



A Note on the Urgency of Digital Health Equity in the COVID-19 Pandemic

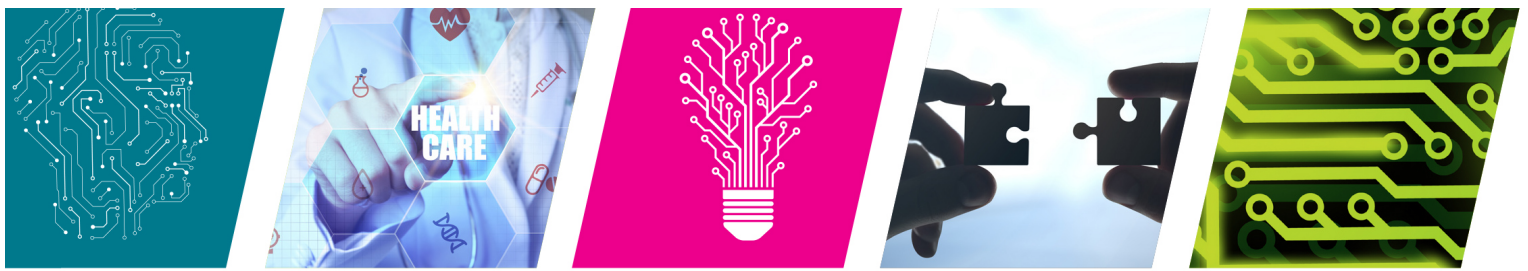
In the attached document, you will find a report of a symposium hosted in September 2019 on the topic of digital health and equity. For communities that have been marginalized and under-served by the healthcare system such as those who are racialized, Indigenous, homeless or under-housed, digital health solutions may further entrench the barriers to care that they already experience. In response to this challenge, researchers from Women's College Hospital Institute for Health Systems Solutions and Virtual Care and the University of Toronto Joint Centre for Bioethics hosted a stakeholder dialogue addressing the links between digital health, virtual care and health equity, to develop recommendations for providers, healthcare leaders and policy-makers when designing and implementing virtual care to address this “digital divide”.

The enclosed report was written prior to the unprecedented global response to COVID-19, including the rapid transformation of health service delivery and widespread adoption of virtual care. Although virtual care has made it possible for many health and social services to continue to be delivered during the pandemic, not all groups engage with, adopt, and benefit equally from technology-enabled approaches to care.

The report is focused specifically on digital health technologies, which include any digital devices that allow for the exchange of health-related information between patients and health care providers. We suggest that the insights described in this report ought to be considered now as plans are made for the future of virtual care both as a result of the pandemic and long-term.

There is an urgent need to adapt virtual care strategies that were reactionary to the global pandemic and offered necessary short-term solutions, to ensure that health needs of under-served populations are met without further exacerbating the “digital divide”. The recommendations described in the enclosed policy discussion paper offer relevant key insights on the impacts that digital health technologies are likely to have on equity, and the ways in which digital health can be used to contribute to an equity-enhancing system. These long-term strategies for the design and implementation of virtual care tools for all populations are more relevant now than ever before.

We acknowledge that much work is yet to be done to advance a health equity agenda in relation to digital health and virtual care, especially in the COVID-19 pandemic. We invite interested readers to please engage with us, by emailing questions or comments to WIHVequity@wchospital.ca. Thank you.



Digital Health Technologies for More Equitable Health Systems: A Discussion Paper

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TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
SUMMARY OF ACTION ITEMS.....	5
INTRODUCTION	7
BACKGROUND.....	8
Success Story: A Community-Focused Electronic Health Record.....	9
THE SYMPOSIUM.....	11
SYMPOSIUM FINDINGS.....	11
ACTION ITEMS	19
CONCLUDING COMMENTS.....	22



EXECUTIVE SUMMARY

Digital health is poised to re-shape health care delivery. In Ontario, the Digital First for Health Strategy has outlined investments that will make digital technologies a more central part of the health system. Technologies offer the opportunity for greater convenience, efficiency, and personalization of health services, but they also bring important risks. These risks are particularly pronounced from an equity perspective, where certain communities might be systematically excluded from the benefits of technology. In this discussion paper we report themes and action items arising from a symposium on digital health and equity that focused on two closely related issues: the impacts that digital health technologies are likely to have on equity, and the ways in which digital health could be used to contribute to an equity-enhancing health system.

In September 2019, the Women's College Hospital Institute for Health System Solutions and Virtual Care (WHV) and the University of Toronto Joint Centre for Bioethics (JCB) hosted an invitational symposium with clinicians, policymakers, health care leaders, researchers, technology vendors, and community members with an interest and expertise in digital health and equity. We present the most important themes of discussion and outline action items for the Government of Ontario that will promote health equity as digital tools become more prominent in the province's health care system. The five themes are presented here, followed by four action items.

- 1. Technology is becoming more pervasive, but not all communities have equal access to connected digital devices.** As health care systems focus on deploying digital health strategies, it is important to acknowledge that not all communities are able to access digital technologies in simple and obvious ways. The fact that particular communities have less access to technology and its positive benefits has been referred to as the “digital divide”, an essential consideration when implementing digital health in Ontario.
- 2. Not all problems are best solved by technology.** Despite the great potential of digital technologies in health care, many issues related to the upstream causes of



'hallway health care' cannot be solved by technology. They require investments that address the social determinants of health and a strengthened health system that has a meaningful focus on complex health and social needs.

- 3. Technology should be designed with underserved communities.** We refer to those communities that are not well served by the health system as 'underserved'. When digital health technologies are designed in collaboration with underserved communities, they can enhance access to health care. Cultural appropriateness should be central to the design of technologies to ensure that they are relevant to the communities they serve.
- 4. Policy and procurement should focus on real needs.** Policy and procurement for digital health technologies should focus on meeting real needs of patients, caregivers and health systems. The vision for health care in Ontario is built around integrated, high functioning teams, the central role of primary health care focused on patients and caregivers, and strong collaboration. Digital health technology should be deployed in service of this vision.
- 5. The fundamentals of a digitized health system need attention before digital health can meet its potential.** As the number of patients with multiple chronic conditions increases, the challenges of an infrastructure for sharing data between digital health applications and electronic health records, and for enabling information sharing in health care more generally, must be overcome to produce a high-quality and sustainable health system. Steps must be taken to ensure that new digital tools do not lead to a more fragmented system and that data collection and data sharing is in alignment with the needs and wishes of patients and communities, and specifically Black and Indigenous populations.



SUMMARY OF ACTION ITEMS

One overarching action item for all stakeholders was to learn more about colonialism and its consequences in present day Canada. The Truth and Reconciliation Commission has advanced this work, and all stakeholders would benefit from becoming familiar with the recommendations generated. In addition, we identified 4 action items for the Government of Ontario that will help ensure that digital health contributes to an equity-enhancing health system.

1. Invest in collaborations that aim to address the digital divide.

- a. Create opportunities for cross-ministerial collaboration on ways to address the digital divide, which might include representation from Economic Development, Job Creation and Trade, Government and Consumer Services, Infrastructure, Seniors Accessibility, Health, and Long Term Care.
- b. Ensure there is representation from diverse communities in discussion about strategies to address the digital divide at the governmental level. Community members can correct misperceptions and help to establish meaningful solutions by ensuring they address real challenges.
- c. Invest in providing digital infrastructure to underserved communities, such as in Ontario's homeless shelters and in rural or remote communities.

2. Promote the design and procurement of digital health technologies in ways that support health equity.

- a. Clarify the importance of considering the health equity implications of implementing digital technologies in the Digital Health Playbook and other Government of Ontario resources.
- b. Provide guidance to digital health vendors about existing resources to inform equity-oriented design of digital health tools.
- c. Establish processes to monitor the performance of digital tools on health equity outcomes specifically.



3. Incorporate equity considerations into the development and review of health information policy.

- a. Conduct reviews of health information policies and legal frameworks in Ontario from a health equity perspective.
- b. Recognizing that Black and Indigenous communities have been historically excluded from the process of data collection about them, efforts regarding the collection of socio-demographic data such as income, race and ethnicity should focus on ways to centre and learn from Black, Indigenous, and other peoples of colour. These groups should be engaged to develop meaningful educational strategies for community organizations, health care providers and researchers regarding when and how health information can be collected and shared, data accessibility and ownership, and the potential ways it can be used.
- c. Develop educational strategies for the public about the nature of health-related and socio-demographic data, circumstances under which they are collected, and the potential ways they can be used, led and informed by racialized and Indigenous community members.

4. Continue to invest in strategies to address complex needs and the social determinants of health.

- a. Support inter-sectorial innovation that involves collaborations across health care, mental health supports, housing, and other social services to address the social determinants of health.
- b. Support the engagement of underserved communities specifically in the effort to co-design and plan health services to ensure they are relevant and addressing real needs.



INTRODUCTION

Digital technologies are increasingly prominent in our everyday lives, with 66% of Canadians and 81% of Americans now reporting they own a smartphone¹. The widespread use of mobile devices and other digital technologies means that the potential for applications of digital innovation to health care is immense². Investment in digital health has grown rapidly over the past several years³, and confidence in the potential of digital health is high⁴. However, the story is not all positive. Researchers have identified situations where digital health technologies used in health care have led to larger inequities between various social groups⁵, meaning that certain communities are excluded from the possible benefits of digital health tools⁶. In this paper we focus on understanding the links between digital health and health equity, and discuss strategies that can be put in place at the policy level to ensure that digital health technologies work in service of more equitable health systems.

Box 1. Defining Digital Health

Digital health has been defined in a variety of ways, with recent work acknowledging the central importance of the collection, exchange and use of health-related data⁷. Although alternative definitions of digital health exist, and related terms such as mobile health and eHealth complicate the effort to define terms with clarity, we use the term digital health to refer broadly to the use of digital devices for the collection, exchange and use of health-related information for purposes of health-related self-management or health care delivery. That means digital health is about the apps on our personal phones, tablets, and laptops that help people manage their health, and also about the tools for connecting people and sharing information in health care settings.

In order to generate insights into the opportunities and challenges posed by digital health for the goal of advancing health equity, the Women's College Hospital Institute for Health System Solutions and Virtual Care (WIHV) and the University of Toronto Joint Centre for Bioethics (JCB) hosted an invitational symposium with clinicians, policymakers, health care leaders, researchers, technology vendors, and



community members with interest and expertise on this topic. The symposium involved invited comments from each of these stakeholders, and focused on group dialogue to better understand the issues requiring attention and strategies to achieve equity-related goals. The dialogue generated diverse ideas, which were distilled into five key themes. Further, numerous action items emerged for different stakeholder groups. In this paper, we synthesize action items specifically for the Government of Ontario, to outline how stakeholders at the provincial policy level can enable provincial investments to work in support of health equity.

BACKGROUND

There is growing awareness among the broader health care community that digital health tools pose important risks as well as opportunities. In the opening editorial of a recent issue of the *Journal of the American Medical Informatics Association* (JAMIA), Veinot and colleagues (2019) outlined a number of recent initiatives in North America focused on addressing the health equity dimensions of digital health⁸. These initiatives include conferences, nationally sponsored workshops, and support for research to better understand how digital health tools relate to health disparities and health equity more generally.

Insights generated from research on digital health and equity need to be understood in the context of the broader trends in health care in Canada and elsewhere. For example, it is increasingly well understood that health systems in North America must deal with structural racism⁹, and that divisive politics can influence health outcomes for particular communities¹⁰. These facts are not stated here to place blame on any stakeholder group, but instead to raise all of our awareness about the realities of the systems in which we plan and deliver health care. If digital health innovations are to be leveraged in ways that promote an equitable and sustainable health system, their use must be accomplished with a clear effort to ensure that digital tools will not worsen existing biases or inequalities in the system.

Our approach to supporting this goal is to focus explicitly on the role of digital technologies in the health system, what they can currently accomplish, and a



meaningful vision for the future. Taking a perspective that focuses on the health system encourages us to use the language of “underserved” communities, as opposed to terms like “marginalized” or “vulnerable”. While there is a tendency to use the terms “marginalized” or “vulnerable” to describe populations that experience different levels of disadvantage based on socially-prescribed identities, we choose to use the term “underserved communities” to place emphasis on what the health system is capable of doing to promote more equitable access for populations that have been historically overlooked or mistreated. Our use of the term underserved is not intended to distract attention from the active processes at play in society by which particular groups are marginalized. We acknowledge that racism and other forms of discrimination and oppression result in the systematic exclusion of particular groups from access to services and to opportunity. Where we refer to particular communities as underserved, we simply mean that the health system is not serving them well enough. This underscores the efforts of the broader collection of health system stakeholders to enhance what the health system is capable of doing.

This is the conversation we intend to promote in this paper in relation to digital health: How can digital health tools be leveraged in ways that enhance the health system’s ability to promote health equity, instead of making existing inequities worse?

Success Story: A Community-Focused Electronic Health Record

One digital tool that is widely regarded as complex but very important for health care is the electronic health record (EHR). The EHR is a way of organizing health information about individual patients, and can offer the possibility of better understanding entire patient populations. The EHR can ideally support more consistent, shared knowledge across a team of health care providers, enabling members of the health care team to have more accurate and relevant knowledge about the patients with whom they work. However, the implementation of EHRs in Canada has been slow, fragmented, and much work across the country is focused on building on the promise of EHRs to contribute to health care and population health.¹¹



In 2002, Ts'ewulhtun (pronounced *say-wool-tun*) Health Centre in British Columbia (BC) needed to evaluate the capacity of its existing EHR system to meet the growing needs of its community. The patient population consisted of Indigenous communities on Vancouver Island in BC, and the Health Centre was committed to ensuring that basic principles of Indigenous Health were advanced through the operations of the EHR. To do so, they commissioned the development of a new EHR, and established a multi-stakeholder development team to put together the specifications for the system and oversee its development. The EHR was ultimately implemented in 2003, and was widely regarded as positive contribution to primary health care in the region.¹²

The development process resulted in the Mustimuhw Health Information System (pronounced *Moose tee mook*, a Coast Salish word, meaning “all of the people”). Mustimuhw incorporated the values, mission and goals of the Ts'ewulhtun Health Centre, meaning that it was built to support culture, support capacity building, house data owned by the community itself, and support excellence in the care delivery process. The EHR included visual representations that were local to the culture, and could be easily changed to represent other Indigenous symbols as the system was procured by other organizations focused on Indigenous Health. The interface was built such that patients could provide direct input and understand the information entered into the record. Mustimuhw is portable and can function on laptops for providers going out into the community. It was found to enable enhanced coordination among the 70 staff working at Ts'ewulhtun Health Centre.

This success case illustrates the possibilities of digital health technology design that is focused on the needs of particular communities to contribute to an equity-enhancing health system. It also exemplifies the principles of Ownership, Control, Access and Possession (OCAP) which outline terms for First Nations self-determination in research processes. These terms should be consulted and implemented whenever data from Indigenous communities is implicated in any research, policy or technological development initiatives¹³.

Although this success case is important as an example of how equity-oriented technology design can be done well, there are many challenges when promoting this



kind of work on a large scale. At the symposium, we heard about the challenges in making such approaches to design a reality, and the ways in which a number of technologies might contribute to an equitable health system in meaningful ways.

THE SYMPOSIUM

WIHV and the JCB collaborated to host a symposium with the overarching goal of generating insights into the links between digital health and health equity, and to identify strategies that can promote the use of digital health technologies for more equitable health outcomes. The symposium was hosted on September 24th, 2019, and took place under the Chatham House rules: that no individual participant's identity would be linked to their individual comments. There were 62 people in attendance during the day, and the agenda is presented in Appendix A. We are especially grateful for the important contributions of the Centre for Indigenous Medical Education at Women's College Hospital (Now the Centre for WISE Practices in Indigenous Health).

The day began with introductory remarks that set the tone for a constructive dialogue that would confront systemic challenges, such as structural discrimination (where the structures of current systems inappropriately privilege particular groups) including racism and colonialism, with attention focused on mutual learning and practical action. Three panels were presented. The first focused on lived experiences of community members; the second on examples of equity-oriented digital health innovation; and the third on the unique considerations of Indigenous Health. The afternoon consisted of breakout sessions focused on community engagement, implications for health care in Ontario, and collaboration with technology companies. Following the symposium, our team analyzed in-depth notes that had been taken throughout the day to identify a series of themes that characterized the day's discussion. Those themes are presented here.

SYMPOSIUM FINDINGS

The symposium addressed a wide variety of topics related to digital health and equity. One point that became clear early in the discussion was that the various



communities of stakeholders involved in digital health have much to learn about health equity. Participants at the symposium agreed that **much more education was needed**, in order to promote greater awareness and deeper knowledge **about the causes and impact of inequities in health care** more generally.

Furthermore, since the symposium, recent events including international protests confronting anti-Black racism have galvanized health care leaders and policymakers to work towards the collection of race-based data. While these efforts are important, these practices must ensure that this data is collected, stored, owned and shared in ways that are based on the meaningful engagement of Black and Indigenous communities as failing to do so can be harmful for many historically underserved groups¹⁴. The collection of race-based and socio-demographic data are undoubtedly linked to the development and deployment of digital health technologies and many of the discussions had at the symposium. This underscores the importance of health care leaders, policymakers and vendors continuing to gain a broader understanding of health inequities; this will form an integral foundation for understanding the role that digital technologies might play in enhancing health equity. The symposium involved group dialogue and breakout sessions that generated a number of practical insights to guide efforts to make changes in health systems, and to mobilize digital health technologies in ways that would enhance health equity. These practical action items are outlined in the final section of our paper. Before outlining practical steps forward, we summarize the most prominent points of discussion that arose during the symposium as represented by five themes.

1. Technology is becoming more pervasive, but not all communities have equal access to connected digital devices.

As health care systems focus on deploying digital health strategies, it will be important to acknowledge that not all communities are able to access digital technologies in simple and obvious ways. This includes the 34% of Canadians who report not owning a smartphone, and those living in rural and remote areas who do not have access to the Internet at all. The issue is not just present among rural and remote communities though; through symposium discussion we learned first-hand that



newcomers to Canada and those in the homeless shelter system struggle to gain access to technology in Canada's urban areas as well. The fact that particular communities have less access to technology has been referred to as the "digital divide",¹⁵ and has been documented across a variety of underserved groups (e.g., Indigenous peoples, older adults, homeless people, and those with lower than average literacy, among others).¹⁶

The digital divide extends beyond simply having access to technologies. The digital divide also includes cases where people distrust technology and the groups of people who govern it, are not educated about technology, or are driven away from using technology by inappropriate or irrelevant content in digital applications. As an example of distrust of technology, a history of active marginalization of Indigenous Peoples through practices of settler colonialism (the continued phenomenon of European and other settlers to North America forcibly making a particular way of life dominant at the expense of Indigenous life and sovereignty) has in some instances created informed distrust in formal systems such as health care. This means that Indigenous communities may be wary of using digital technologies for health, especially when deployed by these same institutions. An example of potential users being driven away from technology is where limited understandings of sex and gender are incorporated directly into digital technologies, such as prompting users to select between only two options of gender (man and woman).

The issue of the digital divide raised two important questions at our symposium. **First, who is responsible for enabling access to technology?** Although there is no single, clear group responsible for enabling access to technology for everyone, many in the discussion agreed that the Provincial Government could lead in the development of programs that progress toward the goal of access to technology for all. However, it was also clear that this would require collaborative effort across sectors, including private companies who build, market, and sell such devices. **Second, what strategies can be employed to promote the deployment of technologies in health care in inclusive ways?** Addressing this second question will also require cross-sector collaboration, as presented in our action items.



2. Not all problems are best solved by technology.

There is much excitement about the potential of digital technologies to contribute to addressing important challenges in health care systems, such as supporting strategies to achieve more integrated care¹⁷. Despite the great potential of digital technologies in health care, many of the most important problems in health systems cannot be addressed by technology. For example, the challenges with housing affordability in many urban settings, and related issues of homelessness, cannot be addressed with digital solutions. These issues arise as a result of a complex interplay of influences that extend from the past experiences of individuals, to the broader economic and social systems in which health care is situated, to the accessibility of mental health care. These broader influences refer to the social determinants of health, and require upstream investment outside of a focus on digital technologies in health care.

3. Technology should be designed with underserved communities.

Efforts to promote the use of digital technologies among underserved communities have taken place around the world, including with Canada's Indigenous communities.¹⁸ One point that was raised repeatedly in symposium discussion was the fact that technology cannot bypass longstanding historical issues, such as Canada's colonial history. This means that technologies cannot just be developed by non-Indigenous people and dropped into Indigenous communities with the expectation that they will be accepted and will help promote health and improve access to health care. The process of reconciliation with Indigenous Peoples in Canada requires humility, time and attention. This process needs to progress substantially before any digital health innovation can be optimally used when providing health care with Indigenous communities. The success story of the Mustimuhw Health Information System is one example of where digital health technology design can take place while respecting this history.

In addition to the need to address broader issues of Canada's colonial past, there was agreement in symposium discussion that digital technology tends to "go upmarket". This means that digital solutions tend to be created with customers in mind who have



extra funds to pay for new and exciting digital tools, a natural goal for technology vendors who need to earn revenue in order to survive. Many of the most complex challenges in health care around the world arise from the inability of health systems to adequately meet the needs of people who live with lower incomes, precarious housing, and other economic disadvantages¹⁹. These are communities of people who are systematically disadvantaged by the digital divide, and have less access to technological solutions that might be deployed in health care²⁰.

In response to these realities, symposium participants discussed the possibility for digital technologies to be designed in ways that acknowledge and address some of these challenges. One suggestion was that **digital tools be designed with particular underserved communities**, including the effort to engage users in technology design that fall outside of the groups considered to be the typical imagined technology user. This could include hosting user experience and other design sessions with Indigenous, LGBTQ+, disabled, newcomer and under-housed communities, and others who might be considered underserved. Such an approach could be considered more ethically oriented and inclusive of diversity, intending to design technology that is relevant for a wider population and capable of addressing some of the challenges faced by health systems and the population at large. Building resources and capacity to support such ethically oriented design is one important action item arising from our symposium.

4. Policy and procurement should focus on real needs.

Policy and procurement for digital health technologies should focus on meeting real needs of patients, caregivers and health systems. A central overarching point in symposium discussion was that the deployment of digital innovations in health care runs the risk of creating an even more fragmented and unequal system, in contrast to patients' expectations of health care. Symposium participants emphasized that digital technologies must meet actual needs in the health system, including real needs of patients and the public. Many such needs were clearly identified, including enabling people to better manage chronic conditions outside of the formal health system. However, the proliferation of health-related apps and challenges in promoting interoperability means that there is real risk of further fragmentation in the system. For



example, where data from a diabetes self-management app cannot be easily shared with a clinician, the information from the app might contradict input from the clinician; this might result in confusion for the patient and a lack of consistent, clear information exchange in the health system. Additionally, if a patient does not want dimensions of the data from their app shared with their clinician(s), as might be the case for patients who do not feel safe sharing this data, these wishes must also be respected. The vision for health care in Ontario is built around integrated, high functioning teams, the central role of primary health care, and strong inter-organizational collaboration. Digital health technology should be deployed in service of this vision.

One strategy to ensure that digital innovation supports the vision for optimal performance in the health system was to build the uses of digital technology around the central feature of patient-provider relationships in primary health care. With primary care as the centerpiece of more integrated care, technology could be deployed to enable patients' improved access to information and support from primary care providers. Assuming that all patients in a particular practice indeed have access to connected digital devices, technology could not only enable patients' to better manage their conditions between primary care visits, but also to better understand the continuum of care in which they are involved. In this way, technology could also help the primary care provider to understand a patient's access to other services within the system. If further work is done to promote access for everyone to such digital technologies, applications of technology for digital health that are focused on enhancing the patient-provider relationship could make meaningful contributions to an integrated, relationship-focused health system.

5. The fundamentals of a digitized health system need attention before digital health can meet its potential.

A variety of foundational issues were raised at the symposium regarding the basic infrastructure for the deployment of digital technologies across the health system. A first and commonly raised issue was the nature of the digital infrastructure in Ontario's health system. There are currently 15 Electronic Medical Record (EMR) offerings that are validated by OntarioMD²¹, and many more are used across community-based,



hospital, and rehabilitation care settings. This fragmentation poses problems for the use of digital technologies to promote more integrated, coordinated care. However, this issue is not currently under the direct control of any single group. The self-regulated nature of health care providers and the privately operated nature of most health care organizations means that each provider group is able to use the health information management system that they can afford and works for them. The same goes for the broader range of digital health technologies. Obviously there is no single, clear solution to this challenge. However, strategies to promote meaningful interoperability warrant a great deal of attention if the vision of a digitally enabled health system is to be achieved.

In addition to the digital infrastructure for personal health information, the policy that structures health information *sharing* and *electronic health records* specifically was identified as requiring attention. The Ontario government is currently undertaking a review of the Personal Health Information Protection Act (PHIPA), and is also in the process of developing a new Ontario Data Strategy. These efforts represent the importance of modernizing policy to enable the sharing of health-relevant information that can be used in service of enhancing health care. These processes should be led and informed by Black and Indigenous communities and should adhere to the terms presented in the OCAP principles. The deployment of digital technologies in health generates new forms of health-related data, and further work needs to be done in partnership with Black and Indigenous communities regarding when and how that data will be accessed by health care providers, healthcare organizations, governments, private companies, patients, caregivers or become a part of a patient's formal health record. One important point that was emphasized by participants was that there are various interpretations of the rules governing health information sharing across Ontario. A key action item raised at the symposium was for the government to clearly identify effective education strategies for the health care community as a whole regarding when and how health information can be shared.

A final and important point in relation to the infrastructures of digital health pertains to the sorts of data that are collected and made available for planning health care strategy and delivery. While symposium participants explained that there is no consistent or systematic process for collecting relevant socio-demographic information



across Ontario's health care organizations and noted that such data (including preferred language, cultural identity, ethnicity, gender identity, and income level) are important for health system planning, these efforts must be approached with a nuanced understanding of the complex challenges associated with collecting this data for many populations. While this data can be used to reveal gaps in health and social care, outcomes and service delivery, a number of issues must be addressed regarding the nature and collection of this data. Prior to collecting new socio-demographic data, existing socio-demographic data should be used to undertake health system planning. Efforts to use this data to address systemic disparities for underserved populations must be prioritized and led by these communities since meaningful reductions in health and social disparities for many of these populations experiencing these gaps have often remained unaddressed²². Moving forward socio-demographic data collection practices should be informed by underserved populations, especially Black and Indigenous populations, who have historically been excluded from the processes used to collect data about them²³. These populations should lead the conversations about ownership, accessibility, and the terms regarding opting out of the collection of this data.

Lastly, applications of artificial intelligence technology that rely on data to train algorithms also illustrate a need to examine how existing datasets represent underserved groups. This is of particular urgency because of racial biases that have been embedded in algorithms which misrepresent the health needs of racialized populations and can lead to undue harm for them²⁴.

Ultimately, these observations points to the need for much greater investment in public education and consultation with underserved groups about the potential reasons for collecting a variety of data in health care settings, how it should be done, how it can be used, how ownership should work, and how individuals can opt-out of such data collection practices. Ethically-oriented design, with a particular focus on issues of health equity, was identified here as another way to contribute to a more equitable health system by building on thoughtfully collected data to inform more equitable decisions in health care delivery.



ACTION ITEMS

Action items raised at the symposium were discussed in terms of their implications for a wide variety of stakeholders, including policymakers, health care providers, and technology vendors. However, many were focused on the role of the Provincial Government as a leader in setting the direction for the role of digital technologies in health care in Ontario. The recent Digital First for Health strategy is a testament to this leadership,²⁵ and represents important future investments in digital health for a sustainable and high-performing health system. The action items we report here are a synthesis of input from stakeholders at the symposium, and are directed to the Provincial Government given its important role in health system planning. Action items for the Provincial Government are organized into a 4-point plan for promoting equity in digital health policy. The 4 points are presented below.

Box 2. Learning About Colonialism

A number of the recommendations arose through stakeholder discussion related to the importance of all stakeholders learning more about colonialism and its consequences in present day Canada. The Truth and Reconciliation Commission has advanced this work, and all stakeholders would benefit from becoming familiar with the insights it has generated.²⁶ The responsibility for enhancing education about existing biases, structural challenges for underserved communities, and the continued impact of history on some communities is shared by all of us. We set out the effort to learn more about these realities as an overarching recommendation that should be adopted by all stakeholders, and would strengthen policymaking oriented toward promoting equity in digital health innovation.

1. Invest in collaborations that aim to address the digital divide.

The Provincial Government is uniquely positioned to coordinate the activities of the many stakeholders who need to work together to address the digital divide. This includes technology vendors, other branches of government, and members of the communities affected. There is important work already under way to enable access to



technology for everyone in Ontario, and this important work is worth further investment. Four specific strategies are linked to this point in the action plan:

- a. Create opportunities for cross-ministerial collaboration on ways to address the digital divide, which might include representation from Economic Development, Job Creation and Trade, Government and Consumer Services, Infrastructure, Seniors Accessibility, Health, and Long Term Care.
- b. Ensure there is representation from diverse communities in discussion about strategies to address the digital divide at the governmental level. Community members can correct misperceptions and help to establish meaningful solutions to challenges. It is important to understand that meaningful engagement requires ongoing efforts to build trust, which includes the long-term effort to build relationships among the people engaging in this work.
- c. Invest in providing digital infrastructure to underserved communities, such as in Ontario's homeless shelters and in rural or remote communities.

2. Promote the design and procurement of digital health technologies in ways that support health equity.

Although the government does not design digital health technologies directly, it does set out the framework and vision for how digital health tools will fit within the health system. The Ministry of Health has the opportunity to emphasize the importance of equity considerations in the design of technologies that are to be used in Ontario's health care system. The Digital Health Playbook produced for Ontario Health Teams does explicitly state that equitable access to digital technologies for health care is essential, but does not provide any guidance related to incorporating equity more strongly into digital health procurement and implementation decisions. A clearer emphasis on the importance of health equity when digital health tools are being considered would promote greater attention to equity-related issues as digital health is deployed across the system. Two specific strategies are linked to this action item:

- a. Clarify the importance of considering health equity implications of implementing digital technologies in Ontario Health Teams in the Digital Health Playbook and other resources.



- b. Provide guidance to digital health vendors about existing resources to inform equity-oriented design of digital health tools.
- c. Establish processes to monitor the performance of digital tools on health equity outcomes specifically.

3. Incorporate equity considerations into the development and review of health information policy.

The value of health-related data will continue to climb as the ability to exchange information between health care settings grows, and as health-related applications of artificial intelligence are designed and built. Modernizing health information policy is an essential step toward enabling such innovation while protecting the rights of patients in Ontario and engaging underserved communities and specifically Black and Indigenous populations in these efforts will be key in advancing this work. The review of the Personal Health Information Protection Act (PHIPA) should be assessed from a health equity perspective, enabling a revised health information policy framework to both enable innovation and promote equity. Three strategies arise from this action item:

- a. Conduct reviews of health information policies and legal frameworks in Ontario from a health equity perspective.
- b. Recognizing that Black and Indigenous communities have been historically excluded from the process of data collection about them, efforts regarding the collection of socio-demographic data such as income, race and ethnicity should focus on ways to centre and learn from Black, Indigenous, and other peoples of colour. These groups should be engaged to develop meaningful educational strategies for community organizations, health care providers and researchers regarding when and how health information can be collected and shared, data accessibility and ownership, and the potential ways it can be used.
- c. Develop educational strategies for the public about the nature of health-related and socio-demographic data, circumstances under which it is collected, and the potential ways it can be used, led and informed by racialized and Indigenous community members.



4. Continue to invest in strategies to address complex needs and the social determinants of health.

One point that became clear at the symposium was the reality that digital technologies cannot solve every problem. There are certain issues that require investment elsewhere in the system if ‘hallway health care’ is going to be addressed, such as enhanced community-based care and investment in supportive housing. These “upstream” investments must continue to be made in order to enable the health care system to achieve goals related to enhancing health equity. Two strategies arise from this action item:

- a. Support inter-sectorial innovation that involves collaborations across health care, mental health supports, housing, and other social services to address the social determinants of health.
- b. Support the engagement of underserved communities specifically in the effort to co-design and plan health services to ensure they are relevant and addressing real needs.

CONCLUDING COMMENTS

The digital health innovation ecosystem is a complex network of stakeholders, each with different incentives and assumptions about the role of digital technologies in health care.²⁷ Promoting the goal of enhancing health equity through digital tools is made challenging by this complexity. However, with appropriate guidance and other supports, enhanced collaboration between stakeholders and stronger community engagement can lead to equity-enhancing digital health innovation.

We believe the community of stakeholders involved in the health innovation ecosystem shares responsibility for one important future direction in particular. If digital technologies, including emerging applications of artificial intelligence, are going to serve the goal of an equity-enhancing health system, then investment must be made in the effort to establish guidance for the design, implementation and evaluation of digital health technologies specifically from an equity perspective and with the input of underserved communities, most notably Black and Indigenous populations. A growing



body of research on ethical design already exists,²⁸ and equity-focused frameworks for implementation science are also beginning to emerge.²⁹ But turning these into practical guidance that is relevant for digital health in the context of health care in Ontario requires work to think about the relevance of these frameworks for each stakeholder involved. Pockets of interest in achieving this goal can be found across Ontario and elsewhere in Canada; it is the responsibility of all stakeholders in Ontario's health innovation system to work together to establish such guidance in ways that are practical, meaningful, and satisfying to members of the communities affected.

If this important work proceeds under the vision and leadership of the Ministry of Health in Ontario, then digital health technologies can fulfill the goal of contributing to a more equitable health system while also contributing to the efficiency and quality of care. The issues and action items we have laid out in this discussion paper help to clarify some important dimensions of the work ahead, and strong collaboration can make the vision articulated here a reality.



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