e-Health in the Age of Paradox: A Position Paper

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Abstract. This position paper examines a critical paradox in e-health: there is a striking gap between critical information services for health care that can be implemented today using existing in information and communication technologies and those services that are actually available. Facets of this paradox are examined in the context of Canadian analyses and policy, advanced research on health care reform, and current technological developments. Hypothetical scenarios are employed as a means of discussing the paradox and, ultimately, of describing potential solutions that are feasible now.

Keywords: e-health, interoperability, patient-centred care.

1 Scenario

Duncan, a computer scientist, was driving an elderly woman, Jessica, and one of her family members, Alia, from Ferney to the Montreux airport in the summer of 2007. During the trip, Jessica, began coughing violently. As Duncan looked over at Jessica in the passenger seat, her head slumped forward and her eyes closed. She, in lay terms, appeared to Duncan to "pass out." He immediately pulled the car over to the side of highway. Shortly after the car had stopped, Jessica opened her eyes and asked what had happened. Jessica appeared not to be in distress of any kind, but the fact that she is a diabetic and over weight made the situation more urgent for Alia and Duncan.

Alia, who is a physician and was acutely aware of Jessica's medical history, began to assess her condition and to make decisions about what she and Duncan should do. Montreux is 177 km from Ferney. The were just over half way to Montreux at that point in a relatively rural part of the Province. It was not yet clear what had happened to Jessica or what her condition was. Should they go forward to one of the two major hospitals in Montreux, which are highly reputable? Or should they return to Ferney, where Alia had far greater knowledge of the health care environment?

They decided to go forward to Montreux, but which hospital? Montreux has the Dr. James Fazy Regional Hospital, which would seem the first choice, and the Montreux City Hospital, another quite capable health care centre. The choice was not so obvious, however. With a sense of urgency, geographic factors weighed heavily in answering this question as they were not at all familiar with Montreux. They did not have a map, but they did have a mobile phone. They soon entered a rest stop and were able to acquire a map of Montreux. They decided that navigating to Fazy Hospital would be relatively easy.

M. Ulieru, P. Palensky, and R. Doursat (Eds.): IT Revolutions 2008, LNICST 11, pp. 240–249, 2009.

The staff at Fazy received Jessica in a professional and courteous manner. She was admitted for tests and observations. While Jessica was made comfortable, a somewhat tedious process ensued with Alia conveying Jessica's insulin regimen to the attending physician. This involved reviewing hand written notes created by Jessica's family and carried by her on her travels. Printouts of prescription information from her pharmacist back in her home province were sought. These were retrieved by another family member and faxed to the hospital after about an hour wait. The two lists had to be reconciled in terms of terminology, quantities, medical history, and other information which differed between the family's informal, though day-to-day, records and those of the pharmacist.

It was early evening when this was finished and they settled in for the night to wait for test results. Jessica was confused and scared, not knowing what had happened to her, much less what was happening in the hospital. Why the wait? What were the physicians doing? Alia, as a physician, was an invaluable resource for Jessica in this context, as she was able to explain to Jessica what was happening. How much more confused would Jessica have been if Alia – a physician -- had not been present? How would that have affected her condition and the task of communicating to the attending physicians about what had happened in the car?

The first attending physician seemed quite open-minded while listening to Duncan and Alia's recounting of the events in the car. The second attending physician who came on duty the next morning seemed to Duncan, a lay person in this context, to convey a much more skeptical, though professional, attitude as they repeated the story. Again, Alia was an invaluable advocate for Jessica in this context. In a way, she, as a proxy for Jessica, was able to achieve a virtual type of patient-centred care where none seemed to exist. As an expert advocate, Alia was able to suggest possibilities to the second attending physician for which diagnostic tests could be sought.

Jessica was released from the hospital two days later. The cause of the event was not conclusively determined. It was felt by Alia that Jessica had experienced a vaso-vagal event, which had caused her to "faint." Because they were not able to cite a definite cause, this episode left Jessica's extended family with a considerable amount of worry for the next month after she finally flew home.

The episode left Duncan, the computer scientist, extremely frustrated by the paradox of information and communication technology (ICT) in this context.

2 Paradoxes

Duncan had actually identified several paradoxes that day. Duncan knew that he and Alia could have easily located a health care facility using widely available and affordable global positioning system (GPS) ICT had they been prepared. Knowing Jessica's general physical condition, Duncan also could have, with a modest amount of money, acquired ICT to monitor and record various of Jessica's vital signs in case the need to provide health care practitioners with that information arose – especially a skeptical attending physician. Duncan knew also that the task of retrieving a current and comprehensive picture of Jessica's medical history and drug regimen could have been achieved using common database management system technology, connecting physicians, pharmacists, hospitals, and other relevant entities. Duncan thought as well that user-centred design and collaborative design approaches -- long in vogue in certain parts of the ICT sector -- could have been leveraged in a straight forward manner in the design of workflow and user interface systems to provide a more patient-centred experience for Jessica and, especially, for others not so fortunate to have a personal physician advocate with them, like Alia. With such a design, hospitals can provide patient-centred experiences, where patients and families are given more information about what is happening, where there is a free exchange of information between patient and physician, where patients can be shown graphical demonstrations that help to explain their condition, or their hypothetical condition until such time as diagnostic tests confirm or deny it. Also, through user-centred design, personal health monitoring systems should now be as easy to use as the telephone for people of Jessica's generation. Duncan knew as well that common social networking, video and other common Web technologies could have been employed to leave Jessica with a summary of her experience, the hospital's findings, and information to help her care for herself in the days that followed as she returned home.

The gaps between what Duncan knew was possible with current ICT and what actually existed within the health care situation Jessica found herself that day constitute a paradox in healthcare. Charles Handy, a well known philosopher of management, has posited that we are in an age of paradoxes, wherein traditional practices confront new situations brought about by rapid advances in some aspect of society [1]. Two of the nine paradoxes Handy has defined are most closely related to the paradox identified by Duncan. These are a paradox of intelligence, where the means of production is no longer dependent as much on physical labour as it is on the knowledge that labourers hold; and a paradox of work, where a few people are over worked while many others are unemployed. Handy's paradoxes speak to broad societal conditions; Duncan's paradox merely defines healthcare-specific variations on Handy's paradoxes. We will call Duncan's paradox the paradox of eHealth.

3 Building Blocks

The paradox of eHealth is not new and has been the attention of many entities for a long time. The “binding sites” for the unravelling of this paradox can be seen, in particular, in the first three of the “four essential building blocks” called for by the *Romanow Commission on the Future of Healthcare in Canada* [2], the last major review of Canada's healthcare system. Romanow's four pillars are “continuity of care, early detection and action, better information on needs and outcomes, and new and stronger incentives for health care providers to participate in primary health care approaches.” They are also in the foundation, the *Canada Health Act* [3], which establishes the criteria for Canada's provinces and territories to provide medicare as public administration, comprehensiveness, universality, portability and accessibility.

It is important to point out that despite Duncan's confusion, Canada enjoys a good health care system. As has been written by Michael Rachlis, M.D. [4], Canada's most widely-recognized health policy analyst, Canadians “still believe in the values of medicare.” Nonetheless, they want a number of things fixed or improved. The Romanow Commission was established in 2001 by the Prime Minister of Canada with the goal of seeking policy recommendations for ensuring “the sustainability of a universally accessible, publicly funded health system, that offers quality services to Canadians and strikes an appropriate balance between investments in prevention and health maintenance and those directed to care and treatment." Among its many recommendations, the Commission called for the following:

- improving access to health care in rural and remote areas;
- reducing wait times for diagnostic services;
- facilitating the transfer of patients to home care when appropriate;
- the establishment of a system for managing personal electronic health records across Canada; and
- improving the coordination of "staffing of physicians, nurses, and other staff in areas where they are needed."

4 What Exists?

The building blocks for comprehensive solutions to fulfill the Romanow Commission's recommendations already exist. Building blocks that take advantage of current generation mobile wireless data communications and service-oriented software architecture technology, including Web services, have been emerging over the past few years. This convergence is being called telemedicine 2.0 [5].

Telemedicine 2.0 is being defined as the "convergence of clinical and personal wireless solutions," where traditional clinical telemedicine enables delivery of care to fixed locations [5]. In this context, telemedicine 2.0 integrates traditional fixed location devices with mobile systems within some comprehensive data management scheme. The mobile phone is seen as the focal point of this convergence. These systems are characterized into the categories of Monitoring, Software and Services, and Tracking. Some telemedicine 2.0 solutions are focused on single disease management, while some are emerging that have multiple disease management capabilities. CardioNet [6] is one example of a focused solution. It provides mobile outpatient cardiac telemetry services. Toumaz Technology [7] of Abingdon in the U.K. is developing a wireless medical monitoring system, called the Sensium, within a "band-aid" form factor that they call a "digital plaster." Multiple sensors can be linked together into a wireless body area network using their technology.

Many of these services employ Mobile Virtual Network Operators (MVNO). They do not own spectrum or infrastructure. They lease these services from mobile telephony and Internet network providers and focus on the provision of their specialized services.

Packet radio protocols exist for the major mobile telephony protocols. These include General Packet Radio Service (GPRS) or Enhanced Data rates for GSM Evolution (EDGE) within the set of Global System for Mobile communications (GSM) 2G mobile telephony standards; High Speed Packet Access (HSPA) within the Universal Mobile Telecommunications System (UMTS) set of 3G mobile telephony standards; and Evolution-Data Optimized (EVDO) within the CDMA2000 set of mobile telephony standards. Efforts are being made to unify GSM and non-GSM protocols as well. Though the choice of packet radio protocols can be encapsulated somewhat through a focus on the Internet Protocol (IP) level when architecting software applications.

5 ICT's Further Potential

The specific characterization of the paradox of eHealth is that current ICT offer the constituent elements of solutions to the problems within the health care system, but they are, for various reasons, slow to be leveraged in a comprehensive way. ICT should not be seen as solutions, only parts of solutions within a responsible approach to systems analysis and design. At an abstract level, and without oversimplification, solutions to the eHealth Paradox must address, in part, the following issues:

- coordination of complex and extensive work flows,
- distributed and secure information sharing,
- management of distributed staff;
- location and tracking of people and objects; and
- providing customized client-centred service.

Workflow management, distributed database management systems, workforce management, location-based services and object tracking are all mature technologies. Interestingly, they are applied successfully by a number of organizations in other domains besides health care that have requirements similar to those listed above and which have addressed these requirements in comprehensive ways. Some have even achieved *Six Sigma* performance in doing so, or so they have claimed. Interestingly, these include organizations such as airlines, postal systems, and couriers.

Healthcare cannot be equated directly to the means by which these types of organizations provide their services. Software systems cannot by themselves “respect the individuality, values, ethnicity, social endowments, and information needs of each patient,” as Rachlis frames the rules for patient-centred care [4]. Nonetheless, healthcare still overlaps in significant ways with the requirements identified above in terms of the types of data communications and operations that are necessary to manage information about a patient.

Rachlis also points out that patient-centred care must include “continuous relationships, care customized to the patient's needs, care controlled by patients, [giving] patients unrestricted access to their records, sharing of knowledge freely between a patient and their different providers using the latest ICT” [4]. These criteria do not differ fundamentally from the functionality provided by the best of the current client relationship management (CRM) systems. Integrated properly into a health system, such ICT could provide elements of solutions that satisfy Rachlis's criteria for patient-centred care.

While key ICT building blocks and mature organizational strategies have been developed, major barriers to creating comprehensive eHealth systems remain. The major barriers are organizational inertia, and ICT and data interoperability.

6 Jumping Organizational Barriers

Canada Health Infoway, a federally-funded, independent, not-for-profit organization whose mandate is to “accelerate the use of electronic health information systems and electronic health records (EHRs) across the country” has been working since 2001 on some of the requirements described in the previous section [8]. Canada has thirteen jurisdictions in which the Health Infoway plan is being implemented. Three jurisdictions were found to be on track to implement an EHR by 2010. Two jurisdictions are predicted to implement a full EHR model during 2010. Four jurisdictions are predicted to have only core EHR functionality in place by 2010. Four jurisdictions will require significant time beyond 2010 to implement core functionality for an EHR.

It was found in a 2007 review of Infoway's progress that the barriers to its vision have not been related to technological issues so much as they have been policy-related. The report found that Infoway made “inconsistent and insufficient commitments” and that they demonstrated an “inability to fully illustrate the impact” of the changes that are required [8].

Interestingly, Rachlis's advice for how to implement change within the justifiably skeptical and conservative domain of health care almost mirrors what are thought to be best practices within the now hot field of design thinking. Design thinking processes are applied to the creation of innovative technologies and services in such a way that the user's (e.g. patient's) concerns and perspectives drive the design activities and ultimately guide the selection of solutions. IDEO CEO Timothy Brown demonstrated this in a 2006 lecture at MIT [9]. He showed how design thinkers, including psychologists, anthropologists, engineers, and people from a wide variety of other disciplines can produce successful designs which are appropriately situated within the given social and organizational environment. This has included putting design staff on hospital gurneys with video cameras so that they can capture authentic patient experiences. This latter practice lead to the insight that patients are often given very little information about what is being done to care for them from that vantage point. Brown suggested the placement of a status monitor on the ceiling above each patient as the beginning of a solution.

Rachlis's advice is specific to health care organizations in this context, however, recognizing that they are often reluctant to try new ideas. Changes, in Rachlis's approach, should be made in incremental ways as follows [4]:

- it must be easy for health care providers to “dip their toes into the water of innovation”;
- providers need the ability to see systems in operation first;
- systems must also fit within the social context in which they are to be employed; and
- changes should be tested using methods such as the Institute for Healthcare Improvement's Plan-Do-Study-Act cycle.

Most interestingly, Rachlis also calls for maximizing the “talents” of patients and providers in facilitating improvements in health care [4]. This is a key design thinking approach.

Helping health care providers “dip their toes into the water of innovation” is the role of independent organizations such as the National Research Council of Canada (NRC). Commercial forces, while necessary for innovation and providing the implementation that are ultimately to be employed, can erect barriers to standardization and interoperability, as von Hippel [10][11] has shown, as a side-effect of their maintenance of proprietary information about their products and services.

Handy's paradoxes of intelligence and work both speak to the need to improve the coordination of staffing of health care teams. In many cases, when patients are in rural and remote areas lacking access to both family doctors and specialists, this has and will continue to require tele-medicine approaches. However, current ICT makes possible far more than what has been implemented in the past. This includes the recording and manipulation of video by patients themselves using easy to obtain Web-based technologies, known as peer-generated video (PGV). PGV looks to be a promising way for patients to communicate with remote care givers. Tele-work and other collaborative technologies also make it possible for health care organizations to balance work loads among existing professionals as well as providing ways to educate more practitioners to increase access to care for all. For example, distance education employing the latest in high definition video and collaborative virtual learning environments make possible the training of physicians, nurses, and diagnostic specialists independent of their residence. This spanning of geographic barriers may be one key to unlocking as of yet unrealized health care labour potential within Canada.

Finally, in the context of organizational barriers, technical capabilities cannot be viewed apart from the political-administrative models of healthcare. Much of the telemedicine 2.0 development seems to be driven by U.S. healthcare companies. They assume a privatized model of healthcare, whereby a health care organization buys into their particular solution. Solutions for a Canada Health Infoway may not be well-served by such an assumption. Universality requirements and norms as well as economies of scale would probably be best served by standardization directed by public processes and not by industry, as this has historically tended to steer technologies away from complete interoperability.

7 Jumping Interoperability Barriers

The work of Canada Health Infoway has gone a long way toward reducing interoperability barriers at the data level and the health management systems level. Much of their effort has involved standardization around the Health Level 7 (HL7) [12] body of standards. HL7 is perhaps the most mature component of all of the issues raised in this paper. It has been in development since 1987. It has evolved to HL7 version 3 (v3). Infoway has adopted HL7 v3 [13].

HL7 v3 is an XML-based standard that allows for both human and machine readable exchange of information [12]. This capability provides a key component for the alternate scenario to Duncan's story, which is described in the next section. HL7 v3 defines both a Clinical Document Architecture (CDA), which evolved out of the earlier Patient Record Architecture, and a Messaging Standard. Clinical documents may contain historical data, medical diagnostic data, narrative information, and should be signed or “attested” using digital signatures. The messaging standard emphasizes machine processability, though they can include human readable information. Both models may be employed together. Recommendations are made by HL7 as to which model to employ in a given use case.

The most serious interoperability barriers seem to remain between devices and software services. Interoperability may exist within silos defined by individual manufacturers or services, but real solutions require broad interoperability across data, device, and health management system layers. The U.S. Food and Drug Administration reported in 2005 that there were 25 blood glucose monitors on the market, each with their own data protocols [14]. It is often not clear whether these devices and, at a higher level, telemedicine 2.0 systems are based on open standards. Thus, individuals and institutions that adopt one set of devices may be locked into a particular MVNO or data communication protocol and, thus, lack the possibility of interoperation with other devices they may require.

Some device manufacturers and MVNOs are responding through the creation of gateways that support an extensible list of devices. The company 4HomeMedia offers an open standards "health hub." Among their digital home products, they provide OEM-oriented solutions for enabling consumer electronic (CE) devices in the home. According to Engaget.com this includes a health monitoring solution [15]. The company LifeComm was announced as a partnership between Qualcomm, the dominant mobile telephony chipset and software provider for the Code Division Multiple Access (CDMA) protocol. LifeComm is working with handset manufacturers to develop mobile telephony-based MVNO hardware and software for a class of monitoring devices [16]. Another multiple disease management system provider is *iMetrikus* [17]. They advertise a "low-cost" gateway to channel personal health monitoring data into clinical systems. They claim that their *MediCompass Connect* system can interface with over 45 different devices. This can be done via IP-based data communications on a personal computing device or via a telephone connection.

At a data level, Google Health [18] allows individuals with Google accounts to import, organize and maintain their own medical records. Facets of one's PHR that can be maintained or automatically generated by Google include the following: medical profile, including conditions, medications, allergies, procedures, test results, and immunizations; notices sent from health providers; and drug interaction information generated by Google based on one's medication profile. Google Health offers the ability to synchronize Google PHRs with other electronic medical record (EMR) sites, including *Epocrates Patient Snapshot, iHealth, Lifestar, MyMedicalRecords.com*, and *NoMoreClipboard*. The capabilities of Google's search technology and its high profile as a central access point to the Web for many people has engendered security and privacy concerns over Google Health.

Interoperability in the end may be best served by having health organizations guide the definition of application programming interfaces and hardware interfaces through public and industry-independent processes which allow corporate input, but which prioritize the best interests of public health systems above other interests.

8 An Alternate Scenario

Duncan imagines the following scenario, all enabled by current ICT. Because Jessica is at risk, her healthcare team has fitted her with a watch containing a heart rate monitor that stores its data on an internal flash drive. Jessica is also carrying a bluetooth-enabled blood glucose meter. All of her monitoring devices are interoperable at a physical layer through common interface standards such as Bluetooth and USB to permit easy transmission of data to her mobile phone and other common computing platforms. This level of interoperability allows the data to be easily delivered to health care providers in situations such as her fainting event in the car. All data formats and exchanges are standardized on either HL7 clinical documents or HL7 messages, as appropriate, providing for interoperability at the data level.

Besides being Bluetooth-enabled, her mobile phone is also capable of using Session Initiation Protocol (SIP), which allows it to establish sessions with the regional health authority's SIP-enabled E911 service. Jessica's mobile phone uses SIP to notify the regional health authority's patient care workflow system of its data communication capabilities, its location, and of all of the types of data about Jessica that it has available. SIP is then employed to negotiate the delivery of these data to the authority. The voice channel on the phone would be employed concurrently by Alia to communicate with an emergency room physician while Duncan continued driving.

The regional health authority would receive Jessica's medicare number within the encrypted SIP message, create a new case file, and place it into its dynamic patient care workflow engine. The workflow engine is capable of managing health care algorithms selected by the health care team and can deliver associated information to appropriate "nodes" within the regional health care authority as Jessica receives care. This could include retrieving and routing her patient health record to the emergency room desk so that an attending physician can review it before she arrives. If necessary, the physician could use the system to call Jessica's phone to consult with her while she is still in route.

Using a decision support system in conjunction with the workflow system, the regional health authority is able to identify available capacity within an appropriate hospital. The authority then arranges the delivery of a map to the cell phone showing detailed directions to the chosen hospital.

Before Jessica arrives at the emergency room, she has undergone a preliminary triage based on both the data received from her mobile phone and communications with Alia in the car. A formal triage is completed on her arrival, but has been made more efficient by information that was made available about her ahead of time.

Schema mapping facilities provided by the distributed database management system are employed to reconcile information provided by the family, such as adjustments to Jessica's insulin regimen made by the family since She last visited her physician. The view mechanisms of the system would be employed by physicians to examine Jessica's patient record in any number of ways. In addition, analytic services provided by the system can be performed over any of the data sets in Jessica's record, including the recent data sent from her mobile phone. These might include new analytic techniques that have been validated by the latest medical science results.

Inside of Fazy hospital, Jessica is given a small, flat electronic paper display by her bed that shows her information about what her health care team is doing for her. The information can be delivered by voice, if appropriate, and in different languages. A virtual learning environment is also available through the electronic paper for Jessica and her family members to retrieve explanations of her condition and of her diagnostic test results. This learning material is structured so that it can be delivered at various levels of complexity. Alia is able to choose an article and graphical demonstration of vaso-vago responses at a level appropriate to Jessica's level of understanding.

Before Jessica is released from the hospital, her Personal Health Portal is synchronized with HL7 CDA-formatted data about the following:

- information about her hospital visit,
- what the findings of the physicians were,
- updates to her patient health record, and
- video-based instructions by her health care team about how she should care for herself at home.

When she arrives back in her home province, her family members help her to sign on to her personal health portal. They all feel much more comfortable about caring for Jessica than they would without having this information.

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