

A Framework for System-level Health Data Sharing

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Abstract: Circle of care is the term that has been used to provide context for health data sharing that is allowed by privacy regulation that occurs when a diverse team is collaborating to provide care to a patient. We introduce the concept of system-level health data sharing to capture the totality of health data that exists for a patient in a healthcare system across multiple health care organizations. MyPHR is a system-level health data-sharing framework that guides any healthcare system to set up interoperable, patient-centred health data sharing. We briefly introduce the components of MyPHR framework and then discuss its evaluation by a panel of experts who reviewed a demonstration walkthrough of the interfaces and data sharing that the framework supports.

1 INTRODUCTION

Health data can be shared at three levels. First, it can be shared within the boundaries of a single health care organization (HCO). In this case, the HCO does not interact with other HCOs so data is not shared outside the HCO. Patients can be involved in their care delivery through a HCO-specific portal that grants access to their personal health data. We call this single-HCO health data sharing (Azarm, Peyton, Backman, & Kuziemyky, 2017).

Second, it can be shared within a group of HCOs who agree to acquire and use a single system in order to facilitate collaboration and data sharing. We call this multi-HCO health data sharing. An example of multi-HCO sharing is the TakeCare system (Cars, et al., 2013) that a few hospitals in Stockholm use to enable data, process, and contextual interoperability (Kuziemyky, 2013) within this alliance. However, no interaction is supported with HCOs outside of this alliance.

Finally, at the third level there is HCO-independent data sharing. Any HCO can share and access health data through a medium that allows the flow of data from and to the existing Electronic Medical Record (EMR) systems. Although not as successful as we would expect, Microsoft HealthVault is an example of HCO-independent data sharing. (Sunyaev, Kaletsch, & Krcmar, 2011).

A framework for system-level health data sharing offers the potential to support better patient-centred care (Haux, 2006). A circle of care (Donga, Samavia, & Topaloglou, 2015) refers to a patient and a team of healthcare providers who are providing care to the patient in order to address a common healthcare goal. A system-level circle of care covers all healthcare providers across an entire health system (Gaynor, Yu, Andrus, Bradner, & Rawn, 2014) who are providing care to a single patient to address multiple goals without necessarily collaborating or being aware of each other (Azarm, Backman, & Kuziemyky, 2019).

1.1 Interoperability

Interoperability can be defined as the ability to exchange and use information across different organizations, enabling cooperation between their entities (Benson & Grieve, 2016). Three types of healthcare interoperability have been defined: data, process, and contextual (Kuziemyky, 2013). Data interoperability refers to the syntactical level of data and whether it is machine interpretable across different systems. Process interoperability focuses on the system users and the processes they engage in. Process interoperability requires system users to be able to use and interpret data across the various tasks of health care delivery. Finally, contextual interoperability refers to the political and social environment where the

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healthcare providers operate and includes different legislation and/or social norms that can help or hinder the shared care provided to a patient when delivered across different providers or settings.

1.2 Quadruple Aim

Berwick et al. introduced the Triple Aim framework for improving the healthcare delivered to individuals in a balanced manner. The triple aim- comprises three principles: improving the individual experience of care, improving the health of population, and reducing per capital cost of care for population (Berwick, Nolan, & Whittington, 2008). However, the success of triple-aim principles is dependent on effective healthcare organizations and healthcare workforce (Sikka, Morath, & Leape, 2015). Therefore, the quadruple aim framework emerged by introducing a fourth principle of improving the experience of providing care (Sikka, Morath, & Leape, 2015). The fourth principle is about care of the providers and enhancing the work life of providers to address emerging issues such as physician burnout (Bodenheimer & Sinsky, 2014). Through a quantitative study, Quanjel et al. proved that how the patient-perceived quality of care is improved by a Primary Care Plus initiative in Netherlands. (Quanjel, Spreuwenberg, Struijs, & Baan, 2019).

1.3 Governance

Healthcare in Canada is legislated and funded by the federal government and administered provincially (Madore, 2005). Electronic health record (EHR) governance models vary from country to country and even from region to region. Various Scandinavian countries, where health services are publicly funded, have embarked on a successive path of regulating, mandating and advancing use of electronic health records. Their endeavours started in the 1990s to push healthcare providers to deploy electronic health record systems and continued until recent years when they are moving towards the implementation of national electronic health record systems. As an example, Denmark published various national IT strategies consisting of national action plans for adoption of EHRs, pushing hospitals to employ HER systems, and governing and harmonizing all EHR systems in the country (Kierkegaard, 2015).

Although healthcare is delivered by the private sector in the United States, the Health Information Technology for Economic and Clinical Health Act (HITECH) provisions of the American Reinvestment and Recovery Act (ARRA) facilitated the adoption of

EHR systems by providing financial incentives for those who succeed at digitizing their health data, automation of their internal processes, and seamless collaboration with other healthcare providers (Marcotte, Kirtane, Lynn, & McKethan, 2014).

US hospitals embarked on a healthcare automation journey from the 1960 with purchase of mainframes to handle their administrative functions (Collen & Ball, 2015). They continued purchasing software to handle different business and admin functions. In 1990s the hospitals were operating with hospital information systems (HISs) and electronic patient record (EPR) systems, when the interoperability became an issue. With the new vendors' promise of better inter-organizational interoperability, most hospitals could benefit from exchange of information among their different acquired software systems after 2010.

Multi-Hospital Information Systems (MHIS) - systems serving three or more hospitals emerged in late 1980s. They often entailed translation databases and other technology to support the exchange of information and forms across the organizations involved (Collen & Ball, 2015). Meditech and Epic are examples of EHR systems used worldwide.

2 MyPHR: A SYSTEM-LEVEL HEALTH DATA SHARING FRAMEWORK

MyPHR is an application framework that guides a healthcare system in setting up a system-level patient-centered infrastructure so that they can have a connected healthcare platform (Azarm, Backman, & Kuziemy, 2019). It has three components. First is an information model that defines exactly what type of information to share by everyone and in particular has a simple definition of an episode so that all stakeholders can understand what is shared without being an expert. Second, it has an architecture that defines a cloud hosted infrastructure like Gmail, where the information can be stored and coordinated amongst all people. And the final piece is the governance model which defines who, how, and when can access any piece of information in the system, and who owns and maintains the system.

Healthcare systems in different political contexts could use this framework to build a patient-centric interoperable health information sharing platform. MyPHR empowers patients to be more involved in their care delivery, they have access to any piece of information that's shared on this platform about them,

they can add/edit some information, and they can always audit who and where has accessed their information.

2.1 Demonstration Walkthrough

In order to test our proposed MyPHR architecture we developed a prototype of the MyPHR portal pages as well as a RESTful API that helps collect and share the data that's formatted in accordance with our proposed ontology. Although, our ontology is mainly expressed in a relational and schema-binding annotation, our prototype data is stored in a No-SQL database (Google Firebase). This speaks to the scalability of our ontology.

Our MyPHR prototype web portal and API include methods to facilitate the Client actions such as viewing care history, updating health profile information, view active practitioners, etc. The prototype has methods that send updates to pull a patient's records from our API, collect information entered by patients, and send them to the API for permanent storage in a cloud environment. The API has methods to register a patient with a healthcare provider (through registering an episode), retrieve a patient's care history, update a patient's care record and terminate a patient's episode of care with a healthcare provider.

3 METHODOLOGY

Our research follows the guidelines of Design Science Research (DSR) (Gregor, Müller, & Seidel, 2013) where we aim at improving the personal health care experience through developing Health Information Systems artifacts (Baskerville, Baiyere, Gregor, Hevner, & Rossi, 2019). DSR is very relevant when it comes to developing information system artifacts that are innovative and solve real-world problems (Hevner & Chatterjee, 2015). Our artifacts include an architectural framework, web portal, API, governance principles, and an ontology. Moreover, through a literature review, we defined a customized set of evaluation criteria for system-level healthcare data sharing systems.

As per DSR guidelines, the project should start with the specification of a problem/opportunity (Baskerville, Baiyere, Gregor, Hevner, & Rossi, 2019). Therefore, through a Systematic Literature Review (SLR) we aimed to identify the gaps in the collaborative health care especially in Ontario, with the possibility of finding a platform-independent solution for interoperability (Azarm, Kuziemy, &

Peyton, 2015). This step was achieved by studying the current body of knowledge (Gregor, Müller, & Seidel, 2013). At the end of the first iteration, we proposed an architecture, defined a set of attributes (minimum dataset) that flows through the proposed architecture, and designed a web portal and an underlying REST-full API.

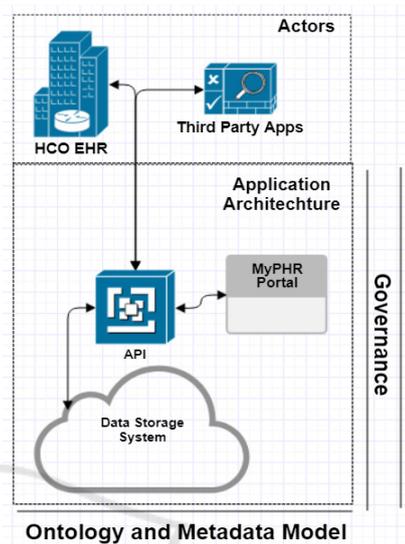


Figure 1: MyPHR High Level Architecture.

In our second iteration of DSR, we honed in on the idea of an ontology, and how we can make our minimum data set more streamlined. Our ontology was developed using an ontology development methodology (Noy & McGuinness, 2001), and we benchmarked HL7 FHIR (Azarm & Peyton, 2018). Based upon Noy's ontology development guidelines, our benchmarking of the FHIR was to conform with a popular health data standardization entity.

The third iteration was conducted to address regulation, security and authorization concerns. We focused on developing a set of data governance principles in our third DSR iteration. We studied a data sharing application that a group of researchers at Elizabeth Bruyère hospital in Ottawa had developed through a third party software company called NexJ. We then studied their application (P2H) as a case with regards to MyPHR framework to test our proposed governance principles (Azarm, Backman, & Kuziemy, 2019). At the end of this iteration, we came up with the concept of "system level circle of care".

Our fourth iteration involved prototyping the architecture to pinpoint the actors and the interfaces. We conducted a usability study through a Patient Case Study that showcased our expectations from the

prototype and how they were met. At the end of this cycle, we conducted an evaluation with a demonstration walkthrough reviewed by a panel of experts (Agarwal, et al., 2016). We gathered a review panel consisting of 5 experts in the healthcare technology domain. This panel of experts included a general practitioner, a nurse practitioner, two healthcare technology directors, and a healthcare management scholar and thought leader.

4 EVALUATION

4.1 Evaluation Criteria

We introduced a set of evaluation criteria to evaluate frameworks and approaches in healthcare data sharing. The evaluation criteria can be leveraged to analyse any data sharing framework in the same domain. We used the evaluation criteria to evaluate our proposed application framework and compared it against some related works.

The set of evaluation criteria identified in this section were derived from:

1. Analysis of the related literature
2. Gap analysis of the current practices in hospital and community care
3. Government regulations and industry norms and concerns
4. Feedback from domain experts and practical experience
5. Experiences we acquired while working through our case studies.

We divided our evaluation criteria into 3 categories depending on the domain and/or the source.

4.1.1 System-level Interoperability

System-level interoperability is our first set of evaluation criteria where we discuss three aspects of interoperability i.e. data, process, and context.

The main question in **data interoperability** is: *Is sharing of data available across various platforms?* 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. The systems that can enable their users to share data regardless of their platform, will get a full score for this criteria.

For **process interoperability** we ask: Are we able to align and map processes across the boundaries of organizations? When a system is not capable of collaborating with other organizations and align their processes with those of other healthcare providers,

they would get a NA; when the system has established allegiance with a group of other healthcare systems and they can all map their processes to each other, they would be partially interoperable, hence a P is assigned; Finally, when processes can be translated and mapped within any organization, that system would get an A.

Context interoperability investigates if a system is capable of operating efficiently across different political/legislative contexts? From this perspective, a perfect system is capable of crossing various political environments e.g. provinces or countries without losing its cohesion and seamless integrity.

4.1.2 System-level Quality of Care

The Quadruple Aim framework that aims at improving the healthcare experience for all stakeholders is employed for this category of criteria. The evaluation criteria in this category are also a product of the Canadian Institute for Health Information (CIHI) framework. Based on CIHI, a care of quality is evidence-based, patient-centric, timely, and safe (CIHI, 2011). The key to evidence-based care is to be able to share previous experiments and experiences. Below, we introduce the criteria in this category.

Evidence-based: this metric comes from the CIHI framework. It focuses on how easy it is to support medical evidence or other processes across different platforms? The perfect system supports sharing of the evidence/process regardless of platform type.

Right Level of Details: the fourth principle of the quadruple aim framework is about improving the experience of providing care. The amount of data we gather in this day and age flood the healthcare workers with enormous amount of information that can leave them overwhelmed, and bear counter-intuitive consequences. What can support many healthcare workers is just the right amount of data at the right time. Therefore, we will examine if the framework under investigation can facilitate the provision of just the right level of details in order to support a healthcare worker in fulfilling their duties.

Patient-centric: this criterion crosses the two frameworks of CIHI (patient-centric) and Quadruple aim (patient's care experience). It measures how informed a patient is in their care delivery process. However, it's not only about the quantity of data, but it's also about the breadth of data, and the care episodes and organizations. A perfect system would enable the patients to access any piece of information available on the data sharing platform.

Timely: this criterion from CIHI framework captures the essence of the two Quadruple Aim principles of patient, and provider experience. If required information is received in a timely manner, this could have a positive impact on the experience of the individuals on both ends of care delivery. It assesses if system users (patients or providers) have the means to autonomously access the information in a timely manner. Here, the ideal system makes the data available and accessible in real-time as they are generated.

Cost: this criterion comes from the Quadruple Aim criteria. It focuses on how the overall cost of healthcare can be decreased. Therefore, the question is if the system helps with any net savings. If the costs of acquiring the system are less than the alternative ways of solving the same problems, that health data sharing system is regarded as successful.

Health: another Quadruple Aim criterion. Here we talk about improving the health of the population. Does the system under investigation help achieve this goal in any way?

4.1.3 System-level Privacy and Confidentiality

Within this category we introduce two criteria; one for regulation compliance, and one for addressing privacy concerns.

Regulations Compliant: in this section we evaluate systems based on how compliant or adaptable they are to health regulations. If a system would not pass regulations without major modifications, it is deemed as a failure.

Privacy: personal health information is considered one of the most confidential type of information. Therefore, it's important that the system we employ, keeps the integrity and confidentiality requirements on the forefront of their specifications.

4.2 Panel of Experts Review

We gathered 5 experts to review a prototype of MyPHR framework. In order to provide context for the demo, we first gave an overview of MyPHR framework and its three major components: Ontology, Governance and architecture. Then, we walked them through a demo of a MyPHR framework-compliant prototype software application. During the framework overview and demo walkthrough there was much free-form discussion and feedback. At the end of the session we asked the experts to give us more structured feedback, using the evaluation criteria we have set as the “objectives to

meet” for our research. For each criterion, we gave a rubric that helped quantify the evaluation of the criterion. The experts were also encouraged to give us comments and free form feedback, either specific to a criterion, or not.

4.2.1 Evaluation Rubric

Our evaluation rubric lists the evaluation criteria that we laid out in section 4.1. We asked each expert to rate our framework against our evaluation criteria using a 5-point scale with the following values: Not Satisfactory, Below Average, Average, Above Average, or Satisfactory. To quantify our score levels, we added a numerical scale (1-10) to our 5-point scale of “Non-Satisfactory” to “Satisfactory” levels. For example, a non-satisfactory evaluation of a criterion could bear a numeric score of 1 or 2. We also invited our experts to add any additional comment in a free text and descriptive format. Our evaluation rubric is shown in Table 1.

Table 1: Evaluation rubric.

Domain	ID	Weight	Criteria
System-Level Interoperability	I1	5	Data interoperability
	I2	3	Process interoperability
	I3	1	Context interoperability
System-Level Quality of Care	Q1	1	Evidence-based
	Q2	1	Right level of details
	Q3	5	Patient-centric
	Q4	5	Timely
	Q5	1	Cost
	Q6	1	Health
System-Level Privacy and Confidentiality	P1	1	Privacy
	P2	5	Regulations compliance

4.2.2 Expert Feedback

During the sessions and through written comments, we received some valuable insights and suggestions that we have summarized below:

1. There shall be a patient identification and matching logic. In Ontario, OHIP number does not include individuals from RCMP and the military.
2. Experts were interested in seeing a place for smart devices in our proposed architecture.
3. Experts were interested in seeing how appointments fit into the Episode concept e.g. a list for appointments that is separate from the list of episodes.
4. Experts were interested in a different presentation format for the health data. For

- example: Diagnoses in reverse chronological, and with a short label/comment.
5. Caregiver information was not clear about connotations such as power of attorney for personal care; hierarchy of substitute decision makers; primary care giver.
 6. The data points that should be editable by the Clients? e.g. diet, advanced directives.
 7. The information presented on the prototype portal such as dates did not always follow a consistent format.
 8. Experts were interested to see practitioners' qualification/speciality level of primary physician on the prototype portal.
 9. Experts were looking for more clarification around service language as it can be assumed any of the following: preferred service language, mother tongue, actual language of service.
 10. Experts were not certain where user comments can be placed.
 11. Experts needed more clarity on meta-data.
 12. The governance principles around HICs' visibility on patient data was discussed. Experts suggested to allow HICs' access to patient data to be beyond the active status of their episodes.
 13. Experts identified an opportunity for new and improved functionalities that can be added to HCO electronic record systems. They thought the framework as presented likely encounters few technical hurdles, and provides for a platform agnostic approach for sharing data across multiple healthcare information systems.
 14. The experts suggested that while the framework and API approach would provide a near real-time solution, the various HCOs may determine to interact with the data in either a batch mode or the preferred triggers to flow information across. Each HCO may also make determinations as to which episodes of care would be included in the information flow, potentially causing inconsistency in the frameworks picture of the patient/client.
 15. The adoption barriers identified by experts were: Financial barriers for HCOs to invest in building the interfaces and rules to submit data through to the API; Political barriers in determining where the primary Health Authority role, at a patient-centric service, should lie; Perception of the shared data and what it is providing, i.e. some HCOs will want to increase the scope of what is shared, while others may not be willing to participate; Privacy controls may need to be enhanced, in that the clients and/or HCOs will want to have some control as to which episodes of care are visible across all partners in the system, or just to some.
 16. Experts also identified a few barriers to implementation: Political barriers, where a centralized Health Authority to host the framework and centralized/consolidated data needs to be determined. Within some regions, the pendulum swings as to whether a centralized or decentralized approach to a Health Authority that would hold client level data, would be put in place. HCOs, particularly individual family physicians and Family Health Groups, may be reluctant to participate, most likely out of cost. The cost to update their systems to interface with the API would be imposed to the individual practices in many regions, if this would be a mandated system to be used. To solve this, the Health Authority may need to help fund vendors to build interfaces, and thus help bring in the smaller HCOs.
 17. Some experts were not sure if the criterion "right level of detail" is from patients point of view, physicians, HCOs or the regulator.

4.2.3 Evaluation Results

After the Panel of Expert Review Session, we reviewed both the structured and unstructured feedback. The unstructured feedback consisted of the verbal comments made during the session (notes were taken) and the written comments appended to the structured feedback that was laid out in section 4.2.2.

We categorized the comments into 5 groups. In the review session, we had presented 4 components to the experts: the demo data, the look and feel of the prototype application, the MyPHR framework, and our proposed evaluation criteria. Naturally, we wanted to identify and isolate the comments related to each of the 4 aforementioned review session components. Therefore, we created 4 categories of usability (for prototype application), demo data, framework, and criteria. Furthermore, we noticed that some expert feedback bore some degree of misunderstanding or communication problems. Therefore, we added a fifth category that encompasses the comments entailing a misunderstanding of a notion.

1. Prototype Usability: Feedback on the prototype application (look and feel and organization)
2. Demo data: Feedback on the demo data used in the presentation
3. Framework: Feedback on the elements of MyPHR framework

4. Criteria: Feedback on the appropriateness, relevance or poor definition, or misunderstanding of the criteria we had specified to use for evaluation
5. Misunderstanding: The comments that indicated certain aspects of the framework overview or demo were either not properly communicated or not properly understood in terms of the context, or objectives.

Table 2: Comment categories.

Category	Comment ID
Prototype Usability	7,8
Demo Data	3,4, 6,8,9,10
Framework	1,2,11,12,13,14,15,16
Criteria	17
Misunderstanding	5

Then, we analyzed the scores given to each criterion by experts. As for the scores given, of all the scores we received from the filled evaluation rubrics (Table 1), the experts rated the prototypes 67% of the times “above average”, 19% of the times “average”, and 14% of the times “below average”.

When a criterion had a score variability (i.e. difference between the highest score and the lowest score given) of less than 4 among experts, we deemed that criterion as having experts’ consensus, and when there was 4 or more score variability, we deemed that as divergent opinions about that criterion. We should point out that when the score variability was between 3 and 5, we manually inspected the results to see where the majority of the experts landed. As summarized in Table 3, experts had consensus on 5 criteria and had divergent opinions on the other six. Based on score averages, the experts scored MyPHR average or above average on all criteria.

We can conclude from the evaluation results that MyPHR appeared very strong on I1-Data Interoperability, Q3-Patient Centric, Q4-Timely, and P2-Regulations compliance, whereas I3-context interoperability, and P1-privacy were not as strong.

Although our evaluation criteria touch on various aspects of interoperable, patient-centric and successful healthcare platforms, we did not put our focus equally on all of them. We decided to concentrate more on developing a patient-centric framework that allows all healthcare stakeholders to communicate their data in a timely and cost-efficient manner. Therefore, not all our evaluation criteria have the same weight for us. To address that issue we created a three-scale numeric weight (1, 3, 5) based on how influential they were in our research.

Table 3: Expert scores.

Criteria	AVG	Min	Max	Overall
Data interoperability	7.9	6	9.5	consensus
Process interoperability	6.5	4	8	divergent
Context interoperability	5.0	4	6	consensus
Privacy	5.9	4	9.5	divergent
Regulations compliance	8.9	8	9.5	consensus
Evidence-based	6.0	4	8	divergent
Right level of details	6.6	4	8	divergent
Patient-centric	8.7	8	9.5	consensus
Timely	8.6	7	9.5	consensus
Cost	6.6	5	9.5	divergent
Health	6.6	2	8	divergent

5 CONCLUSIONS AND FUTURE WORK

In this paper we evaluated a system-level patient-centric health data sharing framework that we had developed previously. One of the methods used for this evaluation was a review by a panel of experts. The review produced structured and unstructured data that was analysed to improve our framework.

The reviewers also suggested features that can be considered for the future work. Developing a universal client matching algorithm and identification system instead of using patient health card number would perfectly fit in the next step agenda. Enabling the flow of information from the personal smart devices and the changes it would impose on our proposed ontology is another good area for future work. Furthermore, inclusion of richer metadata would enable better patient-specific privacy and security settings when it comes to setting proper and access levels for different users. This is an area that can be easily added to our existing ontology. Another enhancement we may tap into is to open up HICs’ access to client information to beyond their active status in the system-level circle of care, i.e. once a healthcare provider takes on a client, they have persistent access to that client’s information without time constraints.

In the context of the structured review results, and through factoring the weights into the scores we

received from our experts, we came to a GPA of 70% for all criteria considered. This figure tells us that our proposed framework is viable, although there is a lot of room for improvement. The proposed framework is perceived to improve the current situation.

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