Realizing the Equity Potential of E-Health: Improving Health Promotion and Self-Management in Ontario
# Table of Contents

Introduction .......................................................................................................................... 1  
  Ontario’s Commitment to Equity .................................................................................... 1  
What is e-Health? ..................................................................................................................... 2  
Ontario’s e-Health Strategy ................................................................................................. 3  
The Potential Benefits of e-Health ....................................................................................... 4  
  Patient Empowerment ....................................................................................................... 5  
  Improved Patient Safety ..................................................................................................... 5  
  Better Communication between Providers and Patients ...................................................... 6  
  Adherence to Preventive Measures ...................................................................................... 6  
  Increased Access to Health Information ................................................................................ 6  
  Better Chronic Disease Management and Prevention ........................................................ 7  
  Improved Health Care System Efficiency ............................................................................ 7  
Barriers to the Effective Use of e-Health Tools .................................................................... 8  
  The Digital Divide and Access to the Internet .................................................................... 10  
  Lack of “Meaningful Access” .............................................................................................. 11  
  Language Ability ................................................................................................................ 11  
  Limited Literacy Skills ........................................................................................................ 12  
    Traditional Literacy ............................................................................................................ 12  
    Health Literacy ................................................................................................................ 13  
    E-Health Literacy ............................................................................................................. 14  
  Age .................................................................................................................................. 15  
  Disability .............................................................................................................................. 16  
  The Cultural Relevance of e-Health Tools .......................................................................... 17  
Using e-Health Tools to Improve Equity: Selected Examples and Lessons Learned .......... 17  
  CHESS ............................................................................................................................... 18  
  MiVIA ................................................................................................................................. 19  
  CAISI ................................................................................................................................. 19  
  The Veterans Health Administration (VHA) ....................................................................... 20  
  Using EHRs in Community Health Centres ....................................................................... 21  
Policy Recommendations: Making e-Health More Equitable in Ontario ............................ 22  
  Policy Recommendations for EHealth Ontario ................................................................... 22  

*Include equity as a specific, clearly articulated goal of EHealth Ontario* .......................... 22
# Table of Contents

Engage diverse users in the design of e-health tools .................................................. 23
Tailor and target e-health tools to diverse groups ......................................................... 24
Ensure that e-health tools are culturally appropriate ..................................................... 24
Develop and sustain key partnerships .............................................................................. 24
Engage community leaders (and “health ambassadors”) ................................................ 25

**Policy Recommendations for Local Health Integration Networks** ................................ 25
  Invest in equity-focused demonstration projects .......................................................... 25

**Policy Recommendations for Government Agencies and Community-Based Organizations** ................................................................. 26
  Increase meaningful access to the Internet ...................................................................... 26
  Improve health literacy .................................................................................................... 27
  Fund e-health tools and programs that improve health equity ........................................ 28
Conclusion ........................................................................................................................... 28
Introduction

The potential for electronic health information technology (e-health) to improve health outcomes, patient safety and efficiency is enormous. Advances in communications and computer technology have revolutionized the way that health information is gathered, disseminated and used by health care providers and patients. More efficient flow of health information can enhance access to services and improve quality of care, while the increased use of real-time data and knowledge can enhance system responsiveness and improve performance. Successful implementation of comprehensive e-health is indispensable for progressive and innovative reform in Ontario.

This paper focuses on the equity implications of e-health at the individual level. More specifically, it focuses on the potential of e-health tools to enable people to better manage their own health care and to support effective health promotion. An earlier Wellesley Institute paper by Bob Gardner analyzed how equity can be built into Ontario’s e-health strategy at the system level.

This paper will argue that while e-health has the potential to improve health equity and self-management, without recognizing and addressing the barriers that vulnerable populations face with respect to Internet access and health literacy, the proliferation of e-health tools will actually reinforce and exacerbate currently existing health disparities. It will begin with a discussion of Ontario’s commitment to equity and its e-health strategy. It will then discuss the potential for consumer-oriented e-health tools and resources to improve health care delivery and health promotion in the province. Its main focus will be on recognizing the barriers that vulnerable populations face to using e-health tools, and policy recommendations for overcoming those barriers and implementing an equitable e-health strategy.

Ontario’s Commitment to Equity


While both “patient-oriented” and “consumer-oriented” are used to refer to e-health tools that improve health promotion and self-management, this paper will use “consumer-oriented” throughout.

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3 While both “patient-oriented” and “consumer-oriented” are used to refer to e-health tools that improve health promotion and self-management, this paper will use “consumer-oriented” throughout.
the Ontario Health Quality Council identified equity as one of its nine attributes of a high performing health system. The Council stated that “there should be continuing efforts to reduce disparities in the health of those groups who may be disadvantaged by social or economic status, age, gender, ethnicity or language.” However, while the case for e-health tools as essential for sustainability and health care quality is commonly understood and frequently made, their impact on equity and reducing health disparities is less prominent or straightforward. Improving sustainability, quality and equity can be achieved through the increased use of e-health tools, but only if EHealth Ontario explicitly focuses on equity implications.

What is e-Health?

Broadly defined, e-health refers to the use of information technology resources, particularly the Internet, to improve the efficiency and accuracy of health care delivery. However, outside of the two key themes of technology and improved health care delivery, the specifics of the definition are fluid. Indeed, Oh et al. found 51 unique published definitions of “e-health” in the literature. The most commonly cited definition is Eysenbach’s:

*e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking to improve health care locally, regionally and worldwide by using information and communication technology.*

Jurisdictions across Canada and around the world have emphasized e-health as a vital element of restructuring and re-aligning their health care systems. Specific e-health tools include:

- Electronic health records (EHRs) in which a patient’s medical history is efficiently stored and easily and securely accessible to the clinician (and often to the patient) online and/or from many clinical locations. EHRs often include demographic data, prescribed and

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dispensed medications, known allergies, immunizations, laboratory test results, diagnostic imaging results and other medical reports;\(^7\)

- Providing platforms and systems for smooth exchange of patient and clinical information among providers across the system, as well as increased communication between providers and patients (such as secure email and instant messaging with physicians);
- Delivering health and health promotion information through the use of health websites (such as www.webmd.com, www.healthfinder.gov and www.healthyontario.com);
- Telehealth and other methods of providing health information and services to patients through the telephone and videoconferencing;
- Web Health Portals that allow individuals to access health information, self-help guides and answers to common health questions. Portals also enable patients to monitor and manage their conditions at home;
- Online wait-list registries that enable providers to share real-time information about patients awaiting medical procedures and allow consumers to choose the facility with the shortest wait.

The primary functions of these e-health tools are to increase access to and the effective use of health information, and to engender behaviour change among the user population.\(^8\) Other functions include personal health data storage, decision support, social or emotional support, chronic disease self-management, secure patient-provider communication and risk assessment.

**Ontario’s e-Health Strategy**

The Ontario Ministry of Health and Long-Term Care (MOHLTC) has amalgamated its various initiatives and programs on electronic health into EHealth Ontario, with a mandate to provide “a single, harmonized, coherent province-wide e-health strategy and align it through a single point of accountability.”\(^9\) EHealth Ontario recently released a new Strategy in which it set out key directions for modernizing health care information technology infrastructure and developing comprehensive electronic health records for all Ontarians by 2015.\(^10\) The proposed e-health Strategy focuses on three fundamental clinical priorities:

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\(^7\) For example, Alberta Netcare has developed EHRs that include each of these elements.


(1) *Diabetes treatment and care management:* to enable patients to self-manage diabetes more effectively and reduce unnecessary complications and costs;

(2) *Medication management:* to implement online management of prescription drugs and reduce preventable adverse drug events;

(3) *Wait times reduction:* reducing wait times in emergency rooms and for elective procedures.

EHealth Ontario will develop and implement information and communication technology systems designed to achieve better care and clinical outcomes in these critical spheres. The total cost of the Strategy is estimated at $2.133 billion over the first three years (2009-2012).

EHealth Ontario’s vision includes “achieving excellence in health care by harnessing the power of information” and the organization’s explicit goals include improving patient care, safety and access. However, the Strategy does not discuss or analyze the equity implications of the increased use of health information technology. A crucial lesson of health system change is that if equity objectives are not explicitly included in strategic priorities and in accompanying deliverables and resources, they simply will not happen.

**The Potential Benefits of e-Health**

The implementation of diverse and coordinated e-health tools could have a dramatic effect on health care delivery and performance in Ontario. Drawing upon research and experiences in other jurisdictions, the benefits of e-health include improvements in *quality, safety and efficiency* of the health care system. Significant evidence from these jurisdictions demonstrates the effectiveness, utility and benefits of e-health tools, although the evidence is uneven across categories of tools and user groups. Some of the potential benefits of e-health tools include:

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12 It should be noted that despite the lack of equity as an acknowledged goal of e-health initiatives, diabetes management is an excellent clinical priority choice from an equity perspective. Its incidence and impact is greater in more health disadvantaged populations and it follows a social gradient in which the poorer and most marginalized suffer most. If well planned and managed, improving diabetes management could have a disproportionately beneficial effect on the most disadvantaged. However, this equity impact was not mentioned in the e-health strategy. See Gardner, February 2008, p.4.

Patient Empowerment

A recent trend in health care provision has focused on empowering patients by enabling and encouraging them to be more active in the management of their own health. The thinking is that knowledgeable patients are better able to make informed health care decisions, stay healthy, seek services when needed and manage chronic diseases, than patients who are not as knowledgeable.

Patient empowerment is one of the key (and most often cited) benefits of increased health information technology use. Most e-health tools give patients access to their medical files and improved (and direct) access to a wide range of health information in order to enable them to make more informed health care decisions. Cashen et al. note that “the potential for e-health technologies in terms of empowering and enlightening patients and promoting improved self-management skills is well documented.”14 However, there are also “significant cognitive, social and cultural barriers” to understanding and using health information for disease self-management as well as inequitable access to computers and the Internet, especially for vulnerable populations.15 These barriers must be addressed if e-health tools are to empower patients with varying backgrounds and capabilities.

Improved Patient Safety

E-health tools can improve patient safety by exposing diagnostic or drug errors, increasing the accessibility of test results and alerting patients to take their medications at the right time. One U.S. study found that interoperable e-health tools could prevent more than two million adverse drug events per year and prevent 190,000 unnecessary hospitalizations.16 Furthermore, the availability of complete patient health information at the point of delivery together with clinical support systems (such as those for medication order entry) can prevent additional errors or adverse events.17


15 Ibid


Better Communication between Providers and Patients

Consumer-oriented e-health tools allow for improved communication between providers and patients (for example, through secure email or instant messaging with physicians). Secure email and web messaging have been shown to be effective in facilitating communication between providers and patients, which allows for better continuity of care and more timely health care interventions. Improved communication between patients and health care professionals also leads to increased trust between them, more confidence in patient self-care, increased compliance with chronic disease management and improved accuracy of health records.

Adherence to Preventive Measures

Providing reminder systems for patients and clinicians can improve compliance with preventive service protocols. For example, electronically generated reminders to patients for screening and follow-up measures have been shown to increase adherence to these measures by 10 to 15 percent. Adherence to preventive measures, in turn, reduces preventable illnesses and improves patient health.

Increased Access to Health Information

The Internet and e-health tools allow patients to access a wide variety of credible, relevant and current health information online, 24 hours a day. Many websites, some of which are publicly funded (like www.healthyontario.com), are designed to provide valid and useful information directly to patients. Furthermore, online health support groups can provide social support and information to participants in an anonymous context at any time. Patients can leverage their increased access to information to improve their health care and manage their diseases more efficiently and effectively.

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18 It should also be noted here that e-health tools should improve communication among providers which should improve efficiency and reduce unnecessary and duplicative procedures.


Although websites that are credible and organize or synthesize complex health information can empower patients, most health information on the Internet is complicated, and some of it is actually misinformation, not credible or outright false. Therefore, if patients are to benefit from the increased dissemination of information, they must have the capacity to understand the online information and to distinguish valid information and credible sources from incorrect information, bogus sources and advertisements. Evidence has shown, however, that vulnerable individuals (particularly older individuals, and those with lower education, literacy problems and disabilities) are not able to make these key distinctions, often do not check the sources of online health information and are distracted by graphics and advertisements.\(^22\)

**Better Chronic Disease Management and Prevention**

Another potential benefit of e-health tools is that they facilitate the management of chronic diseases, like diabetes. Ontario’s e-health Strategy is designed to effectively manage diabetes by providing individuals with access to information, education and tools required to self-manage the disease.\(^23\) EHealth Ontario’s goals are to improve the quality of life of Ontarians with the disease, reduce mortality and morbidity rates and decrease the cost of the disease to Ontario’s health care system.\(^24\) Evidence from Canada Health Infoway – a not-for-profit organization that promotes the accelerated use of electronic health records in Canada – indicated that EHRs and telehealth home care for chronic disease management and prevention can lead to 34 to 40 percent fewer emergency room visits; more than 32 percent fewer hospitalizations and up to 60 percent fewer hospital days; and a 47 percent reduction in long-term care admissions for individuals with chronic diseases.\(^25\)

**Improved Health Care System Efficiency**

Finally, e-health tools are designed to significantly improve the efficiency of the health care system. Currently in Ontario, almost all medical charts and prescriptions are still written out by hand, meaning that information is prone to being misunderstood, lost or not updated. Moreover, there is often little continuity of care as records are not easily shared among providers or across

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\(^24\) *Ibid*

\(^25\) Canada Health Infoway, 2006.
jurisdictions. Computerized e-health tools could, therefore, lead to a substantial improvement in the maintenance, availability and accessibility of patient data. They could also lead to more efficient and fluid sharing of health records among providers at the health care system level. Improved management of patient information will reduce duplication of services, reduce repeated and unnecessary tests and diagnoses, prevent drug interactions of inappropriate prescriptions and realize operational efficiencies. Moreover, increased use of e-health tools in Ontario could save money in the long-term by reducing costs to the system of repeat diagnostic testing and redundant record-keeping. According to Canada Health Infoway, fully implemented EHRs would lead to projected savings of six billion dollars annually across the country while it would only cost about one billion dollars per year over ten years.26

**Barriers to the Effective Use of e-Health Tools**

The potential of consumer-oriented e-health tools to significantly increase the quality, efficiency and safety of Ontario’s health care system is clear. Some health care analysts also believe that e-health tools have the potential to improve equity in health care. Ahern, for example, argues that e-health has the capacity to address health disparities among traditionally underserved populations at relatively low cost due to its scalability, increased efficiency, potential to target specific groups and conditions, and ability to be tailored and customized to culturally and linguistically diverse users.27 However, to achieve this potential, multiple barriers that disadvantaged individuals face in trying to navigate e-health tools would need to be overcome.

Ideally, all Ontarians, regardless of age, income, literacy levels, language spoken, culture or functionality would be able to effectively access, use and benefit from consumer-oriented e-health tools. In practice, however, most e-health tools require access to, familiarity with and competence on computers and the Internet. Even though Ontarians have the third highest percentage of Internet users in Canada (behind British Columbia and Alberta), significant segments of Ontario’s population still do not have access to or competence on the Internet. The most recent (2007) data indicate that 19 percent of Ontarians have not accessed the Internet in

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26 *Ibid*

27 Ahern, David K. et al. “What is eHealth (6): Perspectives on the Evolution of eHealth Research.” *Journal of Medical Internet Research* 8 (1), 2006, e4. For example, if an individual struggles with English communication and has trouble discussing their condition with a doctor, an electronic health record could prove beneficial. The doctor could simply read the EHR to determine what diagnoses were previously made, what tests were ordered and what medications were prescribed, even if the patient is unable to communicate those things. This could both improve health outcomes for the non-English-speaking patient and reduce costs to the health care system from redundant tests and diagnoses.
the past three months and 23 percent do not have Internet access at home. Moreover, the people with limited access to computer technology are largely the same as those who have less access to health information, poor health statuses, are traditionally underserved by the health care system and suffer the greatest disparities.

Since individuals with poorer health statuses also have less access to the Internet and health information, increased use of e-health tools will likely exacerbate health disparities and reduce equity unless the barriers to accessing e-health tools are recognized and addressed. According to Gilmour, “while the Internet could be a powerful medium for the democratization of health knowledge, in practice health inequalities underpinned by differential access to health services may be further reinforced by disparities in access to the Internet linked to ethnicity, education and economic resources.” Individuals with better access to web-based e-health tools will benefit from better health promotion and self-management tools, and will experience better outcomes. Therefore, those who are already advantaged will benefit the most from e-health tools, which will inadvertently widen health disparities. As Baur argues, “the accelerated diffusion of health information technology creates a moral and public health imperative to address e-health disparities” sooner rather than later.

Cashen et al. also argue that the Internet and e-health tools have actually caused and contributed to the persistence of health disparities because of the tools’ current inability to deliver content that is dynamically tailored to meet the cultural, language or literacy needs of the individual user. Most existing Canadian e-health tools are in English or French only, and are directed to those in “mainstream” cultures, out of reach to (or irrelevant for) minority and disadvantaged communities.

There are several barriers to the effective use of e-health tools by vulnerable populations which will be addressed in detail below. These barriers include: lack of meaningful access to the

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29 Viswanath and Kreuter, 2007, p.S131. For example, seniors and individuals with low incomes, low education, low literacy skills, disabilities and chronic diseases experience substantial health disparities and also have limited access to the Internet and computer technology.


32 Cashen et al., 2004.
Internet, limited English language skills, low literacy (both traditional and health literacy), age, disabilities and e-health tools’ lack of cultural relevance.

The Digital Divide and Access to the Internet

Owning or having consistent access to computer technology, including hardware, software and Internet connections, is essential for taking advantage of most consumer-oriented e-health tools. For example, accessing medical records and EHRs, disease management resources, reminder emails, health information websites and secure online communication with doctors all require that an individual regularly access the Internet. But extensive research has shown that communication inequalities exist as the Internet and other information technology is used substantially more by higher-income, more-educated, younger and employed groups.33

A clear digital divide exists in Canada. Country-wide, education, location, gender and age are significant factors in determining access to the Internet, but income (and cost) is the single most important factor affecting Internet access.34 A Canadian Internet Project research study found that while 92 percent of Canadian households earning $80,000 or more per year use the Internet consistently, only 58 percent of households earning less than $40,000 per year have regular access.35 Furthermore, only 53 percent of households earning less than $40,000 per year had home Internet access, compared to 89 percent of households earning more than $80,000 per year.36 Home access is extremely important for using e-health tools because of the sensitivity of health information which makes many people uncomfortable using public Internet kiosks to email health practitioners, search for or discuss sensitive health topics.

Although digital access is rising rapidly for all age groups, a stark digital divide remains for vulnerable populations most likely to be underserved by the health care system.37 Persistent digital disparities in access to and utilization of Internet resources will leave vulnerable groups less able to take advantage of the significant benefits and innovation offered by e-health tools.

36 Ibid., pp. 48 and 61.
Lack of “Meaningful Access”

Even if access to e-health resources were universal, however, the usability and content of e-health programs and services would still pose significant barriers to some user groups. Increasing physical access to the Internet and information technology is insufficient if individuals do not have the skills and resources to find relevant content and services. Access alone, if not accompanied by services, support and resources designed to reach and appeal to diverse populations, will not automatically improve an individual’s access to vital health information or their health outcomes.

This has led the U.S. Department of Health and Human Services to create a concept called “meaningful access,” which recognizes that in addition to physical access to the Internet, individuals need to be taught the skills required to use e-health tools on a sustained basis. Meaningful access includes proper equipment, Internet connections, skill development, ongoing technical support and web content that is appropriate for diverse users who learn and apply knowledge in different ways. Without meaningful access, digital disparities will reinforce health disparities among vulnerable populations, and e-health innovations will reduce health equity in Ontario.

Language Ability

The health professional workforce does not generally match the linguistic demographics of patients in Ontario, and language skills can be a prominent barrier to receiving quality care. Patients who are not comfortable in English often have problems understanding and communicating with their health care professionals which can lead to individuals foregoing health care interventions, failing to adhere to preventive measures and experiencing adverse health outcomes. The inability to speak English (or French) is an “enormous obstacle” for Ontarians – especially newcomers to the province – when seeking out health care.

Language skills are crucial to the use of e-health tools. If an individual speaks one language and the e-health tool is based on a different language, users are extremely unlikely to make use of the tool and its content. According to the 2006 census, more than 3.1 million Ontarians (about 26 percent of the population) have a mother tongue that is neither English nor French.

39 Ibid.
41 Statistics Canada. “Population by Mother Tongue, by Province and Territory (2006 Census).” Available at: http://www40.statcan.gc.ca/l01/cst01/demo11b-eng.htm
meaning that they may have problems with respect to e-health tools that are only available in the official languages. The lack of e-health content in an individual’s first language is a major barrier to the effective use of e-health tools.

**Limited Literacy Skills**

Even if an individual speaks and understands English or French, limited literacy skills act as a major barrier to the effective use of e-health tools. According to the American Medical Association Foundation, limited literacy skills are actually a better predictor of an individual’s health than age, income, employment status, education and racial or ethnic group.\(^{42}\) Moreover, in order to take advantage of e-health tools, an individual must be literate (in the traditional sense), health literate and e-health literate, which are all separate concepts that will be described below. If an individual lacks any of those literacies, he will not be able to take advantage of e-health tools, and he will be left behind in the e-health era.

**Traditional Literacy**

More than four in ten Americans and Canadians have low literacy, making it difficult for them to function in everyday society.\(^{43}\) Literacy skills are also unevenly distributed across the population as literacy rates are significantly lower among older adults and people with less education and lower incomes – those already most susceptible to health disparities in Ontario. That means that forty percent of the population who are already at-risk and might benefit from e-health innovations may have a great deal of difficulty understanding and applying e-health material. The difference between being functionally literate or not with respect to understanding, processing and using e-health information could mean the difference between taking a proper or fatal dosage of medication, or the difference between adhering to or neglecting preventive medical advice.\(^{44}\)

There is also a sharp disconnect between the readability level of online health information and population literacy levels. Large amounts of health information are too complex for a significant percentage of Canadians to understand and use. Studies have found that patient health material – including online material – is generally geared to an eleventh or twelfth grade level,
which is inaccessible to a significant proportion of the population, since the average adult reads at an eighth grade level.\textsuperscript{45} The result is that “the overwhelming amount of [health] information on the Internet is not usable by low literacy, non-English-speaking persons, nor is it appropriate for their information needs.”\textsuperscript{46} The lack of literacy impedes health promotion efforts and diminishes individuals’ ability to participate in effective self-management.

\textit{Health Literacy}

The Institute of Medicine has defined health literacy as “\textbf{the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.}”\textsuperscript{47} Health literacy is vital for individuals to navigate complex health care systems and better manage and improve their own health.\textsuperscript{48}

Currently, an estimated 90 million Americans (about 29 percent of the population) have low health literacy and struggle to follow simple self-care directions or prescription instructions.\textsuperscript{49} Individuals with limited health literacy skills – who generally include seniors, minorities, immigrants, low-income individuals and people with chronic mental or physical conditions – suffer from substantial health disparities because they have less knowledge of disease management and health promotion behaviours, have incomplete understanding of their health problems and treatment, and are less likely to use preventive services than those with average or above average health literacy.\textsuperscript{50} For patients with chronic illnesses, such as diabetes, low health literacy rates pose an additional barrier to education and disease self-management.

The proliferation of e-health tools and the dissemination of health information on the Internet will not benefit those with limited health literacy skills, because these individuals who will not be able to understand or process the information in order to make beneficial health decisions. Health

\textsuperscript{45} Gilmour, 2007, p.1274.

\textsuperscript{46} Baur, 2008, p.422.


\textsuperscript{49} Institute of Medicine, 2004. There is no similar statistic on the health literacy rate of Ontarians or Canadians, but there is little reason to believe that a substantially different percentage would have low health literacy.

literacy must be improved, particularly among underserved and vulnerable populations, before e-health tools will effectively reduce health disparities.

**E-Health Literacy**

In addition to basic literacy skills, the ability to understand and use e-health tools also requires that individuals have a working knowledge of computers and Internet functions, a basic understanding of science, and appreciation of the social context in which online health information is produced, transmitted and received; in other words, that individuals are e-health literate. Norman and Skinner have defined e-health literacy 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.” According to Norman and Skinner, there are six components to becoming an e-health literate person:

- Traditional literacy
- Information literacy
- Media literacy
- Health literacy
- Computer literacy and
- Scientific literacy

E-health tools present challenges to individuals with low literacy in any one of those areas. Indeed, “without moderate skills across all six literacies, effective e-health management will be unlikely.” Moreover, those who lack literacy in one or more of those areas are likely to be the same individuals who lack access to health information and suffer health disparities. In short, the “same barriers presented by reading print materials are being transferred to the Internet and compounded by the need to acquire additional skills to use the Internet and related devices” in order to receive, analyze and use health information.

Improving e-health literacy requires coordinated remediation and education involving partnerships among patients, practitioners, educators and community-based organizations. Without such effort in Ontario, e-health literate individuals who are competent in all six literacies

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52 Ibid
53 Ibid
54 Baur, 2008, p.421.
will benefit from increased access to e-health tools while those who have limited literacy in any one of the six areas will fall further behind.

**Age**

Senior citizens have a greater number of health conditions and use prescription drugs and health care services at a significantly higher rate than younger adults. As a result, seniors could potentially reap the biggest rewards from the Internet and e-health tools that help them manage their illnesses, communicate more frequently with their doctors and stay connected with family, friends and health care professionals. Policymakers are, therefore, increasingly trying to encourage seniors to obtain and use health information from the Internet.

However, a major study by the Kaiser Family Foundation in the United States found that fewer than one-third of seniors over the age of 65 (31 percent) have ever gone online and less than one-half (42 percent) have ever used a computer. There is also a “substantial digital divide” among seniors based on income, education, gender and age (younger seniors are significantly more likely to have used a computer and gone online than older seniors). Moreover, among seniors who do use the Internet, most neglect to check the source of online health information and may be unduly influenced by advertising or marketing.

The report concluded that while the Internet is a potential resource for some (particularly higher-income) seniors, “strategies that rely on the Internet as the primary means of reaching older [citizens] would clearly miss many seniors.” EHealth Ontario needs to recognize that a significant proportion of seniors may not be comfortable using Internet-based tools to access health information.

Moreover, even if they can access the Internet, seniors are more likely to have physical or cognitive impairments that limit their ability to use computers and navigate web-based e-health tools. Kaufman et al. studied how diabetic senior citizens were able to use e-health tools to manage their diseases. They found that elderly diabetics had three major problems using the

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56 Ibid, p.4

57 Ibid, p.10

58 Ibid, p.11

e-health tools: (1) perceptoral-motoric skills (especially with respect to using the mouse); (2) mental models (the basic understanding of system navigation) and (3) health literacy problems, including basic literacy and numeracy. Mastery of the mouse, using scroll bars and an inability to navigate screen transitions were extremely challenging obstacles for most of the diabetic seniors. Kaufman identified several barriers to effective use of e-health tools by diabetic seniors – a group which is especially relevant for EHealth Ontario because diabetes management is one of the agency’s three clinical priorities – that were related both to the web-based system’s complexity and to the essential competencies for self-management of a chronic illness.

Kaufman et al. concluded that there are “cognitive and usability barriers to the productive use of computer-mediated technology” which are “especially acute with respect to seniors.” Recognizing and addressing these barriers is vital for reaching the vast potential of e-health innovations. Otherwise, seniors – particularly older and lower-income seniors – will not be able to take advantage of increased e-health resources.

**Disability**

An estimated 1.85 million Ontarians have some type of disability (including visual, hearing, mobility, cognitive and learning disabilities) and this number is expected to grow as the population ages. Disabled individuals are much less likely to use Internet-based e-health tools because they face substantial physical access barriers, as well as barriers related to the design, content and delivery of electronic health information. In a study of forty current e-health tools, for example, only one made specific accommodations for people with hearing or visual impairments.

Without specific accommodations – which include multimedia presentations, breaking text into small chunks and allowing users to control the font size and other visual attributes – individuals with disabilities will be unable to take advantage of e-health tools and will continue to

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nurse care managers, online review of patients' clinical data and access to web-based educational materials designed to be accessible to elderly novice computer users in both English and Spanish.

60 ibid, p.359

61 ibid, p.360

62 ibid, p.356


64 United States Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2006, p. 29.
experience significant health disparities. Moreover, user-centred design and usability testing by disabled participants are also essential to ensure that e-health tools are accessible to all Ontarians.

The Cultural Relevance of e-Health Tools

Cultural differences affect how people access, process and use health information. Addressing cultural issues can support a person’s care-seeking activities, inspire trust and foster adherence to recommended treatment and self-management plans. However, even though culture is a significant variable in health communication, most current e-health tools have been developed for clients in the “mainstream.” These tools do not provide customized content and do not change dynamically to meet the needs of the individual accessing them.

Many web interface designs communicate ethnic identities in “unnatural and unyielding” ways. As a result, online health information is often seen as insensitive to diverse ethnic, religious, economic and cultural backgrounds by embodying the dominant group’s values and beliefs in its design and content. E-health tools must reflect the cultural values of the user to be acceptable, authoritative and for the user to follow them. Otherwise, these tools will become irrelevant or meaningless to minority populations. This has critical implications for e-health and health outcomes.

Using e-Health Tools to Improve Equity: Selected Examples and Lessons Learned

E-health tools definitely have the potential to improve health equity, but a variety of obstacles can prevent diverse individuals from accessing, using or benefiting from e-health innovation. Like other equity barriers within the health system, however, these problems can be addressed by innovative policy and programs. This section surveys several examples of e-health initiatives

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65 These types of accommodations can also be beneficial to other e-health consumers such as seniors or people with limited English proficiency.


67 Ibid


69 Ibid
– both from the United States and Canada – that have proven effective in reaching diverse and underserved populations.

CHESS

The Comprehensive Health Enhancement Support System (CHESS) was developed by the Center for Health Systems Research and Analysis at the University of Wisconsin. It is an Internet-based consumer health informatics system that focuses on people with serious diseases such as cancer and HIV/AIDS. The program includes consumer-oriented interactive computer-based programs that provide: (1) *information services* such as a Q&A section, reference articles on relevant topics and resource guides; (2) *decision services* through which users receive tailored advice on coping with their illness and tracking their health status; and (3) *emotional support services* which allow users to ask clinicians direct questions and create peer support groups for individuals in similar health predicaments. The program operates through phones, Internet and hand-held devices, personal computers and public kiosks. Some of the organizations that operate CHESS lend computers to patients who do not have their own for up to one year.

CHESS has been shown to improve social support, comfort with doctors and care prescribed, health information understanding, and quality of life among individuals who suffer from these diseases. Moreover, Gustafson et al. found that CHESS users from underserved populations showed greater improvements in outcomes and higher degrees of interest in the e-health tools than middle-class respondents. They found that women with less education and less insurance received more benefits from using CHESS and that the “underserved” used CHESS as much as more affluent whites. Underserved individuals used information services (such as FAQs and the library) and analysis services (such as decision analysis and health tracking) frequently and efficiently. Indeed, two groups traditionally considered to be on the wrong side of the digital divide (African Americans and the elderly) were as likely to accept and use the e-health tools as younger, more affluent whites. CHESS has demonstrated that with proper support and targeted planning, e-health interventions can improve access to information and communication tools in traditionally underserved populations.

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71 Ibid.


73 Ibid., p.173

74 Ibid., p.173
MiVIA

MiVIA (Spanish for “My Way”) is an electronic personal health record (PHR) that was originally designed to engage a very vulnerable population (migrant and seasonal farm workers) in Sonoma County, California. It was later expanded to include homeless people, those with special needs, women and children. It has been very successful and currently has approximately 5,000 members (1,100 of whom use the Spanish version). The PHR allows patients (called “members”) and their health care providers to access their medical information at different locations across the West Coast of the United States. The ability to access medical histories across several health care systems promotes continuity of care and empowers patients to be active partners in their own health care management.

The success of MiVIA is primarily due to the efforts of outreach workers (called “promotores”) who conduct enrolment and provide training in how to use MiVIA, as well as cultural and social support. They also check in with patients about their use of the program. The promotores have earned the MiVIA members’ trust and have been described as an “invaluable” resource for the program. MiVIA has also partnered with local libraries and community-based organizations to provide computers and English as a Second Language (ESL) classes to its members. MiVIA improves health equity by engaging traditionally underserved groups (particularly migrant workers and the homeless) in the management of their own health care. It reduces the divide between those who have access to digital and information technology and those who do not; facilitates access to health care and community services, clinics and libraries; and promotes health literacy.

CAISI

The Client Access to Integrated Services and Information (CAISI) Project was designed to use IT innovation to improve health outcomes and quality of life for Toronto’s homeless – another extremely vulnerable group. It is a collaborative effort between health care providers, agencies and homeless clients that includes two key elements. First, CAISI involves the development of an open source software infrastructure that allows for the e-integration of care between multiple agencies that deal with the homeless (such as shelters, hospitals, drop-in centres, primary care

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75 MiVIA. “About MiVIA.” Available at: https://www.mivia.org/about_us.aspx.
77 Ibid, p.50
78 Ibid
providers, etc.) through an electronic information system. If the client consents, an Electronic Medical Record (EMR) database is used to store their medical information. The EMR can be accessed at whichever hospital, agency or shelter the homeless person is seeking services. Health care (and other service) providers gain access to up-to-date information about homeless clients and can then coordinate care, reduce duplication, improve follow-up care and facilitate appropriate referrals, admissions and discharges, and program placements. Moreover, homeless patients avoid having to repeat their histories as they move from shelter to shelter or hospital to hospital.

The second element of the CAISI Project involves developing and improving the community’s capacity to use the infrastructure. Both the homeless and the multi-disciplinary agencies that serve them receive lessons on how to use and access CAISI. CAISI has been successful in responding to the health needs of homeless individuals in large part because it is a client-centred program that has involved homeless people directly on its planning committee. Chronically homeless clients work on developing the database and determining the kinds of information that need to be collected. CAISI users work with program developers and software programmers to make continuous improvements to the program that directly benefit them. As a result, the homeless – an extremely disadvantaged population – have benefited from improved access to medical (and other important) services.

In addition, CAISI has improved the community’s ability to gather data and information on the homeless population by providing real-time information on who is homeless and enrolled in shelter programs. This data can be used by policymakers, academics and homeless advocates to recognize the plight of the homeless and to encourage improvements in their access to urgently needed health care and social services.

The Veterans Health Administration (VHA)

In April 2000, the Veterans Health Administration (VHA) implemented an expansive telemedicine technology initiative in its Sunshine Network (covering veterans in Georgia, Florida, Puerto Rico and the U.S. Virgin Islands) where 1.5 million veterans reside, 45 percent of whom are over the age of 65. The initiative, the Community Care Coordination Service (CCCS), was designed to improve veterans’ self-management and health outcomes while

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reducing high (and skyrocketing) costs, particularly for high-risk, high-use and high cost veterans.\textsuperscript{82}

The CCCS uses several different technological tools in residential self-management, including telemonitors (which allow the patient to perform vital signs screenings, including blood pressure, heart rate, etc.) with a peripheral attachment that enables audiovisual contact with a physician; in-home audio messaging devices that allows a patient to give responses to screening questions that are then transmitted to a physician over the Internet; videophones; personal computers with Internet access that are placed in the patient’s home to enable him to use supervised chat rooms; and instamatic cameras for diabetic wound management.\textsuperscript{83}

The key feature of the program is that the primary technological tool used is based on the patient’s diagnosis, age and technical abilities, as well as evidence and product reviews, rather than whatever technological tool happens to be available at the time.\textsuperscript{84} After an assessment of the patient’s condition, skills and residential care setting, a care coordinator selects the appropriate technology that will best fit the patient’s needs.

The results of choosing appropriate technological tools have been overwhelmingly positive. Ryan et al. found that the veterans were extremely satisfied with the e-health tools.\textsuperscript{85} Ninety-four percent were satisfied with the primary technology device a year after enrolment, 93 percent found their technology device to be easy to understand, 95 percent found it easy to use and 87 percent found it generally reliable.\textsuperscript{86} The CCCS helped educate the veterans about their chronic diseases, helped them better manage their health, improved communication between patients and providers, and made the patients feel secure.\textsuperscript{87}

\section*{Using EHRs in Community Health Centres}

Community health centres (CHCs) are a major source of primary care for disadvantaged populations in both Canada and the United States. CHCs often deliver care to more complex patients.

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\textsuperscript{82} Ryan, Patricia et al. “Making the Right connection: Matching Patients to Technology. \textit{Telemedicine Journal and e-Health} 9 (1), 2003, p.82.


\textsuperscript{84} Ryan et al., 2003, p.82.

\textsuperscript{85} \textit{Ibid}, p.86

\textsuperscript{86} \textit{Ibid}

\textsuperscript{87} \textit{Ibid}
\end{flushleft}
patients – those with less education, income, lower literacy levels and more chronic illness, psychological and health problems – than traditional hospitals or primary care physicians. They are also a major source for improving health equity because they provide consistent, quality primary care to traditionally underserved populations.

A study in *Health Affairs* found that introducing electronic health records and IT infrastructure into American CHCs led to significant and substantial quality improvements in the delivery of health care.\(^{88}\) Even though the cost of getting EHRs into CHCs was high, patients received significantly better care and experienced improved health outcomes after EHRs were introduced. However, as in Canada, American CHCs tend to be chronically short of financial resources, which may slow their adoption of necessary EHR infrastructure.

**Policy Recommendations: Making e-Health More Equitable in Ontario**

This paper has set out a range of vital pre-conditions for individuals to be able to use e-health technology to increase their health knowledge and manage their own care. But access to these pre-conditions is very unequal and there are significant barriers to less advantaged populations being able to benefit from e-health tools. For Ontario to successfully implement health information technology, it is critical for health care policymakers and managers to identify strategies that recognize and address the significant challenges that disadvantaged populations face to effectively using e-health tools.\(^ {89}\)

Below are specific policy recommendations that would ensure that e-health resources improve health equity in the province. While EHealth Ontario has a substantial role to play in using e-health to improve equity, other policy solutions are better delivered by other government agencies, at the Local Health Integration Network (LHIN) level or by local community-based agencies.

**Policy Recommendations for EHealth Ontario**

*Include equity as a specific, clearly articulated goal of EHealth Ontario*

EHealth Ontario’s current Strategy does not address, or even mention, equity issues. The objective of reducing health disparities needs to be clearly spelled out in the Strategy and

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\(^{89}\) Baur, 2008, p.423.
improving health equity must be an explicit goal of increased e-health resource dissemination. There must be a conscious effort to ensure that advances in health technology work to reduce disparities between groups.90 A broad and inclusive vision of e-health will ensure equitable access to and appropriate content of e-health tools for all population groups.

Engage diverse users in the design of e-health tools

One critical way of ensuring that e-health initiatives benefit disadvantaged populations is for e-health developers to engage consumers – especially those from disadvantaged communities – more fully in the research and design process of specific e-health tools. This user-centred approach should place the needs, preferences, capacities, values and goals of diverse e-health users at the core (rather than the periphery) of e-health innovation.91

CAISI is an excellent example of a program that has engaged diverse users in the development of e-health tools. Homeless individuals are members of CAISI’s Client Advisory Board and are consistently involved in the functioning, updating and re-evaluating of the program.92 CAISI’s client-centred system gives users of the resources a say in how the Project will operate and what aspects need to be emphasized or changed in order to achieve maximum benefits for the homeless.

Engaging intended users in determining the needs for and design of e-health information content and intervention strategies is the most promising method of addressing issues of language and literacy.93 As with CAISI, consumers with diverse perspectives, circumstances, abilities and experiences must be involved in designing the content and services of e-health tools from the beginning through iterative testing and focus group analysis. In short, e-health tools must be created not just for but also by and with diverse communities.94

90 Gilmour, 2007, p.1276.
92 Ibid.
94 United States Department of Health and Human Services, Office of Disease Prevention and Health Promotion (2006) p.91
Tailor and target e-health tools to diverse groups

Currently, most e-health tools are inaccessible to low-income, low-literacy, non-English speaking persons who cannot use them to meet their health information needs. To be effective, user-centred e-health tools must be tailored to and targeted at individuals in these vulnerable populations. EHealth Ontario should consider proven and effective tailoring (audience segmentation) techniques that involve people from diverse communities in interactive and creative roles.95

Tailored e-health tools are more appropriate for diverse users in terms of cultural relevance, consistency, usability and comprehensiveness. They have been shown to be "more satisfying, read more deeply, seen as more personally relevant, and more often discussed with others" than non-personalized tools.96 EHealth Ontario should develop user-friendly web applications in multiple formats (i.e. audio and visual) and in multiple languages that are targeted at the consumers that they are trying to engage.

Moreover, there must be sufficient and effective usability training and testing of potential e-health tools. Effective training is needed to overcome access disparities resulting from poor computer skills (for example, among the elderly). E-health tools must also be tested on target audiences that are culturally and socioeconomically diverse and include limited-literacy populations in order to gauge the effectiveness, ease of use and value of these programs to vulnerable populations.

Ensure that e-health tools are culturally appropriate

Since cultural differences affect how people access, process and use health information, e-health tools must be culturally appropriate if they are to be accepted by and beneficial to diverse populations. Cultural relevance needs to be considered in the design of e-health tools rather than added in after-the-fact. Without culturally appropriate tools and interventions, e-health initiatives will not reach or resonate with diverse groups.

Develop and sustain key partnerships

EHealth Ontario should continue to involve key stakeholders and develop additional partnerships across the province as it implements its strategic goals. In order to provide access to training on e-health tools in underserved communities, the agency should partner with

95 Ibid, p.34
96 Ibid, p.35
hospitals, clinics, community health centres, libraries, community centres, schools, industry and the media to reach out to and involve target audiences. Building strong partnerships with community-based organizations is the only way to reach the most vulnerable populations. These partnerships and stakeholder relationships must encourage sustained consumer access to and use of e-health tools by diverse populations.

EHealth Ontario should also develop meaningful partnerships with each of Ontario's 14 Local Health Integration Networks (LHINs). The LHINs have already developed equity strategies and should work with EHealth Ontario to build e-health tools into these strategies and into their funding and accountability agreements with providers.

Engage community leaders (and “health ambassadors”)

Some members of disadvantaged communities do not feel comfortable with e-health tools and are sceptical of using the Internet as a source of health information. That is why EHealth Ontario and its partners implementing e-health initiatives should engage with community leaders who can define community needs, help design health informatics projects, and provide cultural, social and technological support to disadvantaged communities. If members of diverse communities are encouraged to use e-health tools by someone that they trust within the community, they are far more likely to consider e-health tools to be credible and reliable, and to use them.

Trusted community leaders, peer advisors and “health ambassadors,” like the promotores in the MiVIA program, are crucial to both explaining the potential benefits of e-health tools to their communities as well as teaching and training community members to be computer, health and e-health literate. The promotores are crucial to the success of MiVIA because they conduct substantial outreach initiatives to determine who could benefit from the program and they help disadvantaged individuals understand, appreciate and enrol in the program. Once members are enrolled, the promotores consistently check in with patients about the program, monitor their use and encourage changes in e-health strategies to enable additional community members to take advantage of the e-health tools. The importance of using community leaders as a bridge between e-health tools and disadvantaged communities cannot be overstated.

Policy Recommendations for Local Health Integration Networks

Invest in equity-focused demonstration projects

The fourteen LHINs should invest in demonstration projects that involve targeting e-health tools to disadvantaged populations (minorities, immigrants, poorer individuals) and testing e-health tools designed to overcome specific barriers (language, poor literacy, disabilities).
Experimentation through localized e-health programs is necessary to determine which e-health tools effectively reach diverse populations and which tools do not.

The LHINs can then share best practices across Ontario and invest further in those e-health tools and programs shown to benefit diverse populations.

**Policy Recommendations for Government Agencies and Community-Based Organizations**

*Increase meaningful access to the Internet*

Increasing physical access to the Internet and computers (at libraries, community centres and clinics) is crucial but insufficient to ensure that e-health resources are equitable. Increasing meaningful access includes providing and subsidizing proper equipment for and access to the Internet, as well as developing e-health content that is applicable and appropriate for individuals with different preferences and capabilities. Meaningful access also includes teaching and developing the skills necessary to use web-based resources effectively over a sustained period of time. Diverse users need the skills and support to evaluate, choose and use e-health tools to derive benefits for themselves and those they care for.97

The Ontario government, federal government and community-based organizations all have a critical role to play in increasing meaningful access to the Internet. Federally, Industry Canada’s Community Access Program (CAP)98 has established Internet centres in remote, rural and urban communities across the country in an effort to bridge the digital divide. It is designed to reach Canadians who do not have access to the Internet because of economic, social, educational or geographic barriers. Under CAP, computers have been placed in public locations like schools, libraries and community centres, and computer support and training have also been provided.

Provincially, since 2007, the Ontario government has spent more than $70 million to increase broadband access in rural areas in Southern and Northern Ontario.99 The Ministry of Government Services (MGS) should work with other provincial ministries to continue its investment in Internet access for rural areas, particularly since rural Ontarians suffer significant Internet access and health disparities. Moreover, the MGS should invest more heavily in computer training and support for all disadvantaged Ontarians, not just those in rural areas.


Community-based organizations, including schools, community colleges, libraries and non-profit institutions must also continue to work at both increasing access to the Internet for diverse populations and training individuals to effectively use and understand e-health resources. For example, organizations such as Sky’s the Limit\textsuperscript{100} which purchases refurbished computers and provides Internet access and training to under-resourced students, should be supported to continue their positive work towards reducing Ontario’s digital divide.

\textit{Improve health literacy}

Understanding and improving the gap in health literacy is “an issue of fundamental fairness and equity” and is essential to reducing health disparities.\textsuperscript{101} It is also crucial for developing effective e-health tools. Provincial government agencies and community-based groups can coordinate their efforts in order to educate individuals with limited health literacy so that they can develop the necessary skills and knowledge to use health information resources. The Ministry of Health and Long-Term Care (MOHLTC) and the LHINs must perform significant and substantial outreach in order to enable Ontarians from all backgrounds to find, seek and analyze relevant health information both online and through traditional sources. The Ministry of Training, Colleges and Universities (MTCU) currently provides several useful (often free) adult learning courses.\textsuperscript{102} Literacy and basic skills courses could include components on health literacy and should include elements that are specifically designed to help individuals in the program better manage their own health. Currently, however, the Literacy and Basic Skills Program requires individuals to speak English or French in order to enrol.\textsuperscript{103} The program should be expanded to help all individuals learn basic literacy skills and improve their health literacy capabilities, regardless of their official language competence.

Community-based organizations, such as public libraries, community groups, schools and community colleges should also offer health literacy programs that target low health literacy (and limited English proficiency) Ontarians. This will lead to improvements in health literacy for the least literate and should enable more people to effectively understand and use e-health tools.

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\textsuperscript{100} Sky’s The Limit. “Inspiring Digital Dreams.” Available at: \url{http://www.stlonline.org/}. \\
\textsuperscript{101} United States Department of Health and Human Services, Office of Disease Prevention and Health Promotion. “Healthy People 2010,” pp. 11-15. \\
\textsuperscript{102} Ontario Ministry of Training, Colleges and Universities. “Adult Learning.” Available at: \url{http://www.edu.gov.on.ca/eng/tcu/adultlearning/}. \\
\textsuperscript{103} \textit{Ibid.}
\end{flushright}
Invest in E-Health Infrastructure in Community Health Centres

The increased use of EHRs and other e-health tools in community health centres has the potential to considerably increase the quality of health care for disadvantaged populations who disproportionately use CHCs. This will lead to improved health outcomes for these populations, reduced disparities and increased efficiency at CHCs.

The MOHLTC and LHINs should recognize the quality improvement potential that can be achieved from funding EHR infrastructure in CHCs and other community-based providers, and should commit to investing in e-health infrastructure for Ontario's CHCs. This investment should include adequate technology infrastructure, proper training for front-line intake workers and service providers, and trouble-shooting support staff at CHCs. LHINs should study the effectiveness of, and best practices for, implementing e-health and EHR initiatives at CHCs.

Fund e-health tools and programs that improve health equity

EHealth Ontario should assess and evaluate which e-health tools and programs benefit underserved populations and improve health equity. For example, does increasing computer and Internet access in libraries, community centres, CHCs and clinics most increase access to health information and improve health outcomes? Would providing MiVIA-type outreach or additional Community Health Workers (CHWs) in underserved neighbourhoods improve health literacy and/or computer skills?

Demonstration projects across the province could be used to determine answers to some of these questions. Once the projects are assessed and tested, EHealth Ontario and the LHINs can determine which tools and programs improve health equity. The MOHLTC should then provide appropriate funding and incentives to implement e-health tools that have proven, evidence-based effectiveness in reducing health disparities and improving health outcomes for disadvantaged populations.

Conclusion

E-health is the wave of the future for health care delivery in Ontario and across the developed world. Consumer-oriented e-health tools have tremendous potential benefits, particularly for improving health care quality, efficiency, and patient safety and self-management. They also have the potential to reduce health care disparities and improve health equity. But there are significant barriers for many segments of the population – especially the elderly, low-income, low-education, limited-literacy, disabled and non-English (or French) speaking populations – to realizing the benefits from these technological innovations. Policymakers need to explicitly recognize and address these barriers in order to ensure that promising developments in e-health technology benefit all Ontarians, including the underserved and vulnerable. That is the
only way that e-health tools will work to reduce disparities and fulfill their potential to improve health for all in the province.