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Breaking the Healthcare Interoperability Barrier by Empowering and Engaging Actors in the Healthcare System

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Abstract

There is an increasing need for an interoperable healthcare data system that provides a shared common view of the essential data for a person to any healthcare provider involved in the circle of care regardless of where provider or person are physically located or what organization they belong to. This paper introduces a framework that characterizes the essential elements of such a system: minimal data set, information technology architecture, and legal governance. We evaluate related work and propose a cloud-based portal and a web-service API for accessing and managing shared data. The proposal is evaluated and compared using a representative usage scenario from community care.

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Keywords: healthcare, interoperability, minimum dataset, architecture, governance

1. Introduction and problem definition

Healthcare in Canada is legislated and funded by the federal government and administered provincially[14]. The provincial Ministry of Health allocates funding to the healthcare providers in the province. While urgent and acute care is provided at hospitals and clinics, there are also publicly funded community healthcare providers that deliver care in homes, hospices, long term care facilities, retirement homes, etc. Provincial health ministries in Canada have facilitated the adoption of electronic health record (EHR) systems across various healthcare providers[8]. In this paper we focus on the healthcare systems within the province of Ontario.

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There is an increasing need for an interoperable healthcare data system that provides a shared common view of the essential data for a person to any healthcare provider involved in the circle of care regardless of where provider or person are physically located or what organization they belong to. Too often time is wasted repeating collection of information in an ad hoc manner, and too often critical information is missed or provided too late. Furthermore, cross-organizational collaborations are often not fully compliant with evidence-based, patient-centric, timely, and safe[6] practices. Privacy, continuity of care, and patient care fragmentation[17] are all problematic. As well, individuals receiving care are often under supported in their right to access their own health data[11].

This paper introduces a framework that characterizes the essential elements of such a system: minimal data set, information technology architecture, and legal governance. We evaluate related work and propose a cloud-based portal and a web-service API for accessing and managing shared data. The proposal is evaluated and compared using a representative usage scenario from community care.

2. Background

2.1. Electronic Health Records and Cloud-Based Health Apps

Nowadays, most healthcare organizations (HCOs) each have their own Electronic Health Record (EHR) system that records the care they provide. Within an individual HCO, healthcare data is available to the various stakeholders through software applications. Healthcare data can also be available through healthcare application programing interfaces (APIs) in an ecosystem of applications similar to that of smartphones[15]. Furthermore, EHRs rely heavily on HL7 standards and APIs[3].

At the same time, individuals increasingly track and manage fitness and telemetry data generated by various tracking devices and sensors that send real-time data to their cloud servers. There is the potential for improved healthcare if EHRs can be integrated with this new individually managed cloud-based data. Examples of such integrated data, like predicting an imminent heart attack based on the stream of data from an apple watch that monitors the heart rate, have been explored by various researchers[7].

2.2. Healthcare Data Governance

In Ontario, Personal Health Information Protection Act (PHIPA) regulates healthcare providers involved in handling personal health information (PHI)[5]. To protect privacy, many healthcare providers severely restrict cross organizational data exchanges. However, PHIPPA allows sharing PHI to deliver efficient and effective care delivery[1].

In the United States, the Health Information Technology for Economic and Clinical Health Act was passed to facilitate adoption of EHR systems by providing financial incentives for those who succeed at digitizing their health data, automating their internal processes, and providing seamless collaboration with other healthcare providers[16].

In Europe, governance of EHR systems varies from country to country and even from region to region. As an example, Denmark developed a national action plan for governing and harmonizing all EHR systems in the country, but so far this had met with mixed results[10].

2.3. Interoperability and Related Work

Interoperability can be defined as an efficient transition of data and services that ensures continuity of care across organizations and providers at the level of data, process, and context[12]. Data interoperability focuses on the integration of data across all actors, processes and contextual factors. Process interoperability is integrating work processes across all actors who deliver healthcare services, a key part of which is integrating knowledge and collaborative processes to enable team based care delivery. Finally, contextual factors such as political and social environments, can affect the ability of healthcare providers to achieve complete interoperability.

There are government initiatives to reduce the number of EHR systems in a region and encourage healthcare providers to use one shared system including Sweden[4] and Denmark[10]. Epic[3] is an example of a commercial EHR

system that is adopted by many healthcare providers. In Norway, the government has developed a system to securely share personal health information[19].

Microsoft HealthVault[18] on the other hand, provides a cloud-based service and API that has the potential to expand data interoperability but, it is not widely adopted by the healthcare industry and is now mainly focused on personal health record logging performed by individual private users.

3. Proposed Framework

3.1. Overview

Our proposed framework is composed of a minimum dataset, a technology architecture, and a governance model. We describe the proposed framework through a representative scenario and a MyPHR website and application for sharing healthcare data.

3.2. Scenario Description

An 85-year old female was admitted to the hospital (TOH) with exacerbations of her chronic obstructive pulmonary disease (COPD). The patient's medications included: insulin (diabetes), Lipitor (cholesterol) and Clonidine (hypertension). The patient also has a severe allergy to latex and peanuts. During her hospital stay, she had a fall, and broke her hip, which required hip replacement surgery. Five (5) days post-surgery, she was finally discharged from the hospital. She had previously sold her house, and had moved to a retirement home. The retirement home was not equipped to provide the level of support required and thus she had to be transferred to a convalescent home. In the convalescent home, the patient received daily visits from Home Care nurses and personal care workers, to help with dressing changes, and other activities of daily living. She was also seen twice a week by a physiotherapist. Unfortunately, the convalescent home was not aware that she was an observant Jew and was not able to fully meet her requirement for kosher meals resulting in a less balanced nutritional intake. Two weeks after her discharge, the patient started to develop pain at the surgical site and came down with a fever at which point she visited her family doctor to seek treatment. The family doctor sent the patient for blood work, and provided her with some antibiotics to treat her surgical site infection. During this period, she continued with her monthly visits to her medical specialists: (1) Respirologist for the management and treatment of her COPD, and (2) Endocrinologist for the management of her diabetes. Neither medical specialist knew of her hospitalization for COPD, her subsequent fall and surgery, nor of any of her changes in medications, (and their potential interactions) and of her recent hospital-acquired infection.

The scenario highlights data interoperability issues since data like Agda's dietary restrictions and hospital stay are not readily available, and there are process interoperability issues that prevent integration of providers to support collaborative care delivery, and finally there are contextual factors in terms of the change in her living situation from private home to retirement home to convalescent home.

3.3. Minimum Dataset and Attributes

The essential attributes that stakeholders need access to for this scenario and would be willing to provide are listed in Table *1*. We call this data collection, "the minimum dataset". This dataset is supposed to give an understanding of the patient's trajectory through the health system and clues to where they can get more information, should the need arise. Hence, it would not include details such as procedures done during a hospital stay. Our minimum dataset is composed of 4 categories: Patient profile, medications, health profile, and appointments.

Table 1. The proposed minimum dataset applied to the scenario

Category	Attribute	Value in the Scenario
Patient Profile	Name and Gender	Agda Rajotte, Female
	Date of Birth (DOB)	1932-03-11
	Address	Farhaven Convalescent Care Home, 333 Lee Valley Cres. H8H 8H8, Ottawa, ON
	Phone Number	Business Phone: 16135554433
	Residence Type	Convalescent Care Home
	Living Arrangement	Alone
	Service Language	French
	Primary Care Giver	Granddaughter: Chloé Provost
	Family Doctor	Jean-Philippe Leblanc
	Dietary Regimen	Kosher
	Advanced Directives	Do not resuscitate (DNR)
Medications	Medication Dates and Prescriber	Insulin: 200 ml as needed, on 1997-03-05, prescribed by Dr. Lemay Lipitor: 200 ml as needed, 2016-09-08, prescribed by Dr. Lemay Clonidine: 200 ml as needed, 2016-09-08, prescribed by Dr. Leblanc Antibiotics: 200 ml as needed, 2017-01-27, prescribed by Dr. Leblanc
	Pharmacy Info	Insulin: Rexal, by Nancy Alhava, Lipitor: Rexal, by Nancy Alhava, Antibiotics: Rexal, by Nancy Alhava
	Last Medication Reconciliation Date	2017-01-09
	Allergies	Latex, and peanut
	Medical conditions & dates	COPD: 2016-11-03 - present Diabetes: 1997-03-04 - present Cholesterol: 2016-08-30 - present Hypertension: 2016-08-30 - present Sugical site infection: 2017-02-03 - 2017-02-13
Health Profile	Activity impediments	Difficulty walking, requires wheelchair
	Risks and safety issues	Risk of fall
	Time and place of previous encounters	Admitted to TOH on 2017-01-03 Discharged from TOH on 2017-01-12 X-Ray appointment taken on 2017-01-05 GP (Dr. Jean-Philippe LeBlanc) visit on 2017-01-27 Blood tests completed on 2017-02-03 Respirologist (Dr. Andrea Johal) visit on 2017-01-22 Endocrinologist (Dr. Kayvon Omidi) visit on 2017-01-25 Respirologist (Dr. Andrea Johal) visit on 2017-02-21 Endocrinologist (Dr. Kayvon Omidi) visit scheduled for 2017-09-15
	home care programs, schedule, and frequencies	Home Care, Personal Support: 2017-01-19 to 2017-04-25, 7 visits per week Home Care– Physiotherapy: 2017-01-19 to 2017-04-07, two visits per week

3.4. Technology Architecture

Our technology architecture is shown in Figure 1. It is composed of a web portal (myPHR website) a set of web service APIs, and a data storage system. HCO employees use internal applications that leverage the APIs. Other stakeholders use mobile apps developed by healthcare app developers that leverage the APIs. The architecture is designed to serve variety of users from patients to HCO employees:

Patient is anyone who's registered in the healthcare system. Even when not receiving care, they can access the MyPHR website to update their profiles, and the past healthcare encounters. The patient as an actor is considered a non-professional entity that needs the proposed portal to be able to access and contribute. We should also point out that a patient's care giver could be allowed to access the system on the patient's behalf. In our scenario, Agda -our patient and her designated care provider -Chloé are able to access Agda's profile on myPHR online portal and update information in the two categories of the minimum dataset i.e. patient profile and health profile. Chloé can access her own myPHR as well as Agda's.

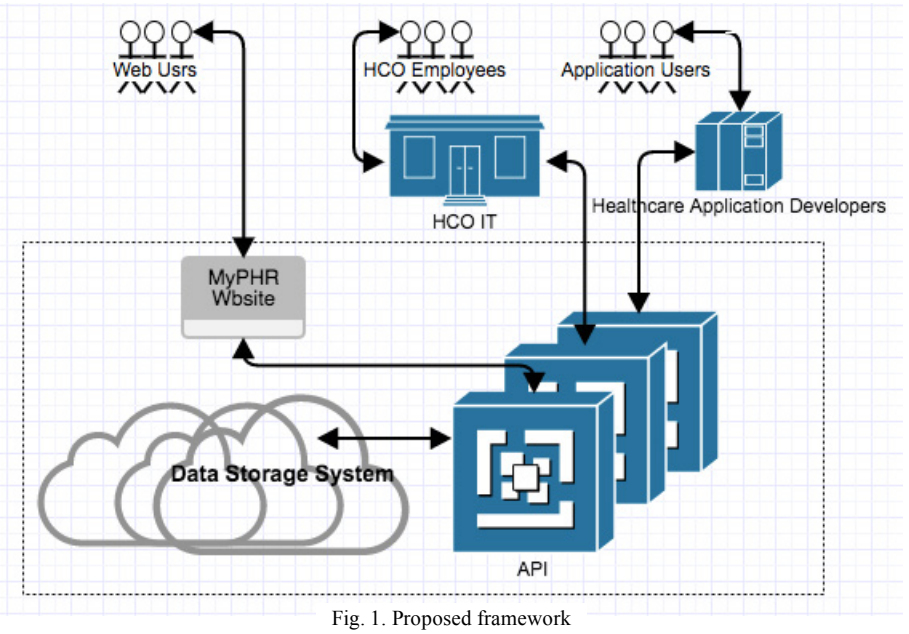

Fig. 1. Proposed framework

HCO actors such as hospitals, generally have an existing Electronic Health Record (EHR) system. The developers of the existing EHR (e.g. IT department), can use the APIs to integrate shared data with their EHR and also send their data to myPHR. In our example scenario, if the hospital that admitted Agda for COPD was integrated with myPHR system, they would be able to see an up-to-date list of Agda's medication and allergies to latex and peanut, integrated into their internal EHR system. The admitting nurse would not be able to tell if that information is supplied by myPHR or their internal system. Also upon admission and discharge, the hospital's EHR system would send data to myPHR through the API to update Agda's encounters.

Physicians, laboratories, pharmacies, physiotherapists and other healthcare providers that are of smaller scale are considered **small-scale healthcare providers**. Most of them have purchased software applications that allow them to sustain an electronic record system. We assume that they can negotiate deals with their EHR provider to get their EHR system integrated with myPHR system. If not, they could still access myPHR website, or they may be able to purchase apps created by **healthcare application developers**. In the scenario, the convalescent care home where Agda was discharged to, after her initial hospitalization, counts as a small-scale healthcare provider which can see Agda's profile and her Allergy and dietary restrictions. Upon Agda's admission to the convalescent care home, her latest address on myPHR was updated accordingly. Similarly, Agda's dates of encounters with the family doctor, Respirologist, endocrinologist would be fed to myPHR system by them. The laboratory in which Agda's blood was

drawn, would also myPHR system with the date they conducted the blood work. And finally, the EHR system of the pharmacy that supplied the antibiotics, would send an update for Agda's medication details.

3.5. Governance

The framework we propose needs to be managed and legally enforced by the governing body responsible for the healthcare system. In Canada, this would be the Ministry of Health for each province. We suggest that this authority should build the proposed solution and ensure that it complies with the regulations and privacy requirements. Similar models have been successfully implemented in Europe. As an example, Norway has established a national project called "Kjernejournal"[19] that provides personal health information delivered by general practitioners, out-of-hours services, and hospitals to the citizens of Norway as well as healthcare professionals treating them. Kjernejournal contains information from national registers, serious medical conditions or allergies registered by physician, and any information patients enter themselves. Patients can also look up their prescription, fees for medication, and the contact information to their regular health practitioners. Kjernejournal is created automatically for all inhabitants of Norway.

4. Evaluation and discussions

4.1. Interoperability

Current healthcare interoperability approaches can be classified into three categories: Single-HCO, multi-HCO, and HCO-independent. The single-HCO approach is specific to a single HealthCare Organization such as a hospital EHR. The multi HCO approach convinces a group of HCOs to use their system and allow the flow of information within the system. Epic system[3] in the US and TakeCare system[9] in Stockholm, Sweden, are examples of multi-HCO approach. The HCO-independent approach provides an Application Programming Interfaces (API) that healthcare providers can adopt to share their data[15]. Table 2 analyzes these three categories in terms of data, process, and contextual interoperability[12]. A system has achieved data interoperability if data can seamlessly be transferred across any authorized HCO in real-time. Process interoperability point if there is no conflict within the processes of each HCO pair that affects the continuity of care. Finally, contextual interoperability is realized if contextual factors are the same, in agreement, or non-threatening for all potential and participating HCOs.

Table 2. Interoperability Classes Applied to EHR Systems

HCO Category	Data	Process	Contextual
Single-HCO	**No**. No attempt has been taken towards data sharing.	**Somewhat**. Only within the HCO process interoperability is handled.	**Somewhat**. There is a single context within the HCO.
Multi-HCO	**Somewhat**. Data interoperability is achieved among the participating HCOs only	**Somewhat**. Process interoperability may or may not be achieved among the participating HCOs only.	**Somewhat**. having consistent context is a prerequisite to adoption of the system,.
HCO-Independent	**Yes**. Theoretically, all healthcare actors should be able to use these tools to share their data.	**Somewhat**. There are some guidelines for example within HL7 to encourage and recommend a single best practice.	**No**. The proposed system is mainly technical and does little towards resolving contextual issues.
Our proposed solution	**Yes.** All healthcare actors are able to send and receive data streams	**Yes.** The minimum dataset is resulted from what's common practice among all HCOs	**Yes.** The proposed system is governed by the Ministry of Health which oversees all HCOs in the province

4.2. Quality of care

According to Canadian Institute for Health Information, quality of care is evidence-based, patient-centric, timely, and safe[6]. The key to evidence-based care is to be able to share previous experiments and experiences; successful or failed. As discussed before, the biggest hole in the current healthcare practice is the absence of or inefficiencies in sharing data inter-organizationally. Our proposed system has the potential to be expanded into a system that includes evidence-based care and the best practices known.

Our proposed system recognizes the patient as a key actor in the healthcare delivery process and promotes the patient's right to timely data about their health. Unfortunately, current HCOs control the data that's produced from a care delivery process and often do not disclose most of that information to the patient. Back to our scenario, Agda would have been able to communicate her dietary preference through myPHR portal and receive a better service that's tailored to her specific needs.

Timely data delivery is inherent in our proposed method. It is designed in a way that the data is presented in real-time without any delays. One of the most prominent features of the proposed system is the timely availability of the most critical data. This is often lacking in the current healthcare system because data is decentralized and the system does not impose any meaningful requirements for sharing. Going back to our scenario, if the convalescent care home had access to Agda's up-to-date profile, they would have known about her dietary regimen and she would not have suffered an imbalanced nutritional intake during her most vulnerable time and she would have had a safer recovery period. If the hospital knew that Agda has a high risk for falling, they might have been able to accommodate her accordingly, with a room with better accessibility features.

4.3. PHI privacy and confidentiality

According to PHIPA, HCOs are allowed to share and access Personal Health Information (PHI) for the purpose of continuation-of-care[2]. HCOs can do so, assuming an implied consent from the patient[1]. Furthermore, it's been proven that patients have positive attitudes toward the implementation and use of a patient portal that provides means to manage patients' health status. Patients would like to see trends on their health status and are willing to feed some basic data into the system[13].

Current practice remains too cautious towards the use of cutting edge technology for sharing healthcare data. In order to avoid any privacy breaches, most HCOs choose to limit data sharing attempts. When a collaboration between different HCOs is required, for example, to deliver a shared care or to perform an investigation, data is shared through email, secure cloud-based file storage and sharing systems like SkyDrive, or a simple fax. When hospital X wanted to investigate "the determining factors for re-hospitalization within 30 days", and they need to collaborate with community care providers, and they usually use secure emails to share their datasets. This means every time a revision needed to be communicated, it would have to be through email and sending and resending of Excel exports of their datasets. They lose track of the versions sent before, what was added to each revision, and manage multiple exports to Excel from their data analysis tools. When a local nursing provider agency wants to send their periodic reports to the funding organization, they use a Dropbox-like application.

Our proposed system, however progressive, still remains compliant with PHIPA guidelines. Multiple access level rules defined within the business tier of the proposed architecture, guarantee the authorized access to the PHI. Our tool provides a unified and integrated privacy approach as opposed to the disintegrated and incoherent use of different tools with different privacy approaches and policies. Healthcare APIs defined by Google and Microsoft have very secure and well-defined privacy safeguards[18].

4.4. Continuity of care and reduction of patient care fragmentation

When appropriate, hospitals are trying to shorten a patient's stay at the hospital by providing care in their home. Community care providers and smaller nursing agencies are contacted to continue the delivery of care after a hospital episode. For a smooth and seamless transition, all the aforementioned healthcare providers need to collaborate and cooperate. With the patient's care being transferred from one HCO to another, there follows a need to transfer their health data as fast as possible in a secure manner.

5. Conclusion and future work

Our proposed solution brings together the three determining components of a successful healthcare integration: minimum dataset, platform-independent technology, and governing body. With perfect alignment of these three components, and engaging various actors in the system, we believe that a reasonable interoperability can be achieved for the healthcare industry in Ontario. Furthermore, assuming an equal spot for patients and empowering them with the right tools, opens doors to better provision of individualized care.

The proposed system is only focused on the minimum dataset as a start. However, a truly interoperable healthcare system should cover most of what happens to a patient, includes best practices in healthcare delivery, and be more comprehensive. Future work can delve into expanding the minimum dataset.

Furthermore, a system that can reliably gather information and make it available to the patient's care team would be one of the missing links to providing truly personalized health care.

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