality* being two of the five principles enshrined in the Canada Health Act, there are populations in Canada that are underserved in the system. These vulnerable populations, who include low socio-economic status (poverty, homelessness), health and lifestyle (LGBTQ+, mental health issues) and racialized Canadians (including newcomers), often encounter barriers to access to care, lack of understanding of the needs of their communities and discrimination. For example, some refugees and newcomers to the country experience language barriers or an inability to navigate the system; racialized populations and marginalized communities also report discrimination in a health system that does not have the cultural or lifestyle knowledge or context to provide a holistic approach to their care.

So, will technology enhance the access and quality of care for these populations or will it further marginalize them? When asked, 61% of Canadians felt confident that all Canadians will have equal access to health care technologies as they become available. A survey of underserved populations was also optimistic about the potential for technology to solve many of the challenges facing health care in Canada. They were especially interested in the role of technology to reduce problems of bias and discrimination and to include social determinants of health in the context of care provision. Overall, they identified the greatest benefit of incorporating more technology into the health system as its ability to empower underserved communities with more information and access to personal health information, allowing them to make informed health decisions.

8.4.3 The Digital Divide

Clearly, reliable internet access and availability to mobile phones and other technology will be imperative to ensure that the benefits of digital health are experienced by all. A single mother with three children, two part-time jobs and who relies on public transit, will benefit greatly from the ability to email or otherwise communicate with a clinician from her home after the children are asleep (no longer needing to take time off work, arrange for child care, pay for public transit etc.…) as long as she has the technical means to do so.

While Canadians are increasingly connected and most have mobile phones, access to data plans or other technology must always be a consideration when talking about technology in health care so that we ensure our most vulnerable populations are helped by it and not further marginalized.[23] In 2019, 31% of Canadians

[23] Paré G, Leaver C, Bourget C, Diffusion of the Digital Health Self-Tracking Movement in Canada: Results of a National Survey, J Med Internet Res 2018;20(5):e177.

listed access to reliable internet as a barrier to the use of digital health technology. Most of these individuals lived in Canada's northern territories and rural regions. Similarly, older Canadians and low-income households were more inclined to identify this as a barrier.

8.4.4 Unconscious Bias

Technology can address issues of bias in health care, as machines are 'blind' to colour, ethnicity and other potential forms of bias. However, there is increasing evidence to suggest that biases may be programmed into the technology that sought to solve the problem. This is unconscious bias—prejudice or unsupported judgements in favour of or against one thing, person, or group compared to another, in a way that is usually considered unfair. Artificial intelligence (AI) is a good example to use to illustrate this point.

In many cases, AI can reduce the subjective interpretation of data, because machine learning algorithms learn to consider only the variables that improve their predictive accuracy, based on the training data used. At the same time, evidence suggests that AI models can embed human and societal biases and deploy them at scale. Often the data upon which algorithms are based are the issue. If AI models are trained on data containing human bias, then those biases remain. Bias can also be introduced into the data through how they are collected or selected for use. The introduction of AI must consider the nuances of social contexts and consider where and when human judgement is required.

8.4.5 Digital Health Literacy

As stated earlier, if a citizen is engaged in managing their health and they have the digital tools and information to do so, they are more inclined to have positive health outcomes. Their ability to use technology to be involved in their care will be influenced by their level of digital health literacy. Digital health literacy is defined as the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.[24] Clearly, if a patient does not have the capacity or the ability to understand or navigate a digital health system, they will not be able to reap the related benefits. Many factors influence digital health literacy including age, socio-economic status and health status. Usually those who are elderly, have lower incomes and are less healthy, have the highest levels of digital health illiteracy. Those who are digitally

[24] Source: Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006;8(2):e9. https://doi.org/10.2196/jmir.8.2.e9.

illiterate are usually impaired in two ways; they are not comfortable with technology in general and they have a low level of understanding of their health information.

As digital health solutions become more common it will be imperative to ensure that issues of digital literacy are addressed. Co-design of solutions with patients may help overcome some of the barriers by building solutions that are user-friendly, use video, infographics and plain language (and multiple languages) so they are less intimidating. It is also important to understand that the introduction of digital health solutions may change the clinician-patient relationship in that clinicians may be asked to take on a role of digital health educator/advisor to some of their patients. It is important that they are comfortable in this role.

For clinicians, like patients, there are different levels of digital health literacy. While the next generation of clinicians will likely be the most digitally savvy to date, tailored education resources and tools can support them in using technology optimally and safely and in educating their patients to do the same. Since 2011, Canada Health Infoway has been working with three national organizations—the Canadian Association of Schools of Nursing (CASN), the Association of Faculties of Medicine (AFMC) and the Association of Faculties of Pharmacy of Canada (AFPC)—to encourage digital health education for clinicians in training. The broader work with all three organizations morphed into a faculty peer network program, the Digital Health Faculty Associations Content and Training Solutions program, which strove to provide faculty in these programs with the tools and resources to integrate health informatics into their teachings. This program received the 2017 Ted Freeman Award for Innovation in Education.

8.5 Nurses Play a Key Role

The healthcare landscape in which nurses are working has never been more complex. The patient demographic is changing such that there is an increased burden of disease on patients who are living longer. Mental health issues are becoming increasingly prevalent and the lines between health and social care are becoming more blurred. In this context, technology solutions can improve patient safety by facilitating access and exchange of information. They can empower patients with information to better manage their health.

Nurses play a pivotal role. As health professionals that are most accessible to patients, nurses can ensure that patients can effectively navigate the system, are aware of the digital options available to them and that they have the skills and confidence to use them. Likewise, nurses can advocate to ensure that technology is being used to support vulnerable and underserved populations and ensure that the benefits of digital health are enjoyed by all.

Review Questions

1. We know that technology has had a significant impact on our lives by giving us, as consumers, more control. Give one or two examples of how empowered con-

sumers have become empowered patients and describe the benefits in terms of the Triple Aim.
2. You have been asked to participate on a team that is looking to develop digital tools and strategies to improve the ability of patients and families to participate in their care. What are some strategies/tactics you might deploy throughout the project to ensure its success?

Answers

1. Technology has given consumers more choice of product, made it more convenient to shop, and given us more information about the product and the buying experience—all these changes have resulted in consumers having more control. The same benefits can accrue when these attributes are available in the health context. For example, a patient with more information about their health condition and the treatment options, can have a more informed discussion with their care team and make a decision that is best for them. A patient who can access digital tools and services at their convenience (e.g. have a virtual visit, renew prescriptions online) can save time and money and not need to take time off work or school to attend an appointment. Answers to this question should speak to the value to the patient (as per above), the value to the health of the (e.g. employing digital solutions to keep vulnerable populations from being exposed) and the cost of care (e.g. telehomecare as a mechanism to keep people at home rather than in the hospital).
2. There are many ways to ensure the success of a project designed to empower patients through technology. First and foremost, patients and their families should co-lead the design of the tools. As per the 'nothing about me, without me' principle outlined in the chapter, including patients from the outset will ensure that their views, experiences, expertise and expectations are incorporated from the beginning. Understanding and addressing some of the barriers to digital health will also be important. The chapter outlined several considerations for digital health solutions. The project team should ensure that these issues have been considered and addressed in the design and implementation plan. For example, is the solution private and secure? Will it be easy to understand by those who are not comfortable with technology and/or don't understand complex health terminology? Does the solution address the needs of vulnerable populations? Is there a way to support users post-implementation? How have patients and clinicians been engaged to help promote the solution?

Glossary

AI Artificial Intelligence

Ambient assistant living The term ambient relates to the use of unobtrusive, or non-invasive sensors, such as motion detectors, which help us understand how people live their lives and to detect when things change—a possible indicator of

health decline. The goal of AAL is to enhance the quality of life of older people through the use of ICT.

CIHR Canadian Institute for Health Research

Digital consumer A trend of escalating consumer use of digital technology

GDHP Global Digital Health Partnership

ICT Information and Communication Technologies.

Independent Able to exist without dependency on another concept, variable, person

Independent living Independent living refers to a person's ability to go about their daily lives and carry out activities of daily living, without the need of help or support from others.

Older adults Typically the target group of many independent living and ICT products and services. There is no wide agreement on what age 'old' age begins. For the purposes of this chapter we will take the term older adults to refer to anyone of or over the age of 60.

Patient engagement A term used to describe patients' ability and desire to being active participants in their health journey and being equipped, enabled, and empowered to do so

Patient portal A website where patients can securely access their own medical and healthcare information

RPM Remote Patient Monitoring

Smart Home Smart Homes are domestic residences, augmented with AAL technologies and ICT-based services, that provide support to facilitate ageing-in-place

SPOR Strategy for Patient-Oriented Research

Telecare *Telecare*—the umbrella term of healthcare services planned, facilitated and delivered using technology

Telehealth Telehealth is the remote exchange of data between a patient and a healthcare professional to assist in the diagnosis and management of a health condition. Examples include blood pressure and blood glucose monitoring. These technologies are generally provided to patients with long-term health conditions such as diabetes

Telehomecare Homecare services delivered or facilitated by digital/telehealth technologies

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