

eHealth Advances in Support of People with Complex Care Needs: Case Examples from Canada, Scotland and the US

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Abstract

Information technology (IT) in healthcare, also referred to as eHealth technologies, may offer a promising solution to the provision of better care and support for people who have multiple conditions and complex care needs, and their caregivers. eHealth technologies can include electronic medical records, telemonitoring systems and web-based portals, and mobile health (mHealth) technologies that enable information sharing between providers, patients, clients and their families. IT often acts as an enabler of improved care delivery, rather than being an intervention per se. But how are different countries seeking to leverage adoption of these technologies to support people who have chronic conditions and complex care needs? This article presents three case examples from Ontario (Canada), Scotland and Kaiser Permanente Colorado (United States) to identify how these jurisdictions are currently using technology to address multimorbidity. A SWOT (strengths, weaknesses, opportunities, threats) analysis is presented for each case and a final discussion addresses the future of eHealth for complex care needs. The case reports presented in this manuscript mark the foundational work of the Multi-National eHealth Research Partnership Supporting Complex Chronic Disease and Disability (the eCCDD Network); a CIHR-funded project intended to support the international development and uptake of eHealth tools for people with complex care needs.

Introduction

Information technology use in healthcare, or eHealth, has become increasingly prominent since the late 1980s. A frequently cited definition of eHealth (Oh 2005) identifies it as “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” (Eysenbach 2001: e20). eHealth technologies may include the following: software systems like electronic medical/health records (EMRs/EHRs); clinical decision-support tools; health information websites; web-based portals for patients, clients and providers; health education programs; and telecare and mobile health (mHealth) technologies used to enable delivery of healthcare and social-care services and support in individuals’ homes (Boonstra and van Offenbeek 2010; Kreps and Neuhauser 2010).

There are a number of areas where eHealth technologies could support the healthcare needs of people living with complex chronic disease and disability (CCDD). People with CCDD can be characterized as having multiple chronic conditions (multimorbidity) as well as social/contextual challenges that make management of their health difficult (Barnett 2012; Schaink et al. 2012). A study of community-dwelling individuals with CCDD revealed that they require improved person-centred bi-directional information sharing between

patients and their primary care and other care providers (such as specialists and allied health professionals), as well as bi-directional information sharing between different professionals and care providers to improve their care delivery (Steele Gray et al. 2014). EMRs and EHRs, telemonitoring and web-based applications and resources may address these needs through improving coordination, continuity and access to services and information for both patients and providers (Barakat 2013; Becker 2014; Burton et al. 2004; IHI 2003; Lester 2011; McLean and Sheikh 2009; Pagliari et al. 2007; Seto et al. 2012).

While there is significant potential to use eHealth to improve care planning and delivery, it is not clear how different countries are leveraging these technologies to support people with chronic conditions and complex care needs. This article presents a SWOT analysis (strengths, weaknesses, opportunities, threats) of three case examples from Ontario (Canada), Scotland and Kaiser Permanente Colorado (KPCO, US) with regard to adopting eHealth technologies to support people with CCDD. The case reports presented mark the foundational work of the Multi-National eHealth Research Partnership Supporting Complex Chronic Disease and Disability (the eCCDD Network), which aims to foster the international development and uptake of eHealth tools for people with complex care needs.

The information presented is based on site visits by the lead author to Scotland and Colorado, as well as the knowledge and input of those in the collaboration who work in the area of eHealth/IT and multimorbidity and complex care needs in each of the three jurisdictions.

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Ontario Overview

Canadian provinces receive federal funding to cover medically necessary hospital and physician services for citizens, as stipulated under the Canada Health Act, 1985 (Canadian Parliament 1985). Provinces have the option to invest more than this minimum requirement to fund other services like rehabilitative care, residential care, home and community care services and medications. This approach results in variation around who pays for what services across Canada (Marchildon 2013). Overall, about 70% of total healthcare expenditure comes from public sources (CIHI 2015).

In Ontario, the Ministry of Health and Long-Term Care (MOHLTC) funds healthcare services through an insurance

model. Funding for services flows through 14 regional bodies called Local Health Integration Networks to healthcare organizations to deliver services to Ontario citizens, with the exception of physicians who are paid primarily through a fee-for-service basis directly from the MOHLTC. In Ontario, 79% of total health-system costs are used by only 10% of the population (Commission on the Reform of Ontario’s Public Services 2012); many of these “high-cost users” tend to be those with multiple chronic conditions and complex care needs living in the community (Rosella et al. 2014).

Ontario SWOT analysis

Strengths

Government support for EHRs, information sharing and telehealth: There are three main government agencies that support eHealth adoption in Ontario: (1) eHealth Ontario, established in 2008 to enable the adoption of EHRs in Ontario; (2) Ontario Telemedicine Network, which develops and supports telemedicine solutions including remote patient monitoring, virtual visits and videoconferencing for multidisciplinary teams (Ontario Telemedicine Network 2015); and (3) Canada Health Infoway, a federally funded agency established in 2001 to co-fund eHealth projects with provinces and territories (Canada Health Infoway 2015). These agencies additionally support several programs to improve patient information sharing across provider teams and organizations (eHealth Ontario 2015). Of particular note is the EHR Connectivity Strategy lead by eHealth Ontario intended to support a provincially integrated EHR system (eHealth Ontario 2016a), which includes the connecting GTA program, to create an information hub that houses EHR data from acute and community care sectors (eHealth Ontario, 2016b).

Foundational legislation and regulations and supportive policies: The Personal Health Information Protection Act, 2004 (Ontario Legislature 2004), along with the Privacy and Data Protection Policy, 2014 (eHealth Ontario 2014), offers important measures to support data security and privacy. In 2010, the MOHLTC expanded subsidies for purchasing and implementing EMRs to all physicians. This initiative helped to increase the saturation of EMR use in the Province from 44% in 2009 to 65% in 2012 (Hutchison and Glazer 2013).

Third sector innovation hubs, incubators and accelerators: A number of innovation hubs and incubators support the development of new eHealth and mHealth solutions for a variety of chronic-disease populations. Many of these hubs operate on a not-for-profit basis and are fully or partially supported through government funding, with many housed within academic hospitals or universities. Innovators from these settings can also reach out to Ontario Centres of Excellence (funded by the Ontario government) to help market, scale and spread innovations (Ontario Centres of Excellence 2015).

Weaknesses

While adoption of EMRs by physicians continues to grow, the existing operations do not adequately support disease management and registries and systems are plagued by interoperability challenges (Hutchison and Glazer 2013: p. 700). A lack of federal or provincial guidance with regard to an eHealth strategy or national infrastructure (Rozenblum et al. 2011) has left Ontario with dozens of legacy EMR systems with “no viable way of assembling a comprehensive and accurate healthcare view of any one patient anywhere in the province” (Powers 2011: p.e30).

Beyond interoperability challenges, other weaknesses in the system include the following:

- eHealth technologies are often insufficiently focused on user needs (Ontario Medical Association 2015)
- Most technologies focus on single-disease populations, with few meeting the needs of “high users” (Becker 2014) like people with CCDD.
- There are few instances of links between healthcare and social-care organizations, making it difficult to wrap a full range of services and supports around individuals who need them.

... the existing operations do not adequately support disease management ...

Opportunities

Since 2013, the MOHLTC has been seeking to address the needs of the “high user” population through improved integration of hospital, primary care and home and community care services via Health Links (Ontario Ministry of Health and Long-Term Care 2015). There is an opportunity for the Ontario government to provide guidance to Health Links, with regard to adopting new technologies that can support people with CCDD. One notable example is a pilot project being run by a branch of the MOHLTC testing the adoption of an electronic Coordinated Care Plan (Huron Perth Health Link 2014).

While Ontario’s eHealth funding with minimal top-down strategy has led to significant system fragmentation, it has also resulted in a wealth of new innovations in the eHealth and mHealth space; a notable unintended consequence of systems with limited top-down government strategies (Webster 2012). Innovation hubs and incubators, as well as clinicians and hospitals, are constantly creating new technologies, many of which may improve information sharing and person-centredness in the health system, thus addressing identified needs of people with CCDD. There are also research-based initiatives that seek to integrate patient information. For example, the University of Toronto Practice-Based Research Network (UTOPIAN) seeks to integrate primary-care data across Ontario for research purposes, which could help to improve

care delivery for people with CCDD (Family & Community Medicine 2016).

Threats

There are a number of potential threats to adopting new technologies for CCDD in the Ontario context:

- Increased fragmentation could occur due to the large number of new eHealth and mHealth solutions being developed in parallel rather than in collaboration.
- There may be insufficient human resources, in particular, Health Informatics and Health Information Management professionals needed to support implementation of eHealth technologies (Atkinson 2009).
- Ongoing support for eHealth initiatives in Ontario needs to demonstrate clear value for money to gain support (Murphy 2010). However, evidence of eHealth impact on health outcomes and cost effectiveness are often mixed (Black 2011).
- Ontario is still largely a provider-centric system.
- Although there is legislation in place to ensure privacy and security of patient information, the introduction of new technologies poses new challenges that must be addressed (Canada Health Infoway 2014).

Scotland

Overview

The National Health Service in Scotland (NHS Scotland) delivers healthcare services free at the point of care to all Scottish residents. NHS Scotland is divided into 14 local health boards responsible for planning and delivery of services and a number of national boards for support functions (training, procurement, health improvement, quality improvement and information and intelligence). Services are paid for through general taxation, as in the rest of the UK, and most providers are employed directly by the NHS, although most general practitioners act as independent contractors, as do some other providers such as dentists, community pharmacists and opticians (National Health Service Scotland 2015a). Many practitioners and specialists offer both NHS-funded and private services.

A notable challenge facing Scotland’s public services is the growing number of seniors and individuals with multimorbidity in the population (Barnett et al. 2012; National Health Service Scotland 2015b). Scottish citizens experience some of the worst health inequalities in Europe. There are huge discrepancies in life expectancy within and across cities, with socioeconomic deprivation being a key driver of inequality (Audit Scotland 2012). The overlap of high health needs and social complexity is similar to the needs of people with CCDD (Schaink et al. 2012). Public bodies in Scotland are now looking toward new solutions to improve outcomes for these individuals and reduce health inequity.

Scotland SWOT analysis

Strengths

Policy shifts to support healthcare and social-care integration: The Public Bodies (Joint Working) Scotland Act (2014) requires the integration of adult healthcare and social-care services in Scotland, providing the groundwork from which to build a truly integrated system to support the needs of individuals with CCDD. All integration arrangements are to be in place by April 2016, including integration schemes, boards, budgets, indicators and governance structures.

EMR interoperability: There is a degree of interoperability between general practitioner (GP) and hospital systems, particularly in respect of laboratory results, letters between hospital and GP practice, and emergency-care summaries. Anticipatory Care Plans for people with complex needs can also be electronically shared by GPs for use by Out of Hours teams, emergency services and Emergency Departments. NHS Scotland is currently increasing the interoperability between systems by developing governance and standards for linking healthcare and social-care information and methods to integrate primary- and secondary-care information via portal systems.

Innovation centres, funding and improvement support: The Digital Health Institute (2015), Telescot (2015), and the Scottish Centre for Telehealth and Telecare (2015) have been leading the development, adoption and the evidence base for the use of new technologies in healthcare settings. Additionally, in 2014, the Scottish Government introduced a Technology-Enabled Care (Scottish Government 2015; Joint Improvement Team 2015) program supported by £10 million funding per annum for three years to support health and care partnerships scale up use of technology and to develop capability and support knowledge exchange across partnerships.

Strong person-centred third sector and research: There is a strong third sector in Scotland to advocate for and help enable person-centred healthcare and social-care delivery. Many third sector healthcare and social-care organizations are represented by the Health and Social Care Alliance (ALLIANCE; 2015), which engages with local and national bodies to influence service delivery, leads a number of programs that support self-management and gives individuals and their caregivers a strong voice in the design and delivery of their health and social care. In addition, Scotland has steadily developed academic capacity in primary-care research over the last decade or so supported by the Scottish Government, particularly through the collaborative work of the Scottish School of Primary Care. This support includes a national program of research on multimorbidity (Scottish School of Primary Care 2015), which produces evidence to improve care for persons with CCDD, as well as other major programs spanning eHealth, Quality and Safety and expertise in complex interventions and health-service evaluation.

Weaknesses

There are a number of challenges with regard to information sharing and communication in the Scottish health system that could make adopting eHealth technologies to support people with CCDD challenging:

- The phased roll out of the clinical portal means many GPs cannot yet access information directly from hospital EMRs, so clinicians generally still rely on paper-based systems to exchange information about patients moving between primary and secondary care.
- Emerging new and mobile technologies cannot easily connect to existing EMR systems.
- Healthcare and social-care have completely different electronic record systems.
- GPs, primary- and community-care teams and hospital staff are often unaware of the community services and non-NHS resources in their neighbourhoods.
- There are very few instances of effective co-location of healthcare and social-care services.

There is a strong third sector in Scotland to advocate for and help enable person-centred healthcare and social-care delivery.

Opportunities

Across Scotland, supported by the Integrated Care Fund (£100 million per annum for three years) and the Primary Care Transformation Fund (£320 million over 3 years), many projects are in early implementation phase and offer opportunities for improved communication and person-centred integrated care for people with CCDD.

- New models of integrated primary care: involves co-location of multiprofessional teams of GPs, nurses, pharmacists, social workers and allied health professionals embedded in GP practices and community hubs and enabled by telehealthcare networks.
- The House of Care – a model of collaborative primary care that is intended to enable individuals to identify their priorities and goals in collaboration with care providers.
- The Links Worker program – places Community Links Practitioners within primary care teams in very deprived areas (Deep End practices) to support improved connections to community resources for patients and their families and caregivers.
- A Local Information System for Scotland (ALISS) – provides an online portal to create connections to community supports, and Living it UP, an online self-management platform, are two examples of national technology-enabled care programs (Joint Improvement Team 2015).

Threats

A number of system-level threats exist which may limit implementation of eHealth solutions which support people with CCDD:

- General access and sustainability issues, notably a growing shortage of GPs and other members of the community workforce.
- A traditionally provider-centric system that exacerbates tensions between practitioner and personalized goals.
- A hesitance to disinvestment in acute care to build capacity in primary and community settings.

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Kaiser Permanente Colorado

Overview

KPCO is a not-for-profit, integrated healthcare delivery system, operating in Colorado, US. For over 45 years, this organization has provided comprehensive health services to members in Denver, Boulder, Southern Colorado and Northern Colorado. Currently KPCO has over 626,000 members, 28 medical offices and 7,000 staff and physicians (with nearly 1,000 physicians from multiple medical specialties and subspecialties) (Kaiser Permanente 2015).

With new Federal legislation in the United States, namely the Patient Protection and Affordable Care Act, 2010 (US Government 2010), KPCO has been experiencing an influx of people with multimorbidity and complex care needs. KPCO is seeking new innovative ways to deliver care for individuals with CCDD and has sought to use its sophisticated IT systems in tandem with new care-delivery models to improve care for these patients.

KPCO SWOT analysis

Strengths

KPCO has been on the forefront of health IT (HIT) for several decades, beginning development of its first EHR in the early 1990s. KPCO's experience in developing and using EHR, ancillary HIT functions, and clinical databases has enabled KPCO to learn how to dovetail these systems within clinical care. Through these learning experiences, KPCO has developed and enabled HIT tools and workflows to improve care-delivery processes and care coordination, enable risk stratification processes and foster patient engagement. KPCO clinical performance-benchmark metrics are at or near the top in the country. There has additionally been heavy investment and 20 years of development in IT from the Kaiser Permanente parent company.

KPCO has four main strengths in relation to delivering care to patients with CCDD:

1. *Integration through co-location and technology:* Integration across multiple health sectors is facilitated through co-location of services and through an integrated EHR and an EHR-tethered patient and provider portal system. All KPCO providers can access EHR patient data to get near instant diagnostic images and quick lab results. The EHR includes a system for adding medication orders, allowing prescriptions to be routed electronically to KPCO-linked pharmacies and messaging systems, so physicians and allied health professionals at KPCO can easily discuss patient care.
2. *Technology enabled patient-provider communication:* Providers and patients are able to communicate easily via the patient portal that is linked to the EHR. The MyHealthManager system pulls data from the EHR to patients' personal health records so they can view lab results, medications and care plans. The system also supports online appointment setting, medication refill requests and patient-provider communication (via secure email). A mobile app is available for download, allowing patient access to the portal through their mobile devices.
3. *EHR-enabled chronic-care management:* KPCO uses "Health Track Registries" to manage people with chronic illnesses, including asthma, COPD, diabetes and mental illness. Chronic care nurse managers (care coordinators) use EHR data to identify individuals at high risk of emergency department or hospital visits and identify gaps in care. The managers engage in patient outreach to reduce risk through improving medication and care plan adherence or helping to improve self-management skills. The care coordinators also field emails from patients regarding their chronic illness.
4. *Centralized oversight and governance:* The centralized oversight and governance model at KPCO helps to avoid a number of barriers to adopting new technology, such as providing medical insurance coverage for providers to cover new models of care. Furthermore, all medical care providers are salaried at KPCO, which allows for a centralized incentive system. The incentive system also actively explores new care-delivery models to achieve Triple Aim objectives (Berwick et al. 2008). The EHR system alerts and decision-support tools also allow for better oversight of the delivery of care to ensure adherence to best practices.

Weaknesses

The KPCO IT system lacks a robust mechanism to capture patient-reported data to proactively meet needs while reducing unnecessary use of the system, which is viewed as particularly important to manage patients with CCDD. While KPCO

has been trying to adopt these capabilities, four IT system weaknesses currently stand in the way:

1. Determining what information would be best to include in the EHR system to avoid data overload on the providers is an ongoing challenge.
2. There is a lack of clarity around how best to package and visualize data to be useful to both providers and patients.
3. Inadequate infrastructure within the EHR system to house patient-reported data and the inability of the systems in place to generate automatic feedback reports to providers to support more efficient delivery of care are resulting in manual workflows to coordinate data sources.
4. Legacy IT systems and interfaces with other healthcare organizations and providers continue to act as obstacles. For instance, KPCO experiences challenges in gaining access to hospital data from contract facilities not on KPCO's IT platform.

Opportunities

The influx of people with CCDD with a number of health and social needs is an opportunity for KPCO to further improve on its already impressive system of care. KPCO is experimenting with new, innovative delivery models, including the following:

- The Health Risk Assessment tool used to quickly identify high-needs patients and tailor programs and services to these individuals (Cross 2004).
- The Special Needs Population team, a new branch of the "Health Track Registries," which uses data from the Health Risk Assessment to develop annual care plans for people with multimorbidity and social complexity.
- The Primary Care Plus model for senior care comprises an interdisciplinary care team, including a registered nurse, community specialist, primary care physician, and geriatrician who come together to develop a care plan for patients, which includes a set of goals. KPCO is also piloting Green Teams, which are integrated primary care models that include multiple providers in a single unit.

Additionally, KPCO is making progress in creating better channels for data flow from contracted healthcare partners. KPCO is currently interfacing several products that exchange health information into its systems, which will provide access to hospital data from other healthcare systems. Opportunities exist to improve the timeliness and accuracy of incorporating these data streams into KPCO HIT systems. Ready access to healthcare-partner information will improve the ability to track the transition of Kaiser patients between care facilities.

Threats

There are five notable organizational level challenges which are threats to moving forward in adopting eHealth technologies to support people with CCDD:

- The system currently supports single-disease management. KPCO currently struggles to identify who manages people with multimorbidity and to develop multidisciplinary care teams to improve integrated care and reduce burden on primary care physicians.
- Patient engagement is an ongoing problem, particularly for care coordinators who are having a difficult time getting patients to become active members of their care team.
- There is uncertainty in how to address social and financial problems that exacerbate health issues and lead to poor health outcomes and higher service use.
- While KPCO is a not-for-profit organization, there is still the need to make a business case for any and all new technology that gets adopted.
- Even with improved health information exchange capabilities, poor interoperability standards may lead to inaccurate data transmission. Additionally, high implementation costs may delay adoption of information transmission processes.

The Future of eHealth for People with Complex Care Needs

When we look across these three cases, there are a number of notable similarities highlighted in Table 1.

In all cases, government and organizational interest in addressing the needs of people with CCDD and building eHealth technologies is promising. However, to mitigate threats and overcome the identified weaknesses in each jurisdiction, we offer the following recommendations.

Recommendation #1: Ensure interoperability between multiple types of systems and data sources

Person-centred care approaches are crucial to address the needs of people with CCDD (Upshur and Weinreb 2008; Sinnott et al. 2013). eHealth technologies can help to enable person-centred care and support by allowing information to be shared between providers and users of services across care systems (King et al. 2012; Winkelman and Choo 2003). The information to be collected could include person-centred data collected through mobile apps and telemonitoring devices; however, most integration efforts in the three cases focus mainly on interoperability between healthcare EMR systems. Integrating data from multiple sources across multiple sectors can improve person-centred care; however, while integration of person-reported outcome data is an important element of person-centred care, it is not sufficient to support person-centred care delivery on its own (Miller et al. 2014).

TABLE 1.
Cross-Case SWOT

Strengths	Weaknesses
<ul style="list-style-type: none"> • Government or organizational commitment and investment in technology • Some supported system interoperability (or movement in this direction) • New innovations and system capabilities being implemented • Growing awareness of the challenge of complexity and requirement for person-centred solutions 	<ul style="list-style-type: none"> • Full interoperability across health sectors and connecting health and social-care not yet realized • Lack of integration between non-EMR/EHR systems like mobile apps and other person-centred data sources • Fragmentation within health systems and/or between health and social-care services (with Scotland way ahead given new legislation)
Opportunities	Threats
<ul style="list-style-type: none"> • Government and/or organization focus on addressing needs of people with CCDD across all sectors with implementation of new models of care and support which can be enabled through eHealth technologies 	<ul style="list-style-type: none"> • Access to sustainable resources (funding and human resources) is tenuous in all sectors • All systems remain provider-centric, which can limit adoption of person-centred technologies • Need to make a business case and demonstrate value for money • Need to ensure privacy and security with adoption of new technologies

Recommendation #2: Identify how eHealth technologies can be used to enhance or support innovative models of care through user-involvement in development and implementation

The numerous innovative models of care delivery in early implementation stages in each of the three jurisdictions are impressive, and many of these models may be enhanced through adoption of eHealth technologies. However, implementing new eHealth solutions can be challenging and requires strong stakeholder involvement (Mair et al. 2012), in particular identifying “implementation leaders” to support the process (Damschroder et al. 2009). Equally important will be designing these technologies to meet user needs by adopting user-centred or co-design methods (Devi et al. 2012), which may be particularly important for people with CCDD (Steele Gray et al. 2016). Ensuring people and their caregivers are part of the design process marks a shift towards more person-centric systems.

Recommendation #3: Ensure implementation strategies include economic evaluations and sustainability plans

A key issue is the need to make a business case for the use of eHealth technologies as a means to support government and public buy-in and to secure investment. Most implementation frameworks suggest the inclusion of robust monitoring and evaluation (Damschroder et al. 2009; Lemaire 2011; Mair et al. 2012; van Gemert-Pijnen et al. 2011) and increasingly economic impact statements in favour of adoption of new technologies (Digital Health Institute Scotland 2015; Ontario Health Innovation Council 2014). Building these considerations into plans for implementing new or existing technologies can help support sustained uptake and scale and spread of tools to support people with CCDD.

Recommendation #4: Adopt national-level eHealth strategies

The World Health Organization has argued that in order to realize the full benefits of IT solutions for healthcare, national-level strategies and integrated actions are required (World Health Organization 2012). Interoperability of eHealth information is an important enabler of coordinated care. National-level strategies may drive a shared vision and perhaps enable coordinated action to achieve long-term goals. In this way, a national-level strategy could enable system-level transformation, which is required in order to meet the needs of persons with CCDD. This communal thrust may also occur through vendors with shared goals and economic incentives. It is still unclear if national strategies, private enterprise or a combination is needed to spur efficient development of interoperable eHealth information tools needed to achieve coordinated care for CCDD patients. **HQ**

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