

A Patient-Centered Framework for System-Level Sharing of Health Records

MANA AZARM

Thesis submitted to the University of Ottawa
in partial Fulfillment of the requirements for the
Doctorate in Philosophy degree in Electronic Business



School of Electrical Engineering and Computer Science
University of Ottawa

© Mana Azarm, Ottawa, Canada, 2020

Abstract

The idea for this thesis developed over a number of years through our professional experiences with management of community-based healthcare delivery in the province of Ontario. We noticed inefficiencies and inconsistencies when it comes to sharing of health records between different health care organizations, as well as challenges in communicating that information in a holistic manner. Most healthcare organizations, today, are working towards online sharing of records within their organization, but community-care organizations are lagging behind hospitals. Even then, current sharing of records is focused on sharing between healthcare professionals on the same team and focused on one particular health outcome for a particular patient. However, at a system-level, a patient may interact with different healthcare professionals from different health organizations on different health outcomes for a patient. For example, a dentist, an orthopedic surgeon, and a home care support worker may all share the same patient, but they have different goals, and are trying to achieve different health outcomes. It remains challenging for patients to understand their health records and the relationship to their quality of life goals for a single organization, never mind trying to have a holistic overview of all their interactions with health care professionals.

We were motivated to develop a systematic framework that could guide the development of system-level interoperable patient-centric sharing of health records. We also recognized and were motivated by patients' enthusiasm for being more involved in, and informed of their health care delivery, and how they can benefit the healthcare system through their involvement. Existing systems developed in Ontario, Sweden, Norway as well as three commercial systems from private industry were identified as related works that were part of our motivation as well.

Our main contribution is a systematic framework consisting of governance principles, an ontology, and a conceptual architecture to guide development of systems for patient-centric sharing of health records. The governance principles define what is meant by system-level sharing of patient records and how it should be managed. The ontology defines the critical minimum dataset of the entities and attributes that healthcare organizations across a healthcare system should know and share. It also includes the data inputs that a patient can provide. The conceptual architecture identifies artifacts such as a patient portal, and a platform independent API that securely enables system-level sharing of health records about a patient. Our proposed framework is validated through a set of case studies and a patient portal prototype (with API) that was reviewed by a panel of healthcare experts.

Acknowledgments

First and foremost, I would like to thank my thesis advisor Dr. Liam Peyton who was my biggest critic and supporter. His mentorship not only guided me in my studies, but also developed my personal and professional points of view. He showed me how to be an academic in the most pragmatic way.

Furthermore, I would like to thank my thesis committee advisors Dr. Craig Kuziemyky and Dr. Chantal Backman. Dr. Kuziemyky's precise and to the point comments paved the way to some of the key findings of this work. Dr. Backman balanced my technical and business-oriented perspective with her clinical and patient-oriented viewpoint.

I would also like to express my gratitude for the time-commitment, participation and the feedback that Jamie Stevens, Paul Boissonneault, and Dr. Cheryl Netterfield provided for evaluating our proposed framework, and Wenyan Li for collaborating with us on building parts of our prototype.

I am also grateful to have received financial support from the University of Ottawa and the Ontario Graduate Scholarship (OGS) program.

Last but not the least, I am forever grateful for the support of my family (my husband, my mother, and my sister) who helped put my mind at ease when I needed help juggling motherhood and my academic pursuit. I want to thank my daughters who always inspire me to be the best version of myself.

Table of Contents

Abstract.....	ii
Acknowledgments	iv
Table of Contents.....	v
List of Figures.....	viii
List of Tables.....	ix
List of Acronyms.....	x
Chapter 1. Introduction	1
1.1. Problem Statement.....	1
1.2. Thesis Contributions	3
1.3. Research Methodology	5
1.4. Thesis Organization	10
Chapter 2. Background and Related Works.....	11
2.1. The Quadruple Aim	11
2.2. Governance in Healthcare.....	12
2.2.1 Health Systems	12
2.2.2 Data governance	13
2.2.3 Health Governance Systems.....	14
2.3. Sharing of Patient Health Records.....	16
2.3.1 Laws and regulations of patient records privacy, ownership and sharing.....	17
2.3.2 Privacy and security risks of exchanging health information.....	18
2.4. Interoperability.....	20
2.4.1 Ad-hoc Dataset Sharing through P2P File Sharing Mechanisms.	21
2.4.2 Single-HCO Electronic Health Record Systems (EHR).....	21
2.4.3 Multi-HCO EHR Systems: TakeCare System in Sweden.....	22
2.4.4 HCO-independent and mobile applications.....	23
2.4.5 Patient-centered healthcare interoperability	25
2.5. Architecture and Standards.....	27
2.5.1 Actors and Digital Persona.....	28
2.5.2 MVC Pattern.....	29
2.5.3 Web services and APIs.....	29
2.5.4 Health Level 7 (HL7)	30
2.5.5 Fast Healthcare Interoperability Resources (FHIR).....	32
2.5.6 Ontology	36
2.5.7 Security.....	39
2.6. Related work	40
2.6.1 CHRIS	40
2.6.2 Epic.....	41
2.6.3 HealthVault.....	42
2.6.1 NexJ.....	42
2.6.2 ClinicalConnect	43
2.6.3 Kjernejournal	44
2.7. Chapter Summary	45

Chapter 3. Problem Definition	47
3.1. Patient-Centered Sharing of Healthcare Records	47
3.2. Gap Analysis.....	51
3.3. Evaluation Criteria.....	53
3.3.1 System-Level Interoperability	54
3.3.2 System-Level Quality of care.....	56
3.3.3 System-Level Privacy and Confidentiality.....	59
3.4. Chapter Summary	60
Chapter 4. A Patient-Centered Framework for System-Level Sharing of Health Records.....	61
4.1. Overview.....	61
4.2. Governance principles	63
4.2.1 Governance authority	64
4.2.2 Data Principles.....	65
4.2.3 Data Quality and Metadata	66
4.2.4 Data Access	66
4.3. Ontology	67
4.3.1 Step 1: Defining the domain and scope	68
4.3.2 Step 2: Reusing the existing ontologies.....	71
4.3.3 Step 3: Providing a list of relevant terminology in the domain.....	72
4.3.4 Step 4: Defining the entities and their relative hierarchy	76
4.3.5 Step 5 & 6: Defining the attributes and data types	85
4.3.6 Step 7: Creating instances.....	86
4.4. Conceptual architecture	87
4.4.1 Actors and Use Case Model	87
4.4.2 Tiered architecture.....	92
4.4.3 Registration and authentication model	97
4.4.4 Using API services to Add/Update an Episode	104
Chapter 5. Case Studies.....	108
5.1. Path2Home (P2H).....	108
5.1.1 Overview	109
5.1.2 Governance.....	111
5.1.3 Ontology	114
5.1.4 Architecture	116
5.1.5 Results	117
5.2. Patient-Centered User Experience	119
5.2.1 Overview	119
5.2.2 Governance.....	121
5.2.3 Ontology.....	123
5.2.4 Architecture	127
5.2.5 Results	128
5.3. MyPHR Prototype.....	130
5.3.1 Overview	131
5.3.2 Governance.....	133
5.3.3 Ontology	133
5.3.4 Architecture	133
5.3.5 Results	149

Chapter 6. Evaluation.....	152
6.1. Panel of Experts Review.....	152
6.1.1 Overview	152
6.1.2 Panel of Experts.....	152
6.1.3 Review Session.....	154
6.1.4 Criterion Ratings and Rubric.....	155
6.1.5 Analysis of Feedback.....	156
6.1.6 Additional Insights	159
6.2. Comparison to Related Work.....	162
6.2.1 Overview	162
6.2.2 System-Level Interoperability	165
6.2.3 System-Level Quality of Care	169
6.2.4 System-Level Privacy and Confidentiality.....	174
6.3. Assumptions, Limitations, and Threats to Validity	175
6.3.1 Assumptions	175
6.3.2 Limitations.....	176
6.3.3 Threats to validity.....	177
Chapter 7. Conclusions and Future Work	179
7.1. Conclusion	179
7.2. Future Work.....	180
7.2.1 Metadata Component.....	180
7.2.2 Security.....	181
7.2.3 Cost analysis.....	181
7.2.4 Smart device integration.....	182
7.2.5 System-level patient-matching algorithm.....	182
REFERENCES	183
Appendix I: Entities and Attributes in the Proposed Ontology	193
Appendix II: A Representative Instance of the Proposed Ontology	203
Appendix III: Data Model of the API Prototype	206

List of Figures

Figure 1 Design Science Research (DSR) Methodology (Vaishnavi & Kuechler , 2015).....	6
Figure 2 Example of CDA formatting in XML.....	32
Figure 3 FHIR Entities	35
Figure 4 Patient transition without information	47
Figure 5 A high-level structure of the proposed framework	62
Figure 6 Proposed Entities.....	77
Figure 7 FHIR entities used in our proposed ontology	84
Figure 8 Use Case Diagram.....	88
Figure 9 Conceptual Architecture Layers.....	93
Figure 10 HCO Authentication.....	101
Figure 11 HCO Employee Authentication Sequence Diagram	102
Figure 12 Different methods of authentication.....	104
Figure 13 NexJ use case diagram (P2H)	111
Figure 14. NexJ object model (P2H).....	115
Figure 15 NexJ conceptual architecture	117
Figure 16 MyPHR portal showing smart device data integration	124
Figure 17 MyPHR history	125
Figure 18 Patient case study interaction diagram.....	126
Figure 19 Patient scenario conceptual architecture	128
Figure 20 Prototype application layers.....	132
Figure 21 Prototype application Use Case Diagram	134
Figure 22 Prototype application Login Page	136
Figure 23 MyPHR Portal Dashboard Page.....	137
Figure 24 MyPHR Portal Prototype - Profile Page	138
Figure 25 MyPHR Portal Prototype - Alerts Page	139
Figure 26 MyPHR Portal - Episodes Page	139
Figure 27 API prototype components.....	140

List of Tables

Table 1 DSR Iterations	7
Table 2 Kjernejournal - Norwegian National PHI System.....	45
Table 3 Interoperability classes and different EHR systems.....	52
Table 4 Evaluation Criteria.....	54
Table 5. Relevant terminology in the domain of the proposed ontology	75
Table 6 HCO registration API call details.....	103
Table 7 Patient registration into the system API call inputs and outputs.....	105
Table 8 Update patient record API service.....	106
Table 9 Overview of the use cases in this thesis	120
Table 10 Evaluation Rubric.....	155
Table 11 Summary of comment categories	156
Table 12 Expert scores analysis.....	158
Table 13 Weights for Evaluation Criteria.....	159
Table 14 Evaluation rubric	163
Table 15 Comparison based on the proposed evaluation criteria.....	165
Table 16 HCO EMR systems vs. our proposed framework	166
Table 17 Estimated cost of an EHR system	173

List of Acronyms

Acronym	Definition
API	Application Programming Interface
DSR	Design Science Research
EHR	Electronic Health Record
EMR	Electronic Medical Record
FHIR	Fast Healthcare Interoperability Resources
GPS	Global Positioning System
HCN	Health Card Number
HCO	HealthCare Organization
HIC	Health Information Custodian
HIS	Health Information System
HL7	Health Level 7
JSON	JavaScript Object Notation
LHIN	Local Health Integration Network
P2H	Path to Home
PHI	Personal Health Information
PHIPA	Personal Health Information Protection Act
REST	Representational State Transfer
SLCoC	System-Level Circle of Care
TOH	The Ottawa Hospital

1.1. Problem Statement

There is an increasing need for an interoperable healthcare record system that can follow a patient from birth to death regardless of which health care organization or which healthcare professional they interact with. Too much time is wasted repeating collection of critical information in an ad hoc manner. Financial systems like credit card processing are able to exchange financial records in an integrated and interoperable fashion. It is time to achieve the same level of integration and interoperability with health records. Healthcare records are generated continually across the country but sharing these records between different healthcare organizations such as pharmacies, labs, hospitals, etc. is still a challenge.

Most healthcare organizations (HCO), today, are working towards online sharing of records within their organization, but community-care organizations are lagging behind hospitals. Even then, current sharing of records is focused on sharing between healthcare professionals on the same team and focused on one particular health outcome for a patient. However, at a system-level, a patient may interact with different healthcare professionals from different health organizations on different health outcomes for a patient (Radwin, Castonguay, Keenan, & Hermann, 2016). For example, a dentist, an orthopedic surgeon, and a home care support worker may all share the same patient, but they have different goals, and are trying to achieve different health outcomes. It remains challenging for patients to understand their health records and the relationship to their quality of life goals for a single organization, never mind trying to have a holistic overview of all their interactions with different HCOs.

Compared to the financial domain, HCOs are generally cautious and fearful of sharing sensitive health information. Also health records can be wider and deeper, and less structured (Dinov, 2016) than financial records, and the information generated from one organization to another can vary widely and hence be more inconsistent (Jothia, Rashidb, & Husain, 2015). Healthcare processes are complex and lack standardization (Alexandru & Coardos, 2016), and making decisions about human life is more difficult and open-ended. On the other hand, the financial sector strives to be customer-centric and increasingly healthcare is trying to be more patient-centric.

Moreover, there is a lack of interoperability between HCOs (Oyeyemi & Scott, 2018), and hence there is fragmented care provided to a patient by different HCOs that do not exchange information with each other (Kuziemyky & Peyton, A framework for understanding process interoperability and health information technology, 2016). Patients find themselves repeating the same information to different care providers. For example, a hospital EHR system does not share info with the community care provider's EMR system. Therefore, none of a client's characteristics information such as history of past illnesses, allergies, etc. that were collected by hospital staff are transferred over. As a result, community care providers need to ask the same questions all over again. Sometimes healthcare procedures like tests are repeated as well.

Furthermore, current cross-organizational collaborations are not fully compliant with the measures of the quality of care to provide evidence-based, patient-centric, timely, and safe (CIHI, 2011) healthcare services. PHI privacy and confidentiality as well as continuity of care and reduction of patient care fragmentation (Newfoundland and Labrador Centre for Health Information, 2015) are other concerns that remain problematic.

And finally, patients are ignored as the proprietors of their own health records. Patients should have the right to access their own health records (Benson & Grieve, 2016). Patients pay for healthcare services directly or indirectly. Therefore, they are entitled to be able to access the documents about the services they have paid for and understand what they entail.

1.2. Thesis Contributions

The main contribution of this thesis is a systematic framework for patient-centered sharing of health records. It provides guidelines for setting up a system-level health record sharing and interoperability platform across an entire healthcare system. The proposed framework includes:

- a) **Governance principles:** designed to ensure regulatory compliance, personal health information privacy, and encourage trust and participation in system-level patient-centered sharing of health records. Governance principles outline who oversees the integrity of the health records sharing platform, who should publish what type of data and who can access what type of data and for how long.
- b) **Ontology:** specifies the entities and attributes that are to be shared across a health record sharing platform, including their data types, and their relationships. Our proposed ontology is strategically aiming for a minimum dataset of information that healthcare organizations could commit to publishing as a system-level patient-centered view of health records for coordination and interoperability of care within a healthcare system. While our ontology complies with HL7 FHIR, we demonstrate how to curate a FHIR-based ontology in order to support health record sharing at a System-Level Circle of Care (SLCoC).

- c) **Conceptual architecture:** defines the actors, interfaces, and applications needed in a system-level health records sharing platform. It specifies the key actors that publish and access system-level health records. Furthermore, it includes artifacts such as patient portal, and a platform independent API that allows actors to share system-level patient-centered health records.

We have also implemented a prototype patient portal and API to validate our proposed framework based on a review of the framework and prototype by a panel of healthcare experts.

The following publications have been generated in relation to this thesis:

1. Azarm, M., Kuziemy, C., Peyton, L., A Framework for System-Level Health Data Sharing, 13th international conference on health informatics (HEALTHINF2020), February 2020, Valletta, Malta.
2. Azarm, M., Backman, C., Kuziemy, C., System-level Patient-Centered Data Sharing, May 2019, 1st international workshop on software engineering for healthcare (SEH 2019), May 2019, Montreal, Canada.
3. Mana Azarm, A Patient-Centric Data Sharing Framework, poster presented at University of Ottawa 2019 engineering poster competition, March 2019, Ottawa, Canada.
4. Azarm, M., Peyton, L., An ontology for a patient-centric healthcare interoperability framework, 2018 IEEE/ACM International Workshop on Software Engineering in Healthcare Systems (SEHS), May 2018, Gothenburg, Sweden.

5. Mana Azarm, Liam Peyton, Towards a Person-Centric Healthcare System, MyPHR, poster presented in CreateBest poster competition, September 2017, Ottawa, Canada.
6. Mana Azarm, Chantal Backman, Craig Kuziemy, Liam Peyton, Breaking the Healthcare Interoperability Barrier by Empowering and Engaging Actors in the Healthcare System, presented in the 7th International Conference on Current and Future Trends of Information and Communication Technologies in Healthcare (ICTH 2017) and published in Procedia Computer Science, September 2017, Lund, Sweden.
7. Mana Azarm, Craig Kuziemy, Liam Peyton, A review of cross organizational healthcare data sharing, submitted to the “The 6th International Conference on Emerging Ubiquitous Systems and Pervasive Networks (EUSPN 2015)/ The 5th International Conference on Current and Future Trends of Information and Communication Technologies in Healthcare (ICTH-2015)” and published in Procedia Computer Science, volume 63, pages 425-432, September 2015, Berlin, Germany.

1.3. Research Methodology

The research methodology followed is Design Science Research (DSR). We want to improve the personal health care experience, and this is done through the development of a few artifacts in the domain of health information systems. DSR is very relevant when it comes to developing information system artifacts that are innovative and solve real-world problems (Hevner & Chatterjee, 2015).

We also make use of use case experiments as case studies in our research in order to demonstrate the artifact we are developing. Case study is a descriptive research about a phenomenon in its natural context that is bound to space and time constraints (Hancock & Algozzine, 2006). Furthermore, a case study is about the intensive study of a case with the goal of extending the results of that study to several other similar cases (Gerring, 2006). One of the techniques for choosing a case in a case study is the typical approach in which the case under study, represents the typical variables and scenarios of the phenomenon under investigation (Gerring, 2006). Our case studies were conducted to validate some aspect of phenomenon related to our thesis in the lab as a use case experiment. This is typical of design science research when wishing to demonstrate the artifact that is being designed and developed. We did not follow a formal case study methodology (Yin, 2017). In this sense, we experimented with a few use case scenarios in our labs to articulate our artifacts and implement our proposed guidelines. Throughout this thesis, we use case study and use case experiment interchangeably.

We went through four iterations of the typical DSR life cycle as shown in Figure 1 (Vaishnavi & Kuechler , 2015).

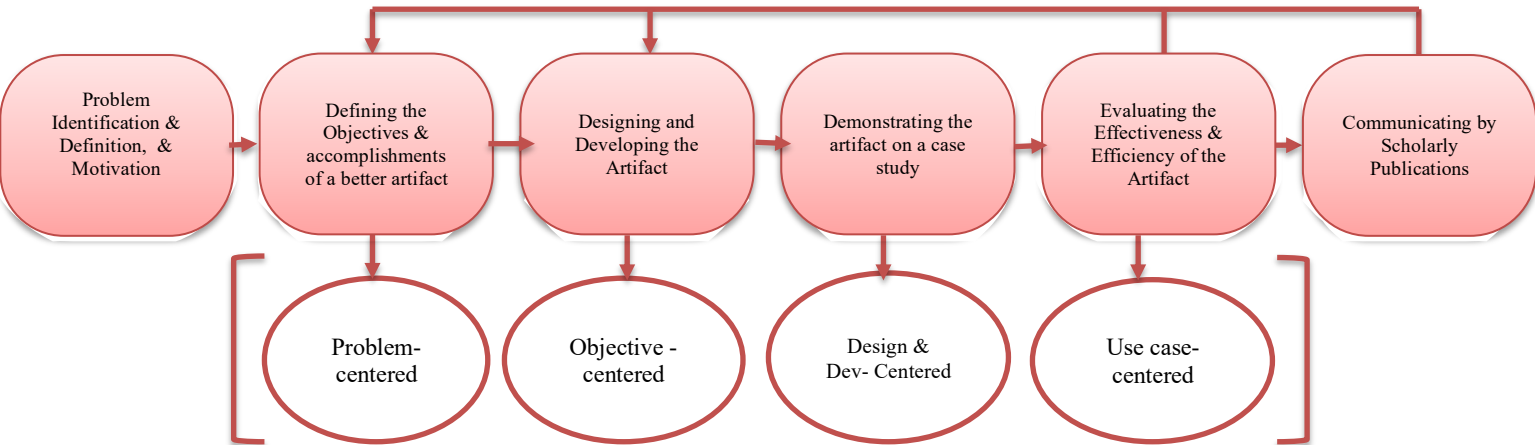


Figure 1 Design Science Research (DSR) Methodology (Vaishnavi & Kuechler , 2015)

Our four iterations are summarized in Table 1 DSR Iterations.

Table 1 DSR Iterations

DSR Phase	Problem Identification & Definition, & Motivation	Defining the Objectives & Accomplishments of a Better Artifact	Designing & Developing the Artifact	Demonstrating the Artifact on a Case Study	Evaluating Effectiveness & Efficiency of Artifact	Communicating by Scholarly Publications
First Iteration	Lack of interoperability among healthcare providers	Literature review to analyze the current body of research and Find solutions for interoperability gaps and issues	The Proposed Framework	Norway's Kjernejournal, and Sweden's Journalen, and Agda's story	Through CIHI criteria, referencing the current healthcare practices, and the systematic review of the literature	EUSPN2015 ICTH2017
Second Iteration	Need an ontology that considers the limitations of professional practice and all its records follow a single syntax and semantics.	well-defined series of concepts, entities, and attributes and Ontology based on popular existing standards	The Ontology	Claire's story	Model-driven study of Claire's scenario.	CreateBest2017 poster competition SEHS2018
Third Iteration	Find enablers of records sharing at a system-level circle of care	patient-centric governance principles	Governance Principles	P2H study	Comparative study of NexJ hosting of P2H Circle of care vs. the proposed framework	OttawaU Eng. Poster Competition 2019 SEH2019
Fourth Iteration	System-level electronic collaboration is a challenge. Also, Patients are often left out of their care loop	To empower patients and HCOs to collaborate and share system-level health records	Prototypes of the Conceptual Architecture: the API, and the Patient Portal	Patient scenarios	Usability scenario, panel of experts	HealthInf2020

First iteration: We performed a systematic literature study of the current body of knowledge in order to identify the current knowledge base (Gregor, Müller, & Seidel, 2013), the current solutions, the gaps and problematic areas related to interoperability and patient-centered sharing of health records. We elaborated on the problems identified and inferred a need for system-level sharing of health records. We focused on a patient-centered framework for system-level sharing of health records and illustrated the concept with a representative use case⁰ as a basis for a gap analysis of related work. This use case and gap analysis set the stage for the deductive steps of elaborating the three main components of our proposed framework (i.e. the conceptual architecture, the ontology, and the governance principles) in the subsequent iterations.

Second iteration: We focused on developing an ontology of the problem domain that addressed the limitations of current practice. It was specifically crucial to define what data should be shared among whom in a healthcare system, and that all shared records have a common syntax and semantics. We developed our ontology based on a standardized methodology using Noy's ontology development methodology and benchmarked HL7 FHIR entities. We implemented the newly developed ontology on a case study that we had developed by modeling the processes of transitioning a patient from hospital care to the community care and evaluated how effective this model is at showcasing the major data points we wanted to capture.

Third iteration: We focused on developing the governance principles that are needed to realise system-level health record sharing. This iteration developed a case study of a commercial health authority enabling regulated and secure data sharing for community care. In particular, our case study involved a health records sharing application (Path2Home) that a group of researchers

at The Bruyère hospital in Ottawa had developed through a third-party software solution called NexJ Connected Wellness.

Even though the initial understanding of the framework from iteration 1 was focused on conceptual architecture first, then ontology, and only then the governance principles, we found this iteration as the critical iteration that resulted in the complete high-level understanding in our proposed framework and what it meant to support patient-centered system-level sharing. Hence, in chapter 4 and chapter 5, the governance principles are covered before the ontology and the conceptual architecture.

Fourth iteration: In this iteration we focused on defining the complete detailed conceptual architecture that was conceived in the first iteration. In particular, this involved the inclusion of an API to secure and enable well-regulated patient-centered system-level sharing of health records. The API was developed using the FHIR standards, and a case study was developed to demonstrate how well a typical developer could use the API to build a patient portal. This case study acted as a usability scenario (5.2Patient) that showcased our expectations from the prototypes. We developed prototypes of the proposed API and the patient portal and evaluated them through a panel of experts. We structured experts' feedback through a rubric that we had developed based on our proposed evaluation criteria.

1.4. Thesis Organization

In chapter 2, we cover background and concepts, starting with the quadruple aim and governance in healthcare. Then, we cover sharing of patient health records and interoperability delving into architecture, platforms and standards. Finally, we cover the research and healthcare technology related to our research.

Chapter 3 defines the problem starting with an analysis of current practice for patient-centered sharing of health records. We identify the gaps observed in the current practice and do a gap analysis of the related work. Finally, we identify the evaluation criteria that proposed solutions to our research problem should be evaluated with.

In chapter 4, we introduce our proposed framework and explain its components in detail in terms of governance principles, ontology and conceptual architecture.

In chapter 5, we present three case studies. These case studies are drawn from current industry practices and are gathered from our literature survey and by our own experience with the operations of a few key healthcare providers such as Champlain Local Health Integration Network (LHIN), The Ottawa Hospital (TOH), and the Bruyère Hospital.

In chapter 6, we evaluate our proposed solution that was applied to the chapter 5 case studies and compare it to the related work described in chapter 2. We bind what is discussed in chapters 2, 3, 4 and 5 by presenting a comparison based on the set of evaluation criteria introduced in chapter 3. We also describe how we performed an end-stage validation with a panel of experts review session. Finally, we discuss the assumptions and limitations of our thesis research.

In chapter 7, we present our conclusions and discuss future work.

Chapter 2. **Background and Related Works**

We start this chapter by introducing the quadruple aim framework for improving healthcare delivery. We then delve into various aspects of healthcare governance and describe a few example systems for governance of health records sharing. We continue by discussing the sharing of patient health records in Ontario: who owns healthcare records, how privacy is protected, and access regulated. Next, we explain the notion of interoperability in healthcare and its different forms. We present the current Electronic Medical Records (EMR) systems through 3 categories. We found that these 3 categories can house most of the systems we studied and presented in this chapter. Next, we present some of the most prominent technologies, standards and platforms in the domain of health records sharing. Finally, we identify the related work. Later in chapter 6, we compare our framework to the related work presented in this chapter.

2.1. The Quadruple Aim

(Berwick, Nolan, & Whittington, 2008) introduce a framework for improving the healthcare delivered to individuals in a balanced manner. This framework -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. The triple-aim framework does not mention health workers in anyway. However, many believe that 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 for the triple aim framework i.e. improving the experience of providing care (Sikka, Morath, & Leape,

2015). The fourth principle is about feeling fulfilled and accomplished by delivering healthcare. Sikka argues that this fourth aim does not necessarily guarantee the success of triple aim framework, however, its absence is indeed damaging (Bodenheimer & Sinsky, 2014).

Studies such as Quanjel et al.'s work on proving the importance of healthcare providers and their improved experience of care attests to the importance of this fourth principal. Through a quantitative study, Quanjel et al. showed how the patient-perceived quality of care is improved by a Primary Care Plus initiative in Netherlands. This initiative basically introduces a group of healthcare professionals as primary care providers that act as a patient's gateway to healthcare. This initiative is quadruple-aim compliant and provides evidence of the potential of the quadruple aim framework (Quanjel, Spreeuwenberg, Struijs, & Baan, 2019).

2.2. Governance in Healthcare

2.2.1 Health Systems

According to the World Health Organization (WHO) a health system is an arrangement of a financing mechanism, workforce, information, facilities, and logistics that deliver health services to people (World Health Organization, 2019).

A health system is at times referred to as a system of systems due to its complexity. This complexity stems from the variety of interactions among various components a health system comprises, and the degree of interrelatedness among them. These components can be wide and deep including systems for information, finance, HR, organizational structure, etc. (Champion, Kuziemsy, Affleck, & Alvarez, 2019).

System thinking as a paradigm in approaching and solving problems has had a good track record when it comes to complex systems. Through system thinking, we can see the system as a whole, and beyond its individual components. System thinking can provide solutions when other approaches fail because of system complexity, challenges in solution implementations and failing to learn from the past mistakes (Adam & Savigny, 2012).

Understanding a system as a whole, and system thinking can reduce the perpetual problems that are caused by solutions implemented to one component of a system, that are often underestimating the complexity of the overall system. Some examples include: wild fire suppression efforts can cause larger and more dangerous fire incidents due to causing more tree density and fuel accumulation; the role of antibiotics in the evolution of medication-resistant pathogens; and health plan policies of prescribing cheaper drugs bear the adverse increase of the overall healthcare costs (Sterman, 2011). Similarly, system thinking can have such positive impacts on the success of healthcare records sharing systems.

2.2.2 Data governance

Data governance provides structured guidelines for roles and responsibilities when it comes to the power of making decisions, and the levels of individual duties, while bearing the final goal of gaining maximum value out of the data assets (Otto, 2011). It is important to note the difference between data assets, versus IT assets in which we are talking about computer hardware and software and not what is stored within them (Khatri & Brown, 2010). Data governance specifically clarifies what decisions need to be made, what roles are required, and what authorities and responsibilities are assigned to each role.

Data governance can provide guidelines in the following domains (Khatri & Brown, 2010):

- **Data Principles:** Defines the use cases where the data is of use and is considered an asset.
- **Data Quality:** Defines requirements for data such as accuracy, timeliness, credibility, etc. and how the quality of the data can be measured
- **Metadata:** Guides how to document the semantics, how to consistently generate data, and how to keep data up to date. It clarifies what is the data all about and how it is represented.
- **Data Access:** Talks about the value of data to the business and how to conduct data risk analysis, audit, compliance, backup on an ongoing basis

2.2.3 Health Governance Systems

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 and in some cases are dictated by individual companies (EHR vendors). 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 endeavors started in the 90s to push healthcare provider to deploy electronic health record systems and continued until recent years when they are moving towards the implementation of national electronic health record system. As an example, Denmark published various national IT strategies consisting of national action plans for adoption of EHRs, pushing hospitals to employ EHR systems, and governing and harmonizing all EHR systems in the country. Unfortunately, many of these national attempts deemed unsuccessful, were shut down,

and faced with resistance due to the drastic changes they exposed to the current systems (Kierkegaard, 2015).

Although healthcare is delivered by the private sector in the United States of America, 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 records, automation of their internal processes, and seamless collaboration with other healthcare providers (Marcotte, Kirtane, Lynn, & McKethan, 2014). Albeit these policies, healthcare interoperability is still a work in progress in the US.

US hospitals embarked on the healthcare automation journey in the 1960s with the purchase of mainframes to handle their administrative functions. Later on in the 1970s and 80s, hospitals acquired smaller desktop computers and were able to set up Local Area Networks to exchange information within their organizations (Collen & Ball, 2015). They continued purchasing software to handle different business and admin functions. In the 1990s the hospitals started operating with hospital information systems (HISs) and EHR 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 that serve three or more hospitals emerged in the 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 among top vendors of such EHR systems in the US.

2.3. Sharing of Patient Health Records

While this thesis looks at other systems from other countries, most of the thesis assumes the regulatory framework we are familiar with from our professional and academic experience in Ontario, Canada. Canada has comparable regulations with the US and the European countries e.g. PIPEDA is compliant with European Union Prime Directive on privacy. Canada is similar to the European Union on safeguards against industry, but similar to US in terms of a lack of a national patient identification system.

Healthcare in Canada is legislated and funded by the federal government and administered provincially (Madore, 2005). The provincial ministry of health allocates funding to the healthcare providers in the province (Canada Health Infoway, n.d.). While urgent and acute care is provided at the hospitals and clinics, there are also publicly funded community healthcare providers that deliver care outside of the hospital settings such as at home, school, retirement home, etc. Provincial health ministries in Canada have facilitated the adoption of electronic health record (EHR) systems across various healthcare providers (Health Canada, 2007).

Personal Health Information Privacy Act (PHIPA) is an Ontario legislation specific to healthcare that is compliant with the federal Personal Information Protection and Electronic Documents Act (PIPEDA). PIPEDA is not specific to healthcare and sets obligations on organizations that collect and store personal information, in favor of individual privacy protection (Austin, 2006). Most of other provinces in Canada have similar legislation to PHIPA. PHIPA provides guidelines on what is considered Personal Health Information (PHI), who can use PHI, to whom it can be disclosed, and the rights and obligations of the parties involved (Cavoukian, A Guide to the Personal Health Information Protection Act, 2004), (Government of Ontario, 2020).

PHIPA only allows healthcare providers with a Health Information Custodian (HIC) designation use and disclose PHI. According to PHIPA, HICs may disclose PHI to other HICs without an explicit consent from the patient. Therefore, the patient consent is implied unless the patients specifically withdraw their consent. In this sense, PHIPA supports interoperability among Health Information Custodians (HICs).

2.3.1 Laws and regulations of patient records privacy, ownership and sharing

Personal Health Information Protection Act (PHIPA) is an example of legislation (from Ontario, Canada) that provides detailed guidelines for all the players involved in producing and handling Personal Health Information (PHI) (Cavoukian, A Guide to the Personal Health Information Protection Act, 2004). PHIPA defines Health Information Custodian (HIC) as persons involved in delivering healthcare services and patient would be the person receiving this healthcare service. PHIPA also identifies the recipients who are individuals receiving information from a HIC. HICs must make sure that the information they generate, use, and maintain is accurate and secure. HICs may access and share PHI among themselves from one organization to another as long as this records transfer does not jeopardize the privacy of the individuals affected. Individuals breaching the PHIPA guidelines can be fined up to \$50000 and corporations are liable for up to \$250000 (Beardwood & Kerr, 2005).

According to the PHIPA guidelines, PHI includes information about an individual's physical or mental health, the provision of the healthcare services, the length of stay on the healthcare program, payment information, eligibility for healthcare services, results of tests /examinations on the individual, details of donation of body parts, identity of the individual's substitute decision maker, and individual's personal health number also known as Health Card

Number (HCN). The act authorizes healthcare information custodians (HIC) to use PHI to share and access information among themselves for the continuation-of-care purposes. HICs may disclose PHI to another HIC without an explicit consent from the patient. In this sense, the consent is implied unless the patients specifically withdraw their consent. The act implies that the owner of each piece of health information is the care provider who documents that piece of data, but the subject of the health information (i.e. patient) should be able to see their information on a per request basis.

According to a study conducted in UK in 2013, public views on the use of the electronic health records are positive and they would support a national health record system that can be used for individuals' continuation of care, planning health services, and health research purposes (Luchenski, et al., 2013).

2.3.2 Privacy and security risks of exchanging health information

While there has been regulatory authority as well as public support for PHI sharing and accessing by authorized persons for continuation of care services, we have to bear in mind that these processes should be done in a secure and reliable fashion. There have been some studies that question the efficacy of recent ad-hoc records sharing efforts.

Khaled El Emam and other co-authors have investigated some P2P file sharing software such as LimeWire and Morpheus to estimate the risk of PHI disclosure. The authors modified an open-source P2P file-sharing client to automatically download files shared through P2P file sharing networks. When a file was downloaded, it was then stored in a repository and the IP associated with the sender was recorded. According to their study, there was a significant risk of

disclosure of PHI through P2P file sharing applications (El Emam, The inadvertent disclosure of personal health information through peer-to- peer file sharing programs, 2010).

In another study (El Emam, Jonker, Arbuckle, & Malin, 2011), El Emam and his co-authors reviewed 14 re-identification attacks on de-identified datasets. Of these 14 attacks, 6 involved healthcare records. Only 2 out of 14 attacked datasets were de-identified according to existing standards and the rest were not de-identified properly. Of the two de-identified datasets, one of them was in healthcare domain to which the attacks were not completely successful. The paper implies that proper de-identification endeavors have made the datasets more resilient towards re-identification attacks.

Later on, El Emam and his partners explore the success rate of two de-identification methods in the context of Electronic Medical Records (EMR) datasets. This study suggests that publication of membership list practiced by professional associations such as College of Physicians and Surgeons of Ontario (CPSO) should be revised, as there is serious risk of personal data identifications by unauthorized parties (El Emam, Jabouri, Sams, Drouet, & Power, 2010).

In the same context, Tu et al. attempted to modify an open source de-identification software in order to protect specifically healthcare EMR in Ontario, Canada (Tu, Klein-Geltink, Mitiku, Mihai, & Martin, 2010). They tested the success rate statistically and concluded that their techniques could reasonably de-identify EMR free-text datasets and therefore protecting the clinical information against attacks.

2.4. Interoperability

Interoperability can be defined as a smooth transition of records and services through various organizations or systems with the perfect harmony and cooperation among their entities. (Kuziemy, Interoperability, A Multi-Tiered Perspective on Healthcare, 2013) categorize interoperability into three levels of data, process, and contextual factors. Data interoperability focuses on the consistent flow of data among all healthcare actors. At this level, we mainly focus on transmission of data and not so much on the content it bears. Therefore, if there is the ability to share data/records across all healthcare providers, then the data interoperability is achieved.

Process interoperability focuses on the system users. It is commonly discussed through the ability to share knowledge, and the ability to map processes across various healthcare providers. We reach process interoperability if all healthcare providers share and use a common knowledge. Evidence-Based medicine that is defined as the best known practices in making clinical decisions, has a positive effect on achieving knowledge interoperability in a healthcare setting (Kuziemy, Interoperability, A Multi-Tiered Perspective on Healthcare, 2013). Furthermore, process interoperability requires the interoperability among the front-line staff who administer and deliver the healthcare services. Workflows, communications, and power distribution should be well aligned with other healthcare providers. Finally, process interoperability requires the complete collaboration among healthcare providers where there will not be any misunderstanding or contradictions while delivering a collaborative care (Kuziemy & Peyton, A framework for understanding process interoperability and health information technology, 2016).

Contextual factors such as political and social environments within which the healthcare providers operate, can affect their chances of achieving interoperability. Different legislation

and/or social norms can help or hinder a shared care provided to a patient when crossing multiple regions or municipalities. For example, health record sharing regulations are different in different countries and a task as simple as patient identification is challenging. Below, we discuss healthcare interoperability within several different system contexts.

2.4.1 Ad-hoc Dataset Sharing through P2P File Sharing Mechanisms.

Based on our observations on a records-sharing endeavor between a local hospital and a community service corporation, it is not unfair to say that healthcare organizations in Ontario are reluctant towards disseminating their datasets with other qualified healthcare providers. Every attempt at sharing records so far has been an unavoidable solution to a cross-organizational problem like a high rate of unplanned readmission to emergency rooms (ER) through an ad-hoc records pull and a static temporary dataset sharing through a Drop Box-like application. Therefore, the shared records are very specific and limited to that narrow problem and are not useful for other questions/problems. The ad-hoc datasets are generated by a specific query designed for a specific problem by a data analyst. The analysts within each organization have to match their own dataset with the one from the other organization and this can take weeks if not months. Our case study showed a high rate of record loss when it comes to finding a cohesive shared dataset that can describe a patient in one single record. The first dataset from the community care provider included 58000 records for readmission problems, which was then reduced to 27000 after multiple rounds of matching processes.

2.4.2 Single-HCO Electronic Health Record Systems (EHR)

An Electronic Health Record (EHR) system consists of a software application and a data repository to support the management and communications of healthcare records in a

computerized environment. In Canada, most healthcare organizations (HCOs) have a single Electronic Health Record (EHR) system that is bound to be used within the premises of that HCO and shows what the healthcare provider agent had previously entered into the system (CIHI, 2011). The major EHR vendors may also develop mobile applications to be used within the same environment of the HCO.

2.4.3 Multi-HCO EHR Systems: TakeCare System in Sweden

Apotti (Abbot) system by Epic Systems Corporation in Finland, and Takecare system in Stockholm, Sweden have adopted one integrated electronic health record system across an entire region. Hence, we call them multi-HCO EHR system which denotes the participation of various HCOs in investing and using a single EHR system.

Many countries in Europe are trying to reduce the number of EHR systems adopted in one region and encourage the healthcare providers to buy in on the most common ones. Sweden (Cars, et al., 2013) and Denmark (Kierkegaard, 2015) are perfect examples of such policies. Epic system in the US is an example of a popular EHR software that is adopted by many healthcare providers. In Norway, the government has developed a system for all HCOs to securely share and view shared personal health records (The Norwegian Directorate of eHealth, 2016).

As for Takecare system, this united region translates into the entire province of Stockholm, which covers 22% of the 9.5 million inhabitants of Sweden (Cars, et al., 2013). The significant outcome of this system is one single record per patient that is shared between general practice, geriatrics, psychiatry, and hospital services.

2.4.4 HCO-independent and mobile applications

HCO-independent architectures can be applied to any context and technology platform. They are built to bridge between traditionally incompatible applications. Google Health and Microsoft HealthVault are examples of HCO-independent systems, designed to provide cloud services to store, combine, and share health records among individuals, their social circle, and also the participating healthcare providers (Do, Barnhill, Heermann-Do, Salzman, & Gimbel, 2011). Their APIs have the potential to alleviate data interoperability issues. Unfortunately, these solutions are either abandoned (Google Health) or not widely adopted (MS HealthVault) by the healthcare industry (Sunyaev, Kaletsch, & Krcmar, 2011).

Newly added to the mix, are the fitness and vital telemetry records generated by various tracking devices and sensors that can send real-time records to their cloud servers. Marriage between this stream of health-related records and the conventional healthcare records is immensely valuable to the healthcare providers as well as patients. To use these integrated records to predict an imminent heart attack based on the stream of records from an apple watch that monitors the heart rate, does not seem far-fetched, but is yet unavailable. Mobile applications can indeed help us get to that scenario faster and easier (Gay & Leijdekkers, 2015).

Soon healthcare records would be available to the various stakeholders through competitive software applications. Healthcare records delivery can be based on widely accessible healthcare application programming interfaces (APIs) and nourished by an ecosystem of applications similar to that of smartphones (Mandel, Mandel, & Kohane, 2015).

In countries like Sweden, the Ministry of Health and Social Affairs has outlined a national eHealth strategy (Ministry of Health and Social Affairs, 2011) to make health and social care

information available to the citizens by 2020 (Hägglund, 2017). The goal of the strategy is to benefit three groups: individuals, health and social care employees, and the decision makers.

The individual in his or her role as citizen, patient, end-user and close relative/friend shall have access to easily accessible, quality-assured information on all forms of health and social care as well as access to documentation on previous care interventions and treatments. He or she shall be offered customized service and interactive eServices in order to be able to participate and exercise self-determination based on his or her own prerequisites. Health and social care staff shall have access to well-functioning, concurrent electronic decision support that both guarantees a high level of quality and security and facilitates their day-to-day work. Necessary and structured information shall be available as a basis for taking decisions on care interventions and treatments. Decision-makers in all care services shall have the appropriate tools to continuously monitor the quality and security of activities and obtain an up-to-date and comprehensive basis for taking decisions on organizational governance, planning and resource allocation. Public and private research shall have easy access to high-quality data, with total respect for citizen integrity (Ministry of Health and Social Affairs, 2011) (p. 7).

Based on this strategy, a system has been built and operationalized. The system called Journalen includes a national patient portal and a national health information exchange platform. In 2017, Stockholm as the last Swedish county joined this national initiative. Through this system, patients can view their medications, test results, referrals, diagnosis, vaccination, warnings, notes

from healthcare professionals, and a log of anyone who has viewed their records. They can also leave comments e.g. for correcting a mistake in their records (Armstrong, 2017).

However, there are hidden problems. For one, the patients' history of care still looks fragmented as the amount of information shared by various healthcare providers differs widely, and this is due to the disagreements across the country as to whether or not the patients should be allowed to view their health records (Hägglund, 2017). Furthermore, many healthcare professionals in Sweden oppose to the idea of sharing health information with patients. They argue that their workload is increased due to having to explain the records shared on Journalen platform because of the patients' conflict, misunderstanding and misinterpretation of data. Although, studies show that 90% of the patients who have interacted with the Journalen, have positive experiences whereas the physicians were more negative (Scandurraa, Jansson, Forsberg-Fransson, & Ålander, 2015).

2.4.5 Patient-centered healthcare interoperability

In 2006, Haux studied past, present, and future of health information systems (HIS). He reported "patient-centered" characteristics of HISs in Austria, Germany, Italy, or Switzerland in the 00s vs. the former "institution-centered" HISs. He pictures an ideal health information system that is integrated at a regional and even global caliber (Haux, 2006). Linking this to the aforementioned 3 levels of health records sharing practices, we can conclude that the larger the health records sharing span, the more patient-centered that practice is.

(De Freitas Dias, Alves, & Felipe, 2014) propose a general method for mapping different health terminologies to help with semantic interoperability. Their method is based on association rules in data mining in an integrated database as well as string matching and text search. The tool

design process started by looking at two separate databases containing similar information, which are encoded with different terminologies. Then, they conducted association rules mining. Finally, the results are validated by presenting them to a few domain experts.

(Dixon, Vreeman, & Grannis, 2014) provide three approaches in order to increase semantic interoperability. They argue that although standard terminologies for encoding clinical data exist, there is little incentive for private sector healthcare providers in the state of Indianapolis, US to use them, since there is not enough government funding. On the other hand, if healthcare providers use their own mapping systems, the mapping to standard terminology process in any interoperability attempt is costly and challenging. They recommend: 1) To require records senders to use standard terminologies; 2) If standard terminology is resisted, public health should be the only responsible entity for translating and mapping various terminologies; and 3) A strategic, cooperative approach from the public health organization that involves the partnership of all the stakeholders.

The Generic Component Model (GCM) expanded by Lopez and Blobel provides an interoperability framework at a semantic level by combining HL7 methodologies and RUP instructions. They extrapolated an advanced software development framework for health information systems. Their proposed framework is implemented in the National Public Health Surveillance Information System in Colombia (Lopez & Blobel, 2009). This framework guides you through describing a real system. Its abstraction model reduces the complexity of the problem in hand by providing three simplification steps. First step separates the domains of interest within the problem environment, second step decomposes the system into basic services/functions, and the third step puts different standard views (defined in ISO/IEC 10746) on the system.

(Vida, et al., 2014) demonstrate how HL7 and web service technologies can be implemented to achieve an enhanced level of interoperability between multiple medical information systems and clinical decision support systems. The proposed solution is applied to an Ob-Gyn IS, a pediatric IS, a GP's office IS and a decision support system. HL7 CDA standards are used to encapsulate a message in an XML format, which is then sent through the Internet using the web services. Service messages are sent through Microsoft Windows Communication Foundation (WCF), which is used to send asynchronous messages where services have remote users.

(Tapuria, Kalra, & Kobayashi, 2013) demonstrate how archetypes that represent EHR entities can be used to reach semantic interoperability due to their standardized nature. This paper refers to the 50 archetypes designed in Japan to represent 6 model-diseases in order to be used at a national level. The study also magnifies the challenge of de-fining archetypes that can be widely adopted and hence the difficulty in reaching de-sired levels of semantic interoperability in healthcare industry. They believe some level of specifications should be applied when defining the archetypes. On the other hand, the archetypes should be based on the healthcare industry's best practices and at the same time be applicable to multiple clinical areas. In other words, instead of using a general archetype that can be used in any industry, one should design archetypes that are intended to be used in a clinical setting. The results of this paper is based on the authors' first hand experience, international research, and collaborating in initiation of openEHR foundation.

2.5. Architecture and Standards

As mentioned earlier, each healthcare provider today, uses some sort of EHR system. In order to be able to integrate these systems within different healthcare providers (Jha, et al., 2009), we need a common healthcare platform that includes an ontology and common standardization

systems. There are different technologies and architectures to facilitate the integration of different EHR systems such as APIs that use the common standardization systems and ontologies to achieve the ultimate integration. Subsequently, we expand on the ontology systems and standards.

2.5.1 Actors and Digital Persona

User-Centered Design (UCD) is an approach in Human-Computer Interaction (HCI) that tackles software design through a multi-stage problem-solving method where requirements, preferences, and limitations of end-users are gathered and considered. Software prototypes are drawn from user behavior analysis. User persona is a UCD technique that conceptually models the users (LeRouge, Ma, Sneha, & Tolle, 2013).

Most software application developers have user in mind (Lethbridge & Laganier, 2001). But, thinking about the user without a systematic user behavior analysis is not enough to really develop a user-centric application that meets all the requirements and limitations of end users. It's important to understand the end users of a system but it is not enough. When we fully analyze and understand the users, then we still have to incorporate the knowledge gained in the application design. In order to create a rich computer user experience, we need to follow a systematic approach incorporating the end users in the design (Pruitt & Adlin, 2006).

An actor corresponds to a role that a user can take when interacting with a system. Actors can be derived from use cases. According to Lethbridge and Laganier "a use case is a typical sequence of actions that an actor performs in order to complete a given task" mind (Lethbridge & Laganier, 2001).

Big data as a new emerging field of interest pays little heed to user persona techniques (Kuziemy, et al., 2014). The first step to design a system using user-persona techniques is to understand the user groups and define the relevant ontology. User groups are the cohorts of end users that use the final product.

2.5.2 MVC Pattern

Although the Model-View-Controller (MVC) design pattern has been around for a long time (since 70s), it is still widely used specially by the web industry. Web frameworks such as ASP.Net, Django, Ruby on Rails, etc. are all based on MVC architecture (Aniche, Bavota, Treude, Gerosa, & Deursen, 2018). MVC was introduced to separate the core of an application from its interfaces, because most interfaces go through dramatics changes throughout the lifecycle of an application. Through an MVC pattern, we can re-use an application logic and keep it intact while the interfaces go through changes (Krasner & Pope, 1988).

Model in Model-View-Controller (MVC) within an object-oriented context, refers to the underlying objects and classes that deliver the underlying structure and how information is encapsulated. View is how the information is presented to users of an application. View can range from a GUI to API or command line interfaces. Finally, Control is the layer that handles and processes the user requests and houses the functions (Leff & Rayfield, 2001).

2.5.3 Web services and APIs

Web service is a software component that provides an interface to the outside world and delivers a piece of functionality. Web services isolate logic and data representation from their users and provide either a service or gives access to pieces of data.

Application Programming Interface (API) is a newer concept that emerged after Service-Oriented Architecture (SOA). An API is a collection of services that is provided by a programming library in order to be used by other software applications. Roy Fielding's REST (Representational State Transfer) API has been a popular paradigm to API designs (Benson & Grieve, 2016).

RESTful APIs are based on the following principles:

- **Uniform Interface:** Services are identified through URLs. The arguments that a service may require are passed in through adding parameters to the URL in XML, JSON, etc. format.
- **Stateless Interactions:** A client of a RESTful API does not store any information on the API servers. The arguments are passed through the URL.
- **Cacheable:** The response that is received from a RESTful API can be cached or not.
- **Client and Server:** RESTful APIs are based on a client-server relationship and their concerns are separated. Clients do not need to worry about data storage while using the API whereas servers do not need to worry about interfaces.
- **Layered System:** A client of a RESTful API is not aware of the type of server they are connected to; be it an end server or a scalable intermediate server.

2.5.4 Health Level 7 (HL7)

The normalization and standardization of electronic health records is a key driver in healthcare collaborations and integration of systems. HL7 is an organization that creates standards for packaging healthcare records for exchange, management, sharing, retrieval and integration

purposes. HL7 is followed and adopted internationally. HL7 does not develop software but develop guidelines and standards for integrating software suits in a healthcare setting.

HL7 standards and APIs are widely recognized and adopted in the healthcare industry. HL7 has the vision of a world in which everyone can securely access and use the right health records when and where they need it (Benson & Grieve, 2016). HL7 standards are grouped into the following categories (International Health Level Seven, 2017):

- **Primary Standards** are the standards for system integration, interoperability and compliance
- **Foundational Standards** describe the tools and building blocks for developing the standards, and the technology infrastructure
- **Clinical and Administrative Domains** that define messaging and document standards for clinical specialties
- **EHR Profiles** supply the functional models that enable the constructs for management of EHRs
- **Implementation Guides** provide implementation guides and supplemental material for a parent standard
- **Rules and References** are technical specifications, programming structures and guidelines for software and standards development
- **Education & Awareness** section provides helpful resources and tools for understanding and adoption of HL7 standards

2.5.5 Fast Healthcare Interoperability Resources (FHIR)

HL7 Fast Healthcare Interoperability Resources Specification (FHIR®) is a standards framework for exchange of electronic health records among systems. It supports both central patient care systems and more distributed environments where records resides in departmental systems. It includes CDA® R2 -Continuity of Care Document (CCD®) that allows for sending electronic medical information to other providers without loss of meaning, provides a snapshot-in-time, capturing a summary of a patient’s clinical, demographic, and administrative data, and facilitates the ability to represent professional society recommendations, national clinical practice guidelines, standardized data sets,... (Health Level 7 International, 2017).

```
<section>
  <templateId root='2.16.840.1.113883.10.20.1.1' /> <!-- Advance directives section template -->
  <code code="42348-3" codeSystem="2.16.840.1.113883.6.1" />
  <title>Advance Directives</title>
  <text>
    <table border="1" width="100%">
      <thead>
        <tr><th>Directive</th><th>Description</th><th>Verification</th><th>Supporting Document(s)</th></tr>
      </thead>
      <tbody>
        <tr>
          <td>Resuscitation status</td> |
          <td><content ID="AD1">Do not resuscitate</content></td>
          <td>Dr. Robert Dolin, Nov 07, 1999</td>
          <td><linkHtml href="AdvanceDirective.b50b7910-7ffb-4f4c-bbe4-177ed68cbbf3.pdf">Advance directive</linkHtml></td>
        </tr>
      </tbody>
    </table>
  </text>
  <entry typeCode="DRIV">
    <observation classCode="OBS" moodCode="EVN">
      <templateId root='2.16.840.1.113883.10.20.1.17' /> <!-- Advance directive observation template -->
      <id root="9b54c3c9-1673-49c7-aef9-b037ed72ed27" />
      <code code="304251008" codeSystem="2.16.840.1.113883.6.96" displayName="Resuscitation" />
      <statusCode code="completed" />
      <value xsi:type="CD" code="304253006" codeSystem="2.16.840.1.113883.6.96" displayName="Do not resuscitate">
        <originalText><reference value="#AD1" /></originalText>
      </value>
      <participant typeCode="VRF">
        <templateId root='2.16.840.1.113883.10.20.1.58' /> <!-- Verification of an advance directive observation template -->
        <time value="19991107" />
        <participantRole>
          <id root="20cf14fb-b65c-4c8c-a54d-b0cca834c18c" />
        </participantRole>
      </participant>
      <entryRelationship typeCode="REFR">
        <observation classCode="OBS" moodCode="EVN">
          <templateId root='2.16.840.1.113883.10.20.1.37' /> <!-- Advance directive status observation template -->
          <code code="33999-4" codeSystem="2.16.840.1.113883.6.1" displayName="Status" />
          <statusCode code="completed" />
          <value xsi:type="CE" code="15240007" codeSystem="2.16.840.1.113883.6.96" displayName="Current and verified" />
        </observation>
      </entryRelationship>
      <reference typeCode="REFR">
        <externalDocument>
          <templateId root='2.16.840.1.113883.10.20.1.36' /> <!-- Advance directive reference template -->
          <id root="b50b7910-7ffb-4f4c-bbe4-177ed68cbbf3" />
          <code code="371538006" codeSystem="2.16.840.1.113883.6.96" displayName="Advance directive" />
          <text mediaType="application/pdf"><reference value="AdvanceDirective.b50b7910-7ffb-4f4c-bbe4-177ed68cbbf3.pdf" /></text>
        </externalDocument>
      </reference>
    </observation>
  </entry>
</section>
```

Figure 2 Example of CDA formatting in XML

CDA explicitly defines how to package and present each piece of information. As an example, below we can see how CDA captures the information about Advance Directives in and XML format. It can contain data such as the existence of living wills, healthcare proxies, and CPR and resuscitation status. If referenced documents are available, they can be included in the CCD exchange package (HL7 International, 2007). In this thesis, we benchmarked how FHIR formats health records. Figure 2 Example of CDA formatting in XML provides an example of how CDA formats an Advanced Directive message in XML.

FHIR is a HL7 standard and collection of tools and resource templates to facilitate adoption of integrated healthcare practices across various healthcare providers globally (HL7 Community). FHIR encapsulates clinical records as resources where entities, attributes, and data types are clearly defined. Although FHIR may not contain every imaginable entity in the healthcare domain, it provides an extensibility mechanism in order to expand their existing resource pool. Resources signify an instance of a healthcare entity with some common features such as: identification URL, common metadata, a set of data elements per resource, and a framework that supports extensibility to different healthcare providers. They can be presented in most common formats like XML, JSON, etc. As an example, in FHIR the Patient entity can be described using the following attributes:

- Metadata
 - An attribute that defines the resource type i.e. Patient as opposed to any other resource e.g. Organization
 - An identifier number
 - The FHIR version this record is defined in

- The last time this record was updated
 - Description of the Entity type
- Identifiers
 - Identity value
 - Intent
 - Label
 - System scope
- Name
 - Surname
 - First name
 - Suffix
- Gender
- Birthdate
 - Active status that determines if the patient is alive

FHIR provides a REST API to set and modify resources with functions such as create, read, update, delete, search, etc. and also provides detailed guidelines as to how to send the requests and read responses from the API. FHIR API serializes resources through XML and JSON (Mandel, Kreda, Mandl, Kohane, & Ramoni, 2016).

It also provides an ontology where each resource and attribute is provided. Figure 3 FHIR Entities shows a few entities from FHIR ontology that are related to our domain (HL7, 2019).

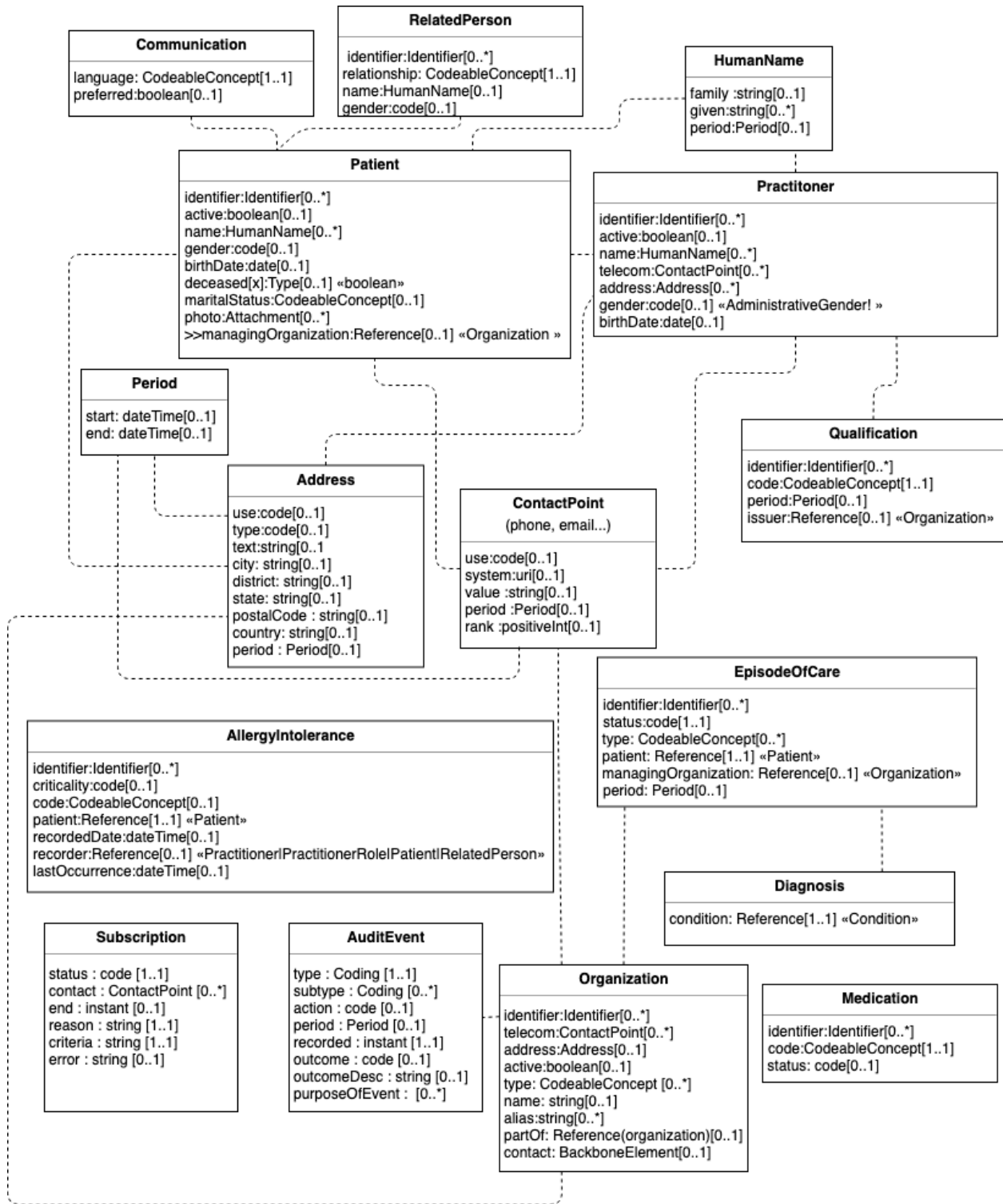


Figure 3 FHIR Entities

2.5.6 Ontology

When sharing health records, it is important that all records follow a single syntax and semantic. Due to different practices in healthcare and these organizations' evolution in silos, there can be different terminologies for the same types of information such as name of diseases, procedures, equipment names, demographic data, etc. Terminology standardization of medical records enhances the quality and effectiveness of communications among different healthcare professionals and organizations (Macedo & Isaías, 2013). The terminology standardization is essential to the implementation of successful information systems integration from different organizations.

Often developed by a panel of domain experts, ontology provides a well-defined series of concepts, entities, and attributes. One of the most important components of an integrated Electronic Health Record (EHR) system is a standardized database of common terminologies in healthcare industry. ICD (International Classification Disease) and SNOMED are examples of the standard coding systems that can be used to standardize an integrated healthcare database. SNOMED is one of the most comprehensive clinical terminology systems in the world (Sanchez-Caro, et al., 2014).

For records sharing and interoperability in healthcare, it is important that all records follow a single syntax and semantics. Due to different practices and data silos in different healthcare organizations, there are different terminologies for the same types of information such as the name of diseases, procedures, equipment names, demographic data, etc. Terminology standardization of medical records enhances the quality and effectiveness of communications among different healthcare professionals and organizations (Sunyaev, Kaletsch, & Krcmar, 2011). Terminology

standardization is essential to successful information systems integration from different organizations.

Ontology i.e. a formal representation of the entities defined in a domain is defined for

- Establishing a unified understanding of the information structure among all stakeholders
- Making the entities reusable
- Clarifying the assumptions
- Making a distinction between the domain information and operational ones
- Analyzing domain knowledge

There are various ontology development methodologies in the body of literature (Casellas, 2011). In this section we name a few that are more relevant to our domain of study i.e. healthcare applications. In 1990 Lunat and Guha proposed a process to create an ontology that describes a shared knowledge through the steps they took to develop their Cyc ontology in the AI domain (Casellas, 2011). Their process includes 1) manual extraction of shared terms and a simple diagram for representing them; 2) computer-aided representations; and 3) device-level extraction and representations.

The TOVE methodology was introduced in 1995 by Grüninger and Fox who described 5 steps in defining an ontology (Lenat & Guha, 1990):

1. Providing the motivating scenario
2. Form the questions that the ontology must be able to answer

3. Defining the terminology through identifying objects, their attributes and the relations among objects
4. Defining the possible definitions and constraints on the terminology
5. Putting the developed ontology to test by proving its completeness against the defined questions.

HL7 recommends a simple and general methodology to guide ontology defining in healthcare setting i.e. Noy's ontology development methodology (FHIR Ontology Module, 2020). They specify a sequence of steps but leave the developers to follow whatever order they see fit in following them. Noy's ontology development methodology includes the following steps (Noy & McGuinness, 2001):

1. Defining the domain and scope: In this step, the domain that the ontology is covering, the reasoning for this ontology definition, target users of the ontology, the kind of questions that the ontology is answering, and the ontology maintenance plan should be defined.
2. Reusing the existing ontologies: this methodology recommends searching for similar ontologies that have been developed already and try to reuse them. This would help interoperability among different systems.
3. Providing a list of relevant terminology in the domain: this makes it easier for the users to understand and adopt the ontology
4. Defining the entities and their relative hierarchy (if any): at this step, we start introducing the terms captured previous step. The entities may have different

relationships and associations with each other that should also be laid out at this step.

5. Defining the attributes of the entities defined in the previous step
6. Defining the data types of the attributes defined the previous step
7. Creating instances for the defined entities

2.5.7 Security

Authentication and authorization play a key role in information security. Authentication validates if the user is really who they claim to be. Authentication can be single factor e.g. entering a username and password, or multifactor e.g. entering a username and password and then the PIN that is sent to one's mobile phone. Authorization is to determine what an authenticated user can do and access within the system. When selecting a security model for a system, it is important to weigh in the user comfort versus security level (Siriwardena & Peacock, 2014).

Initially, when two services needed to interact with each other, web service A would ask for user credential from web service B. This proved to be very problematic. By having full credentials, service A now has full power over the user account and could potentially modify the account on behalf of the owner or even guess other accounts associated with that user; like their bank account credentials when the user chose to reuse their username and password for banking.

The OAuth framework enables a third-party application to gain limited access to a service (D. Hardt, 2012). OAuth framework solves this problem by providing a restricted access to service A. Through OAuth, service B can create an access token that would only allow for limited access for service A for a single or limited time (Leiba, 2012). This is accomplished by service A directing

the user to service B's token granting endpoint. Service B then issues the token and redirects the user back to service A, which is now able to access service B on their behalf.

2.6. Related work

We compare the results of our research to the three types of EHR systems we introduced in section 2.4. A hospital's internal EMR system or a community care provider's EMR system such as CHRIS is a good example of a single-HCO system. Sweden's TakeCare system or Epic system in the US are good examples of multi-HCO systems. Finally, Microsoft HealthVault that is operated by Telus in Canada is a great example of HCO-independent system.

In this section, we add to the mix a few more systems that do not exactly fit in the aforementioned three categories. What makes them different is their technology solution that is similar to the HCO-independent category, and their governance structure that is closer to that of Multi-HCO systems. These systems have had the fortune of being in use by a big network of healthcare providers within the reign of a health authority, but they employ platform independent technologies to merge records from different EMR systems. The two systems that we discuss subsequently are ClinicalConnect in Ontario and the national health information system in Norway called Kjernejournal. We also discuss the NexJ Connected Wellness platform, that is similar to HealthVault in terms of being a commercial platform, but it does a better job of integrating the privacy protection.

2.6.1 CHRIS

In 2008, the Ontario Association of Community Care Access Centres (OACCAC) rolled out an information system called The Client Health & Related Information System (CHRIS).

CHRIS is a web-based application and the main system for tracking the health and other related information of the patients of the then Ontario's 14 Community Care Access Centers (CCAC) (Ontario Association of Community Care Access Centres, 2016). CHRIS incorporates information such as patient intake, patient assessment details, care and delivery planning and tracking (Costa, Poss, Peirce, & Hirdes, 2012). Although this system is used by all 14 branches of the Ontario CCACs, we still consider it a single-HCO system as it is serving one healthcare organization being the Ontario CCAC and does not share its records with other HCOs on a regular basis.

It is noteworthy to mention that in 2017 CCACs were dissolved. However, the community care and all the assets previously used stayed practically unchanged when CCACs became a division of their previously funding agency – the Local Health Integration Networks (LHIN) (Porter, 2017). In 2019, another round of change came across the community care service delivery. This time, the LHINs got dismantled and absorbed by a super health agency called Ontario Health Agency (Payne, 2019). Nevertheless, CHRIS remained as the information system for tracking community care services.

2.6.2 Epic

Epic is a multi-HCO EMR system provider that holds multiple patents on how to collect, share and synchronize health records from multiple institutions. Some of their patents include System and method of synchronizing data sets across distributed systems (US Patent No. US20050071195A1, 2009), and Method and apparatus for accommodating diverse healthcare record centers (US Patent No. US20090216562A1, 2009). Many healthcare providers shifted their healthcare system to Epic that is based on the software developed by the Massachusetts General Hospital in 1968. As of 2013, reportedly half of the US large hospitals were on the Epic system

after having paid between US\$250 million to US\$1.1 billion to acquire this system (Koppel & Lehmann, 2014). Epic is on its way to create a monopoly in its US market.

However, some studies indicated that Epic system has not shown to be superior nor inferior when compared to other health IT systems (Koppel & Lehmann, 2014). Advantages of the Epic system lies in providing a consistent and familiar tool for a wide range of healthcare providers simply due to its popularity. They also offer APIs that have been criticized due to delayed access to the latest records and providing only a selected data set. Finally, the high cost of acquiring an Epic system is one of their biggest disadvantages.

2.6.3 HealthVault

Microsoft HealthVault is a cloud provider for managing personal health records. As mentioned in 2.4.4, HealthVault is technically a capable system that has not yet had much luck with attracting the healthcare providers (Sunyaev, Kaletsch, & Krcmar, 2011). We point this system out because it is very relevant to the framework proposed in this thesis. Use of cloud storage and API methods for collecting, sharing and synchronizing records across distributed and various healthcare systems has inspired some of our technology recommendations.

MS HealthVault is not widely used by the healthcare industry. If at all, it is used for personal health record logging performed by individual private users. Their perceived failure is associated with their relevance, perceived usefulness and added value (Spil & Klein, 2014).

2.6.1 NexJ

Path2Home (P2H) (Backman, et al., 2018) is a project to support coordination of healthcare within a patient's circle of care for geriatric rehabilitation after hospital discharge from hip surgery.

P2H is implemented using the NexJ Connected Wellness Platform (NexJ Connected Wellness Platform, 2020) which provides cloud-hosted sharing of patient records. NexJ platform is an HCO-Independent health record sharing platform, similar to HealthVault. Although, NexJ's platform has been actually adopted by a group of healthcare providers in P2H project. NexJ platform is designed to maximize and improve information exchange in a patient's circle of care during care transition. Through this application, patients are able to track their progress on discharge plans and care transition, make decisions about their needs and health, and have interactions with their healthcare team after their hospital discharge (Backman, et al., 2018). We describe and study this platform in more details in chapter 5.

2.6.2 ClinicalConnect

The Local Health Integrator Networks (LHIN) in Hamilton Niagara Haldimand Brant (HNHB) in Ontario pride itself in achieving a number of successful integration projects, one of which is an integrated decision support strategy that includes a data repository (HNHB LHIN, 2011) that combines patient records from Community Care Access Centers (CCAC) and hospitals in HNHBB region. It also offers a patient portal a.k.a. ClinicalConnect for healthcare providers in the region such as doctors, nurses, and pharmacist to access their patient's electronic health information (Local Health Integration Network, 2011). Through this system, all the participating healthcare providers send a batch update on a weekly or nightly schedule. By March 2017, about 93000 authorized healthcare providers across the province on Ontario could gain viewing rights to ClinicalConnect (Webster, 2017).

2.6.3 Kjernejournal

A national project in Norway that provides personal health information kept 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 will be created automatically for all inhabitants of Norway (The Norwegian Directorate of eHealth, 2016).

An investigative study about the success of Kjernejournal reported that 76% of the patients were interested in having electronic access to their medical records so that they could be informed of their diagnosis and treatments, verify if their information is correct, and share it with others (Tove Sorenson, 2016).

Table 2 Kjernejournal - Norwegian National PHI System

FIELD IN KJERNEJOURNAL	WHAT YOU CAN DO
About me Source: National Registry	View information concerning your regular GP, registered address and family
Own entries	Register your next of kin and others to contact in a medical emergency, medical conditions, hearing, sight or speech impediments, and if you need an interpreter
Medication Source: Pharmacy, Prescriptions supplier	View medication dispensed to you on prescription by Norwegian pharmacies
Critical information Source: Your physician, in consultation with you	View serious medical conditions or allergies registered by your physician in consultation with you
A record of your appointments within the specialist health services Source: Norwegian Patient Register	View the time and place of any previous hospital stays
Activity log	View which health care professionals have accessed your kjernejournal
Settings	The possibility to opt out of, block or limit access by health care professionals to your kjernejournal
A record of your appointments within the specialist health services Source: Norwegian Patient Register	View the time and place of any previous hospital stays

2.7. Chapter Summary

In this chapter we presented the background concepts and relevant information that are helpful in understanding the context for this thesis. We provided an overview of concepts such as laws and regulations in Ontario around use and sharing of personal health information. Then, we delved into interoperability concept and current practices and attempts to achieve interoperability

with the existing infrastructure. Related architectures, platforms and standards in healthcare were discussed next. We explained what an ontology is and talked about digital persona concept. Then, we open the doors to the realm of HL7 standards and methodologies and described the pieces that we are going to touch upon in the upcoming chapters. We mainly focused on HL7's Fast Healthcare Interoperability Resources (FHIR) that opens doors to standardization of healthcare RESTful APIs. Finally, we discussed security.

The next chapter will describe the problem and challenges of healthcare records sharing in healthcare industry. In addition, we will provide a gap analysis, and define a set of evaluation criteria used for evaluating our proposed framework.

Chapter 3. Problem Definition

This chapter defines more precisely the problem of patient-centered sharing of health records. We analyze the issues faced in current practice while using an idealized scenario to highlight opportunities for improvement. Next a gap analysis of related works in terms of these issues is discussed. Finally, this chapter lays out a set of evaluation criteria applicable to proposed solutions in this context.

3.1. Patient-Centered Sharing of Healthcare Records

Patient-centered interoperable healthcare across different HCOs is challenging (Friedman, et al., 2016). As an example, when a patient is discharged from a hospital to start care at the community care providers, important details of the patient's history remains at the hospital, leaving community care providers unaware of the procedures offered at the hospital (see Figure 4 Patient transition without information). If there was a diagnostic procedure taken at the hospital that did not prove the final diagnosis, that info would not be available to other HCOs and therefore, they may order the same tests again, only to find out the same results as the hospital.

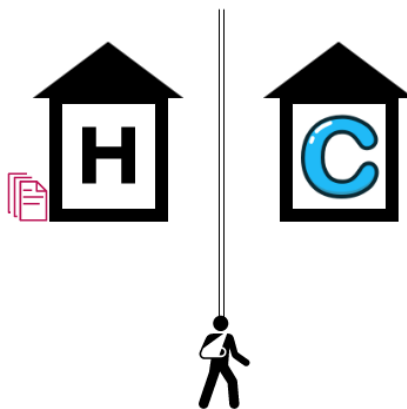


Figure 4 Patient transition without information

Delivering healthcare records at a system-level e.g. from one HCO to another is often inefficient at best. Hospitals often have formal procedures to request info for a patient (Cavoukian & Emam, *Dispelling the Myths Surrounding De-identification: Anonymization Remains a Strong Tool for Protecting Privacy*, 2011). A typical process requires filling out a request form, getting the necessary permissions, and mailing or faxing the results to the requester in order to share information between one HCO and another. On top of that, there are many instances where one HCO is not even aware that another HCO is treating the same patient, so they do not even know that there is information to be requested. Similarly, collecting information for evaluation and measuring healthcare system performance is lengthy and bureaucratic (Health Standards, 2020).

HCOs should be able to cooperate efficiently when providing shared care to a patient (Weber-Jahnke, Price, & Williams, 2013). When appropriate, hospitals are trying to shorten a patient's stay at the hospital and transition their care to their homes. Community care HCOs are contacted to continue the delivery of care after a hospital episode. For a smooth and seamless transition of care at a system-level, all the HCOs need to collaborate and cooperate (V.Eikey, Reddy, & Kuziemy, 2015).

It is noteworthy to say that in some cases and in some jurisdictions, there is good progress on interoperability. However, this interoperability is often uneven (V.Eikey, Reddy, & Kuziemy, 2015). There is a need for an intellectual framework to understand this problem, and guide solutions that are consistent and more complete when it comes to system-level health record sharing. Nevertheless, the ultimate goal i.e. world-wide interoperability (which is largely achieved for financial results) will be hard to achieve because of political/regulatory challenges and it requires larger health authorities such as WHO to break down the barriers.

Most of the existing collaborative efforts focus on a single circle of care i.e. the healthcare providers from different HCOs that focus on a specific health outcome. What is missing is a system-level circle of care that includes the patient and all their HCOs regardless of what health outcome they are focusing on at any point in time. Furthermore, interoperability between these HCOs needs to be provided in a timely, convenient, effective and efficient manner.

Finally, patients and caregivers need to be included as they should be the central focus and purpose for system-level sharing of health records. They would like to participate in the delivery of care and be informed in a timely manner. Healthcare providers and patients have positive attitudes toward the implementation and use of patient portals that provides the means to manage patients' health records (Luchenski, et al., 2013). Patients would like to see trends on their health status and are able to contribute records into the system and provide comments and feedback.

To illustrate the need for interoperability in multi-HCO systems, we present an idealized scenario that we created from discussions with healthcare professionals in Sweden that use the TakeCare system in Stockholm (Cars, et al., 2013). Please note that while the description below is meant to be representative of the issues faced, the names and details are fictitious:

Erik Johan is a Physiotherapist at Jakobsberg geriatric care hospital in Stockholm, Sweden. He is meeting with Agda in order to help her relieve some of her back pain. He needs to know a bit about Agda's health history. Therefore, he inserts his badge into the card reader of his computer and gets logged into the Takecare system. He is now able to view the list of his current patients. Agda is on the list, of course. Erik starts reading Agda's record filled by their Jakobsberg hospital nurse Linda at the time of Agda's admission 3 days ago. Then he reads the note from Dr. Adolfsson - the Orthopedics specialist at

Jakobsberg hospital who performed a knee replacement surgery 3 days ago on Agda. Erik clicks on the link to view Agda's health history anywhere in the greater Stockholm area, from the hospitals who also acquired the TakeCare system. Based on records in the Takecare system, Agda uses a mobility aid device i.e. a cane, and she is suffering from asthma. Erik proceeds to read Agda's latest epicrisis from Dr. Ericsson at Karolinska hospital about a year ago, which indicates Agda was diagnosed with arthritis.

The Takecare system allows Erik to only view the level of history that can help him better serve Agda e.g. he would not have access to Agda's mental health information. Prior to this system, Erik had to request each piece of his patients' history from separate healthcare providers individually.

Although this system solved some interoperability issues, it still has some challenges, especially in terms of adoption. As an example, the hospitals who acquired TakeCare, had to scrap their previous operational systems in-part or entirely. Hospitals who chose to keep both old and the new TakeCare systems, increased their admin workload of data entry, copying records from one system to another, or system maintenance. On the other hand, not every HCO in Stockholm has the means to make such considerable upfront investment. Therefore, complete, consistent health record sharing across the entire system is not achieved. Furthermore, TakeCare was not designed for the patients of a healthcare system and did not authorize a patient's access to their system.

In the recent years, there has been other implementations of software platforms that enable data interoperability among a team of healthcare providers from different organizations. These teams are mainly collaborating in order to achieve a certain health outcome. For example, a

hospital that transitions patients to the community care used NexJ P2H web application (explained in 5.1Path2H). However, these solutions enable the records sharing among the healthcare providers, and sometimes patients involved in a specific circle of care (Donga, Samavia, & Topaloglou, 2015) that is formed to support one health outcome. What is still missing is the system-level collaborations and records sharing. At a system-level, all healthcare providers and their patients can share and access records; regardless of their health goals and outcomes. For example, a dentist, an orthopedic, a personal support worker can all share and access records (according to their predefined access-level) while focusing on different health problems of their patients.

There should be a loosely-defined and HCO-independent system-level solution that can sit on top of the existing healthcare information systems, which would allow them to share relevant records and collaborate in their efforts in providing a shared care (continuous or transient) to a patient in real time. In this system, the patient should be able to see the relevant aspects of their health records that is accessible anywhere electronically (Kish & Topol, 2015). The same mechanism that publishes these records to the patients, enables records sharing with healthcare organization records and enables patients to contribute and correct relevant information such as demographics, family history, contact information etc.

3.2. Gap Analysis

Our gap analysis consists of classifying existing healthcare information systems according to the three types of systems identified in chapter 2.4 (Single HCO, Multi-HCO, and HCO-Independent) and, comparing them. In the related works described in chapter 2.6 there are examples of each type of system. Here, we compare our aforementioned HCO categories based on

three levels of interoperability defined in (Kuziemy, Interoperability, A Multi-Tiered Perspective on Healthcare, 2013).

Table 3 Interoperability classes and different EHR systems

HCO Category	Data	Process	Contextual
Single-HCO	No. No attempt has been taken towards records 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 stakeholders should be able to use these tools to share their records.	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.

From Table 3, we conclude that there is a gap and need for a system that is fully interoperable considering all three aspects of interoperability. A single-HCO system is not concerned with technological interoperability as they make close to no attempt at sharing their records with other counterparts in an effective and sustainable manner. Procedural interoperability is however achieved to some extent as different departments of the organization need to have coordinated processes in order to deliver meaningful value to their patients. Similarly, political and social factors are somewhat achieved here too. The various departments of an organization with a single-HCO system in healthcare must operate within the same juridical and political environment. Therefore, they have somewhat of an internal political and social interoperability by nature.

Multi-HCO systems have somewhat of a technological interoperability as they can relay information among all participants of the system if they choose to do so. However, the organizations outside of this alliance are not able to access that shared information in the same way. Procedural interoperability may or may not be achieved among all participating organizations, but if it is, then some form of procedural interoperability is present. And finally,

political and social factors are controlled in these systems because having a consistent regulatory system is a prerequisite to being able to adopt such multi-HCO systems in the first place.

HCO-independent systems have mastered the art of information sharing in an effective, meaningful and sustainable manner. You do not need to have similar software platforms for your EHR systems to be able to talk. Systems can interact regardless of the technological platforms they are designed in. Most of HCO-independent systems follow common standards and formatting techniques and this leads to more consistent procedural understandings. We can therefore say that these systems are procedurally interoperable to some extents. However, these systems often face major shortcomings when it comes to political and social factors. These systems are focused on the technology aspect and have close to no consideration for different political and regulatory systems.

3.3. Evaluation Criteria

We introduce a set of evaluation criteria to evaluate and assess patient-centered system-level health record sharing. We will use these evaluation criteria in chapter 6 to evaluate our proposed framework and compare it against the related works described in chapter 2.

Table 4 Evaluation Criteria summarizes all the aforementioned evaluation criteria. The evaluation criteria identified in this section were determined based on:

1. Careful analysis of the related literature
2. Gap analysis of the current practices in hospital and community care
3. Government regulations as well as industry norms and concerns
4. Feedback from domain experts and practical experience

5. Experiences we acquired while working through our case studies.

Table 4 Evaluation Criteria

Domain	Criteria	Main question
System-Level Interoperability	Data interoperability	Is sharing of patient-specific records available across various platforms at a system-level?
	Process interoperability	Are we able to align and map processes across the system-level circles of care?
	Context interoperability	Can we share PHI across a system-level circle of care across different political and legislative context? This is not possible when no process interoperability and no patient matching algorithm is present.
System-Level Quality of Care	Evidence-based	Is system-level sharing of diagnosis and healthcare evidence analysis available?
	Right level of details	Is sharing the right details available in order to know what the other HCOs at a system-level are doing?
	Patient-centric	Are all data shared across the record sharing platform visible and accessible to patients autonomously & easily?
	Timely	Is system-level data shared and made available to others in a timely manner?
	Cost	How much effort is required for an HCO to publish into the framework and integrate the framework into their system?
	Health	Does the system under investigation help improve the system-level health of the population?
System-Level Privacy and Confidentiality	Privacy	Does the platform secure system-level sharing of health records in a manner that it ensures PHI is kept confidential and visible only to the system-level circle of care, as needed?
	Regulations compliance	Is the platform compliant with healthcare regulations in the healthcare system it is being applied to?

3.3.1 System-Level Interoperability

We introduced the interoperability concept in chapter 2.4, and then used it in our gap analysis to compare existing options in healthcare records sharing and collaborations in section

3.2. Now, we go back to interoperability and this time we want to use it for a set of evaluation criteria.

- **Data interoperability:** Is sharing of patient-specific records available across various platforms at a system-level? With the patient's care being transferred from one HCO to another, there follows a need to transfer their health records as fast as possible in a secure manner. If a system is only capable of sharing records within the boundaries of an organization (e.g. single-HCO), Only sharing non-PHI and/or aggregate records at a system-level will get a P; and the systems that can enable their users to share records regardless of their platform at a system-level, will receive an A value.
- **Process Interoperability:** Are we able to align and map processes across the system-level circles of care? 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. 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, a P value is assigned; Finally, when processes can be automatically and intelligently translated and mapped at a system-level, an A is assigned.

- **Context interoperability:** Is a system capable of operate smoothly across different political/legislative contexts? A single-HCO system would receive a NA value for this criterion as the system in not concerned with any context outside the boundaries of one organization; The multi-HCO systems in general would get a P value as they can share similar data formats and reports at least at an aggregate and non-PHI stage across a system-level circle of care; and finally, if a system is capable of crossing various political environments e.g. provinces or countries without losing its cohesion and seamless integrity, they would receive an A (for Available) for this criterion.

3.3.2 System-Level Quality of care

In chapter 2, we introduced The Quadruple Aim framework that aims at improving the healthcare experience for all stakeholders. The four quadruple aim aspects: care, health, cost, and provider, can set a good foundation for evaluating a system-level healthcare platform.

Furthermore, According to Canadian Institute for Health Information, 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; successful or failed. As discussed before, the biggest hole in the current healthcare practice is the absence of or inefficiencies in sharing records inter-organizationally.

Therefore, with this evaluation criteria, we evaluate healthcare electronic systems by measuring the following criteria:

- **Evidence-based:** This criterion comes from the CIHI framework. It focuses on how easy it is to support medical evidence or other processes across different platforms. Is system-level sharing of diagnosis and healthcare evidence analysis available? If sharing of diagnosis, medical evidence or health processes is not available across multiple platform, that solution is deemed as NA; When diagnosis information is shared at a system-level or across multiple platforms, but the analysis of all patient diagnosis at an aggregate level and across all patients is not available, the platform under investigation would get a P; and if system-level analysis of diagnostic information and healthcare evidence is available, the value would be an A (for Available).
- **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 and the data-oriented world that we live in, 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 details in order to know what the other healthcare workers are doing at the system-level. If the platform allows for the right details to be shared at the right level i.e. the system-level, in a way that contributes to the improving the experience of providing healthcare, an A is assigned. If data is shared at a system level but either not enough or too much detail is shared, or the right details are shared at the wrong

level i.e. not a system-level, a P is assigned. Finally, the lack of sharing of the right details and no system-level record sharing availability, would be marked with NA.

- **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 is not only about the quantity of data, but it is also about the extent of data, the episodes and organizations. Everyone should know about the system-level organizations and episodes. If patients cannot autonomously access any of their information, the evaluation of that platform would have a NA value; if the patients can autonomously access a portion of the available records on that platform, the value would be P; and if the patients can access any piece of information available of the platform, the value would be A.
- **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 (that can be patients or providers) have the means to autonomously access the information in a timely manner. Is system-level data shared and made available to others in a timely manner? If the platform does not make the information available to the users within 1 day, it will get an NA value; If the records are made available with a delay of up to 1 day the platform would receive a P; and if the records are accessible in real-time, the platform would receive an A. We test our proposed

framework through our prototype and a set of case studies. This metric is measured through usability testing that brings the testing of the system closer to real context.

- **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 platform helps with any net savings. If the costs of acquiring the platform are less than the alternative ways of sharing healthcare data at a system-level, that system gets the mark for this criterion (hence an A). Otherwise, NA would be assigned.
- **Health:** Another Quadruple Aim criterion. here we talk about improving the health of the population. Does the platform under investigation help achieve this goal in any way? We would rate systems qualitatively on a three-level scale i.e. NA (Not Available), P (Partially), A (Available).

3.3.3 System-Level Privacy and Confidentiality

According to PHIPA, HCOs are allowed to share and access Personal Health Information (PHI) for the purpose of continuation-of-care (Beardwood & Kerr, 2005). HCOs can do so, assuming an implied consent from the patient (Azarm, Kuziemsy, & Peyton, A Review of Cross Organizational Healthcare Data Sharing, 2015). Furthermore, it is 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 (Luchenski, et al., 2013). Our suggested criterion for this section id as follows:

- **Regulations compliant:** Is the platform compliant with healthcare regulations in the healthcare system it is being applied to? For example, is the system under

review compliant with healthcare regulations in Canada? If a system would not pass Canadian regulations without major modifications, it is deemed as NA, when they can be easily adapted to Canada's health regulations, they would receive a P, and if they are already fully compliant without any modification, an A is assigned to them.

- **Privacy:** Personal health information is considered one of the most confidential type of information. Therefore, it is important that the system we employ, keeps the integrity and confidentiality requirements on the forefront of their specifications. In this criterion, we would only assess systems on a two-level scale. Does the platform allow for the system-level sharing of the health records in a manner that the PHI is kept private and only among the custodians and owners of the records? A platform can either keep PHI fully private (to the system-level circle of care), and get an A, or demonstrate risky practice that would lead to breach of PHI confidentiality (hence a NA).

3.4. Chapter Summary

In this chapter we explained and defined the scope of the problem. Then, through a gap-analysis based on interoperability framework guidelines, we depicted the existing gaps in the system. Finally, we introduced the evaluation criteria that are relevant to the problem. These evaluation criteria are used in 0 to evaluate our proposed framework.

Chapter 4. **A Patient-Centered Framework for System-Level Sharing of Health Records**

4.1. Overview

A high-level diagram of our proposed conceptual framework for guiding the design, implementation and management of system-level sharing of health records, is shown in Figure 5. The key stakeholders in approaching system-level sharing of health records are the Health Authority which is legally responsible for cloud-hosted, system-level sharing of health records, the Patients that receive care within the system and would like access to their health records, the HCOs who are responsible for the health records related to the care they provide but who need to be aware of care provided by other HCOs, and 3rd Party Developers who develop software for system-level sharing of health records.

Governance principles are the starting point for understanding the design and management of system-level sharing of health records and are the responsibility of the Health Authority for ensuring quality of care, security of records and complying with all applicable laws and regulations. The sharing of health records is patient-centered to ensure that all stakeholders have a view of the all the records relevant to a particular patient in order to optimize quality of care for that patient.

Governance defines who has the legal responsibility for hosting and enabling patient-centered sharing of health records, including decision making rights and responsibilities around data usage (Otto, 2011), how accessible the records are to each of the actors (Khatri & Brown, 2010), and how the records are shared and protected.

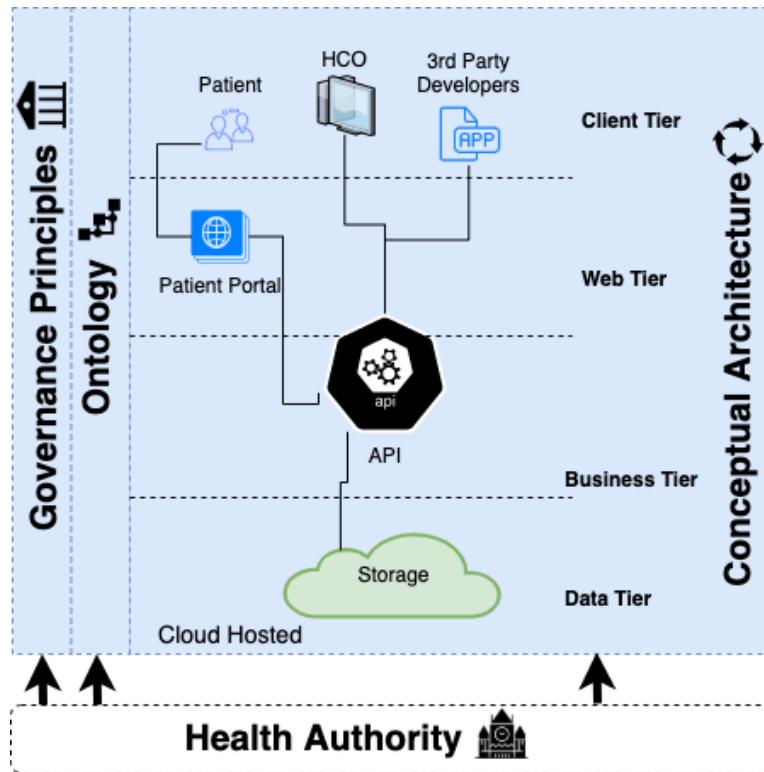


Figure 5 A high-level structure of the proposed framework

Ontology defines the data entities and their attributes in our proposed framework. The ontology is a key driver of data interoperability, since it defines clear and specific data entities and their data types for sharing health records. Ontology is critical to know at what level of granularity the records sharing will occur at, which organizations should be sharing records, and who is authorized to have what type of access to what type of data in what situations. Once we know how to format our data, then our proposed conceptual architecture can take care of the logistics.

The conceptual architecture focuses on the definition of an API that makes system-level sharing of health records accessible to the stakeholders within a classic four tier architecture relevant to cloud-hosted services (Alur, Malks, & Crupi, 2003). The client tier is where access is enabled from any web-enabled device, including simple browser-based accessed for patients through a portal that is provided in the web-tier of the architecture. The shared records are stored

in a data tier but accessed over the web through an API in the business tier that ensures security and access based on the governance principles and ontology defined by the Health Authority.

In other words, our proposed framework takes a typical data-centric cloud-based architecture and extends it with appropriate security mechanisms and user registrations for healthcare to support the governance principles and ontology. One of the best practices in creating an interoperable system is to utilize open standards in order to define syntax and semantics. Throughout this chapter, as we go into detail with respect to governance, ontology and architecture, we follow HL7 FHIR standards as they relate both to the ontology (An architectural design for self-reporting e-health systems, 2019) and the API that are central to our framework.

4.2. Governance principles

Our governance principles apply to a health system as defined in 2.2.1. For us a health system is a set of services provided by a set of HCOs to a set of patients managed by a single Health Authority with legal, financial and technical authority over those services. It could be just the healthcare services provided by one hospital (which does not have much interoperability complexities except for when they have multiple campuses), or all the community service providers (excluding the hospitals) coordinated by a regional health authority, or all the services supported by a government run health insurance across many organizations. It could also be all the patients and organizations hosted by a corporate vendor like NextJ (introduced in **Error! Reference source not found.**) or Microsoft HealthVault (introduced in 2.6.3), or all the services provided by all the registered organizations for all the citizens of a country such as Norway (2.6.3)

System-Level Circle of Care (SLCoC) is a critical concept that is at the foundation of our governance principles. Traditionally, Circle of Care has referred to the team of individual

healthcare providers who are coordinating care for a specific patient and for a specific purpose (e.g. geriatric rehabilitation after discharge from hip surgery). We use SLCoC to refer to all healthcare organizations that may be interacting with a patient across a healthcare system at a given moment in time, because different organizations may be interacting with the same patient for different purposes. For example, a geriatric rehabilitation patient may also be interacting with other teams for chronic conditions like diabetes or heart disease. System-level records sharing refers to the records sharing needed to coordinate patient-centered care between these different health care organizations in the system-level circle of care (Gaynor, Yu, Andrus, Bradner, & Rawn, 2014).

4.2.1 Governance authority

For any healthcare system, there is a Health Authority (HA) which is legally responsible for the health records in the system. It could be a governmental body e.g. the ministry of health; or a commercial entity, such as a cloud hosted health record service or Health Maintenance Organization (HMO) company like Kaiser Permanente in the US. HAs must establish and enforce governance.

In consultation with stakeholders, the HA must establish which HCOs and patients can be registered and authorized for health record sharing. The stakeholders can also agree on what data can and must be shared. In practice, the scope of the governance system equals the union of the HCOs and patients with respect to the data entities and attributes defined by the ontology.

HAs are responsible for registering all HCOs and patients into the system, including the signing of contracts or terms of use for protecting data, and ensuring thorough audit trails and performance management reports that both the application and the health care system as a whole

are functioning properly. On the other hand, HAs are not considered a direct healthcare provider in a SLCoC, and therefore, are not authorized to see personal health information (PHI).

Governance principles need to address three aspects: current care, history, and audit logs. Each HCO within a HA can create an Episode when they start interacting with a patient (admission to service). This adds the HCO to the SLCoC for the patient for as long as the Episode is active (discharge from service). All HCOs within a patient's SLCoC can view the current care for the patient (all active Episodes from any HCO) and the history (all closed Episodes). HCOs without an active Episode are not part of the SLCoC for the patient and can only access their own Episodes. Any access to view or modify records for the patient will be recorded in the audit log. Just like the history, the audit log for the Patient is viewable by any HCO within the SLCoC. The Patient is always able to view all records related to their current care and history.

As mentioned earlier, the framework we propose needs to be managed and legally enforced by the HA responsible for a healthcare system. The HA is legally responsible for hosting the proposed solution, controlling/mandating the access and sharing of records, ensuring the security and safety of the records, and ensuring that it complies with the regulations and privacy requirements.

4.2.2 Data Principles

The two main stakeholders for access to shared health records at the system-level are patients and HCOs.

- **Patients:** Patient-centered record sharing should enable a patient to see the entire history of their interactions with HCOs in the system at a System-Level Circle of

Care (SLCoC). They should be allowed to comment on their records including the ability to flag possible errors. They should also be entitled to see an audit log of who has been adding, modifying or viewing health records.

Health Care Organizations (HCOs): HCOs should be able to access the shared health records of their patients during active episodes of care. Employees of the HCO can be authorized by their HCO. However, it is expected that HCOs apply their own access model and grant different viewing capabilities to their various employees. Interaction with the system-level record sharing platform should be integrated with the existing EHR system used by an HCO. This ensures that once an employee's employment is terminated with an HCO, their access to the EHR system is deactivated and so is their access to system-level record sharing.

4.2.3 Data Quality and Metadata

In chapter 2 and specifically in section 2.2.2, we mentioned that a data governance structure can determine requirements for data quality such as accuracy, timeliness, and credibility, as well as metadata guidelines on the semantics. In section 4.2.4.3 we propose an ontology to address these issues that describes the kind of data that should be recorded and guarantees the consistency and homogeneousness of data that is shared. The proposed ontology is developed using a methodology endorsed by HL7.

4.2.4 Data Access

Governance has four pillars that maps to what typically is known as "Data Access" in a data governance structure that we discussed in 2.2.2:

- Control: that is the control of policies and is directed by the system Health Authority;
- Administration: that is the control of registration of HCOs and patients;
- Access: determining who has access to the records and when e.g. HCO's can see PHI when they have an active episode with a patient, but the patient can always see their full care history;
- Secure hosting: Health Authority (HA) is responsible for physical storage of the records (cloud hosting), protection of the records, and auditing of the access.

Various actors can unlock different functionalities of the system based on the different permission levels. Patients for one, must be able to view all the shared records about them, but they can only modify certain pieces of information. For example, a patient can edit their profile information (as laid out in 4.3.4) such as address, but they cannot modify their care history such as an episode of care at a hospital. Healthcare providers can always access their own records. However, they can only access shared records when part of the SLCoC.

Based on the privacy laws and protection guidelines, the Health Authority should also regulate users' permissions and validate that the access is conforming to policies. According to PHIPPA, consent to share PHI among HCOs is implied when they are actively providing care to a patient, unless a patient revokes their consent. HA should ensure that there are proper consent forms in place, in case of a patient wanting to remove their consent to share their information.

4.3. Ontology

According to Toronto Virtual Enterprise (TOVE) methodology, creation of an ontology should start by defining a scenario and depicting the problems faced, and then forming a set of

informal questions that the ontology must be able to answer, describing the set of entities and attributes, formal definition of terminology, and definition of terms and constraints (Cristani & Cuel, 2005).

While TOVE methodology was informative and inspired some of our work (Grüninger & Fox, 1995), we decided to systematically follow the Noy's ontology development methodology (Noy & McGuinness, 2001) in order to define our proposed ontology. We chose Noy's methodology as our guiding ontology development methodology, because it is a recommended method by HL7, and also because we found that its well-laid-out seven steps are straight forward and more specific than other methods. As a matter of fact, Noy's method is one of the most popular methods in healthcare ontology development efforts (Knublauch, Ferguson, Noy, & Musen, 2004), based on our literature search. Subsequently, we explain each step of the Noy's methodology that lead to the generation of our ontology.

4.3.1 Step 1: Defining the domain and scope

The goal of the first step in Noy's methodology is to clarify the ontology domain, the reasoning behind it, its target audience, and the sort of questions that the ontology can provide answers for.

Therefore, we developed a prototypical care scenario to highlight the need for system-level sharing of health records. This scenario was built based on our experience working for a community care organization and our interactions with healthcare professionals who worked with The Ottawa Hospital (TOH) or other HCOs in the community. The scenario was analyzed to determine what health records each actor in the scenario needed from other HCOs in order to complete their tasks. The professionals we talked with specifically were focused on the transition

of care from hospital to community care providers. In this scenario, we changed proper names and places. The scenario is representative but does not correspond to a specific patient.

The scenario below highlights data interoperability issues. Some key pieces of information such as a patient's "dietary restrictions" and "hospital stay" are not readily available when their care is transitioned from one healthcare provider to another. There are also process interoperability issues that prevent integration of providers to support collaborative care delivery. Finally, there are contextual factors that need proper attention; for example, when a patient's living situation changes from a private home to a retirement home and then again to a convalescent care home. It is the story of an 85-year-old patient as her healthcare transitions from the hospital to home.

An 85-year old female (Claire) 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) Respiriologist 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 domain of our proposed ontology is system-level sharing of records. This ontology should define the minimum necessary pieces of information that are useful to HCOs and patients, and the information that HCOs are willing to share (Azarm, Peyton, Backman, & Kuziemy, 2017). In other words, our ontology focuses on the minimum set of records that the HCOs need to share in order to achieve a System-Level Circle of Care (SLCoC) interoperability.

The information in our ontology describes the patients, and HCOs and their interactions with each other. It also provides an entity for communications between healthcare service providers at an HCO and their patients (i.e. comments). Examples of the questions that the ontology provides answers to are (Azarm & Peyton, An Ontology for a Patient-Centric Healthcare Interoperability Framework, 2018):

1. What are my upcoming medical appointments? And when are they scheduled for?
2. Who is the primary care provider of my patient? (the Respirologist may ask)
3. Who is the primary caregiver for my patient?
4. What is my patient's current address?
5. What were the past medical conditions of my patient?

6. What risk factors is my patient exposed to?

4.3.2 Step 2: Reusing the existing ontologies

The second step of Noy's ontology recommends the use of existing relevant vocabulary. A 2014 research publication in Korea identified seven categories for a healthcare context information model (Kim & Chung, 2014). We adopt some of their vocabulary in our proposed ontology, because we found that Kim and Chung categorize health information at a higher level, which matches to our goals. We wanted to create an ontology for a SLCoC and that means a wide but shallow coverage of the health-related entities and attributes. Their categories are:

1. Individual Data: Individual data includes attributes such as name, age, and other information describing a patient's profile.
2. Medical Data: Medical data includes information about history of diseases, symptoms, examination and vital metrics such as blood pressure, blood sugar, weight, etc.
3. Auxiliary Data: Auxiliary data include biological data analysis and management, and exercise and nutrition consulting services.
4. Location Data: Location data describes the indoor/outdoor location.
5. Device Data: Device data include the device-specific data from smart phones, medical detectors, etc.
6. Activity Data: Activity data describes states of one's activity levels such as sedentary, walk, run, etc.
7. Environment Data: Finally, environment data focuses on environment variable such as temperature, humidity, illumination, etc.

In our proposed ontology, we adopt Kim & Chung's medical data categorization. This matches to our HealthProfile that combines all symptoms, conditions, and diagnosis in one spot. We will explain this further in section 4.3.4. This categorization is key to having a consistent record sharing platform where any HCO can contribute to whether they are concerned with a health attribute such as having a risk of fall, or a health condition (diagnosis) such as diabetes.

On the other hand, FHIR provides comprehensive and exhaustive resources when it comes to healthcare data domain. As discussed in Chapter 2, they have a comprehensive data model that defines most common and needed entities and attributes. As discussed in step 1, our scope is a minimum dataset that all HCOs are comfortable with. This is what distinguishes our proposed ontology from FHIR. Therefore, our proposed ontology that is geared towards a SLCoc implements a subset of FHIR entities and attributes that correspond to our minimum dataset scope. Nevertheless, our proposed entities are compliant with FHIR.

4.3.3 Step 3: Providing a list of relevant terminology in the domain

In this section we provide the relevant terminology from the ontologies and domains we introduced in the previous steps. We start by the relevant entities we considered from FHIR:

1. Patient: in FHIR, Patient entity includes basic information such as name and gender, as well as custom data types such as address and telecom. It also includes a reference to Practitioner entity and one to the managing Organization. And finally, there is binary information in this entity such as photo.
2. RelatedPerson: this is FHIR's entity for capturing information about a person who is somehow related to a patient and provides non-professional care for them. In

FHIR this entity is under Person entity which includes any human information such as those of patients, practitioners, and caregivers.

3. Address: An entity that keeps address information. All other entities with an address reference this data type.
4. ContactPoint: FHIR's custom data type for email and phone numbers.
5. Communication: FHIR has created this entity to have a custom data type for language information.
6. Organization: FHIR defines this entity as a formally or informally recognized grouping of people or organizations formed for the purpose of achieving some form of collective action. Includes companies, institutions, corporations, departments, community groups, healthcare practice groups, payer/insurer, etc.
7. Practitioner: an entity to capture physician or other licensed health practitioner information. This entity also includes basic data types such as name, status, birthdate and gender as well as custom types of Address and telecom.
8. Appointment: Details about past and future medical appointments.
9. Qualification: This entity captures a Practitioner's qualifications such as their specialty; and the associated dates.
10. Period: This is a custom data type for all dates. Instead of dedicating an entity, in our proposed ontology we use start date and end date attributes.
11. AllergyIntolerance: entails details about a patient's allergy.
12. Diagnosis: captures diagnosis information.
13. Medication: captures the medication data.
14. EpisodeOfCare: In FHIR this entity associates a patient to an organization.

15. AuditEvent: This entity in FHIR is supposed to maintain security logs such as software start and shutdowns, logins, access control decisions, etc.

16. Subscription: this entity is used in pushing a resource to another server or system.

Apart from the aforementioned entities from the existing ontologies, some of the relevant terminology in healthcare domain and their descriptions are listed in Table 5. We use this terminology in our proposed attributes. This terminology help motivate the attributes we propose in Steps 5 ad 6 of the ontology development methodology. For example, “dietary regimen” is an attribute in our proposed “Patient” entity. These attributes are inspired by FHIR resources (HL7, 2020), and our interactions with the Champlain Community Care Access Centers (Ontario Association of Community Care Access Centres, 2016).

Table 5. Relevant terminology in the domain of the proposed ontology

Term	Descriptions
Activity Impediments	An obstacle or difficulty that hinders one’s progress in motion, daily activities of living, etc.
Advance Directives	Advance directive is a description of one’s wishes with regards to medical treatments in order to be followed if the person is at a state where they would not be able to communicate those wishes.
Community Care Providers	These are healthcare organizations that deliver healthcare services outside of the hospitals. They may provide their services at patient’s home, at patient’s school, retirement home, etc. Example of the services provided by them are: Wound care, speech therapy, personal support with bathing, etc.
Dietary Regimen	A plan regarding food and nutritional intake that someone carries out temporarily or permanently, e.g. Kosher food, gluten free, etc.
Primary Physician	A person’s designated general medical practitioner and first point of contact with healthcare services. Should the person require further or more complicated medical interventions, their family physician sends the referrals accordingly
Healthcare Service	The actions taken to improve one’s physical and/or mental health or prevent negative conditions especially through providing medical services.
Living Arrangement	The way someone’s living condition is organized. For example, if they live alone, with a partner, with kids, with parents, etc.
Primary Care Giver	The person who’s dedicated in assisting with someone else’s daily activities of living or conducting personal health tasks. This person is available to help in the majority of occasions. This person is usually someone in the patient’s family
Residence Type	Where a person is living such as private dwelling, apartment, retirement home, convalescent care home, etc.
Service Language	The official language that one wishes to receive their healthcare services in. In Ontario, service language may be either French or English

4.3.4 Step 4: Defining the entities and their relative hierarchy

At this step, we introduce our entities and their hierarchy and relationships. Our proposed ontology focuses on the critical entities, also known as the minimum dataset i.e. the set of entities that all healthcare providers in our study (sample of hospitals and community care providers in Ontario) are comfortable sharing.

Figure 6 shows an overview of the proposed entities through an Entity Relationship Diagram. In this figure the parent entities are colored in orange. There are two parent entities: Client (generalizes Patient, and Caregiver), and HIC (generalizes HCO and Practitioner).

We should point out that the Caregiver entity does not link to every entity that the Client entity is linked with. The only entities that a Caregiver is linked with are the ContactPoint, Address, AuditEvent, and Comment. Furthermore, each Practitioner has one or more corresponding HCOs that hires them. The reason that we have created a separate entity for practitioners as opposed to other employees of an HCO is that we need to identify the authorizing or responsible practitioner in many health records types such as an Episode, a diagnosis, etc. Subsequently, we explain each entity in detail and Figure 6 pictures the proposed ontology and its entities.

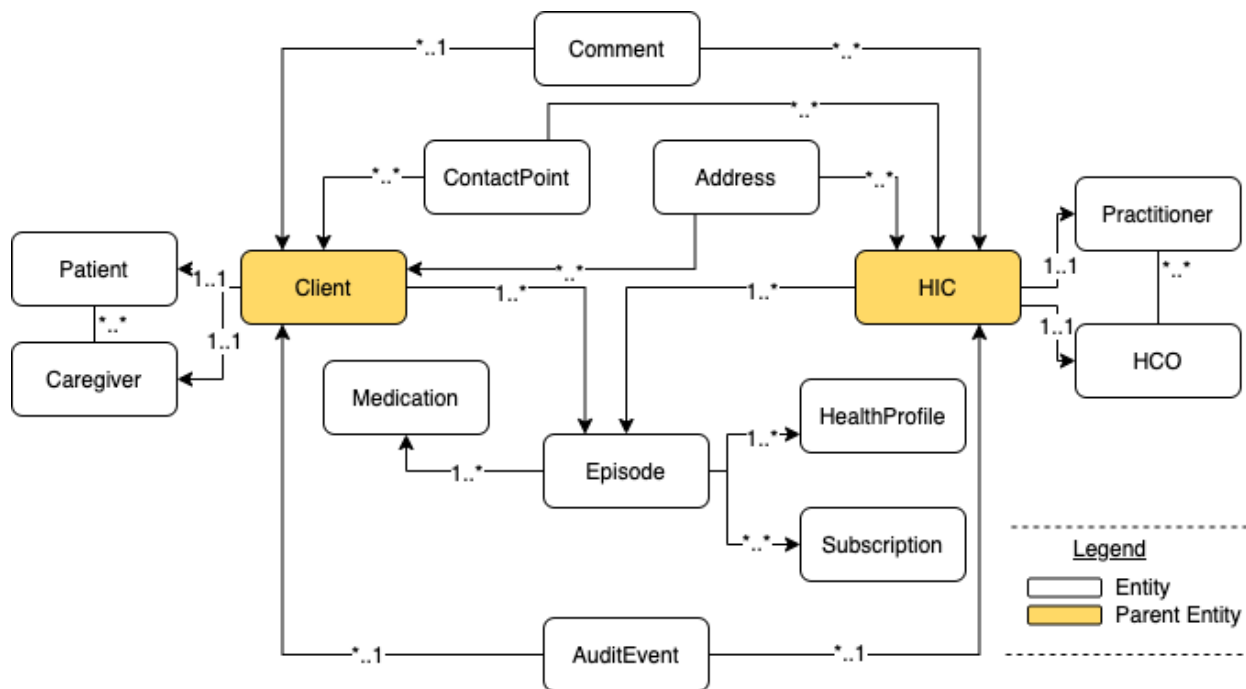


Figure 6 Proposed Entities

Address

In our proposed ontology, we suggest an entity that captures the address information of all other entities. Therefore, both HICs and Clients are linked to this entity. This entity is identical to that of FHIR.

Audit Event

Another entity that we designed to be part of our ontology is Audit Event. We foresee that this information is going to be useful for privacy audits, or in case of investigations, for privacy breaches. This way we keep logs on every record access including any web login, data pull, and data push. Using the stored data, we can generate access reports and monitor the requests for any potential breach. This entity is identical to FHIR’s AuditEvent.

Caregiver

Caregivers are the individuals who provide personal and non-professional care to patients but are not the target of the healthcare. They are trusted with the patient's PHI information. This trust is documented through the proposed portal that allows patient to add/remove caregivers. We employ all of the FHIR attributes in "RelatedPerson" entity for our Caregiver entity.

Client

According to our proposed ontology, we frame patients and caregivers under a parent entity called Client. Patient and caregivers have many similar attributes and can perform similar functions. A client can:

- Add/Edit addresses
- Add/Edit phone numbers
- Add/Edit their photo
- Add/Edit their caregiver information

Comment

We defined a separate entity for comments that may be written by a user. These comments are proved to be valuable assets in healthcare service evaluations. A team of researchers in London, UK have used the comments left by patients in their national online repository (Kowalski, 2017). Having applied natural language processing techniques, they determined that there is a great potential for an automated and accurate performance measurement system (Antoniou & Harmelen, 2008).

Using the portal, Web Users are empowered to post a comment about a HCO or about an Episode of care they have received.

Episode

Similar to FHIR, our Episode entity for any patient-healthcare provider interaction. This entity captures the encounters between Clients and HCOs. An HCO can register an episode with a patient and set the start date of the episode. When a new patient is added to an HCO's EHR system (possibly under a specific practitioner's care), a method in that EHR system should trigger the registration of this new patient for that specific practitioner/HCO. Once the HCO-patient episode ends, the HCO must send the patient episode end date immediately through the API methods.

In our proposed ontology the records in this entity are a snapshot of the event with minimum information such as type of encounter (category), date, name of the organization or practitioner, etc. Contrary to FHIR that created an entity for all dates i.e. Period entity, we keep it simpler by just having date attributes in each entity.

Our ontology gives an understanding of the patient's trajectory through the health system and provides clues as to where they can get more information, should the need arise. Hence, we do not include details such as procedures done during a hospital stay. It should suffice to capture a snapshot of the encounter at a high level.

Episode is the very entity that contributes in establishing process interoperability. This is achieved by homogenously considering any Client-HIC interaction as an episode, be it a blood test, tooth filling, or a hip surgery.

HCO

Our ontology has an obvious spot for this entity. Healthcare organizations are the healthcare provider companies that provide services through a well established organization, such as hospitals, community care access centres, pharmacy, laboratory, office of a practitioner, etc.

Health Profile

Health profile provides ways of describing a patient's situation. It can be a diagnosis, health condition, allergy, risk and safety issue, or an activity impediment. For credibility reasons, we only allow the diagnosing HIC to add or terminate a health profile record. This is where we used Kim and Chung's categorization of information. The FHIR attributes are definitely more detailed than those of our proposed ontology. This entity combines the three FHIR entities: "AllergyIntolerance", Medication, and Diagnosis; and it only cares about the name, code, and dates. Therefore, our ontology is less detailed than FHIR in this sense.

HIC (Health Information Custodian)

Since HCOs and practitioners have a lot of common actions and attributes, we decided to create a parent entity that both HCO and practitioner entities inherit from. To name a few, a HIC can:

- Start an episode
- Terminate an episode
- Request patient history
- Request patient info
- Create health profile
- Create health condition
- End health profile
- End health condition
- Create medication
- Add address

- End address
- Add phone number
- End phone number

Medication

This entity describes the medications prescribed by a healthcare provider for a patient. For credibility and accountability reasons, only a HIC can add a new record for this entity and the Clients are not allowed to edit this information.

Patient

Patient is the most important entity in the proposed framework. Their data is especially sensitive and subject to many privacy concerns and regulations. Patient is a child of Client entity. Patient includes anyone with a Health Card Number (HCN) whether or not they are actively receiving healthcare. This entity corresponds to FHIR's Patient entity.

We should point out that the proposed framework assumes that the Patients' table in the data storage system is fully loaded by the Health Authority (HA). Patient's consent is implied unless they revoke it. Therefore, no actor can add/remove Patient instances. The Patient entity is very similar to that of FHIR's.

Practitioner

This entity corresponds to the FHIR's Practitioner. In our proposed ontology, we simply add an attribute for specialty inside the Practitioner entity, as opposed to creating an entity for it (like FHIR does).

We established a separate entity for practitioners. One may argue that practitioners could be considered the employees of the family health team or even their own private practice. While this is true, we needed a distinct position for practitioners since the proposed patient portal grants individual web access to practitioners and we need to store the possible communications between practitioners and their patients through comments. We also need to specifically identify the practitioners that are providing care to a patient and those who wrote prescriptions. The patient-practitioner relationship and the duration of their episode is received through the HIC the practitioner belongs to.

Subscription

One of the services that the conceptual architecture offers is subscription to certain events within one's circle of care and responsibilities. Practitioners, HCOs, and patients can set up subscriptions to these notifications through the patient portal or API web service to receive notifications when certain events happen.

Web User

Web users are Clients and Practitioners with access to the patient portal and have their own unique credentials. For patients, web access is the only medium they can view and contribute to their health profile. Web User entity is therefore related to Patient and Practitioner entities. Each web user may have a practitioner ID or a patient ID.

Throughout this step, we compared our proposed entities with the two ontologies we reused. Figure 7 summarizes this comparison by showing the entities that we adopt from FHIR. The FHIR entities that have an identical entity in our framework are marked with a check mark. Those marked with a half-filled star, denote the entities that are partially present in the ontology.

We either capture the essence of their information through an attribute (as opposed to an entity), like Communication entity that's captured through the ServiceLanguage attribute in Client entity; or we combine a few entities into one like symptoms, AllergyIntolerance, and diagnosis that are combined into the HealthProfile.

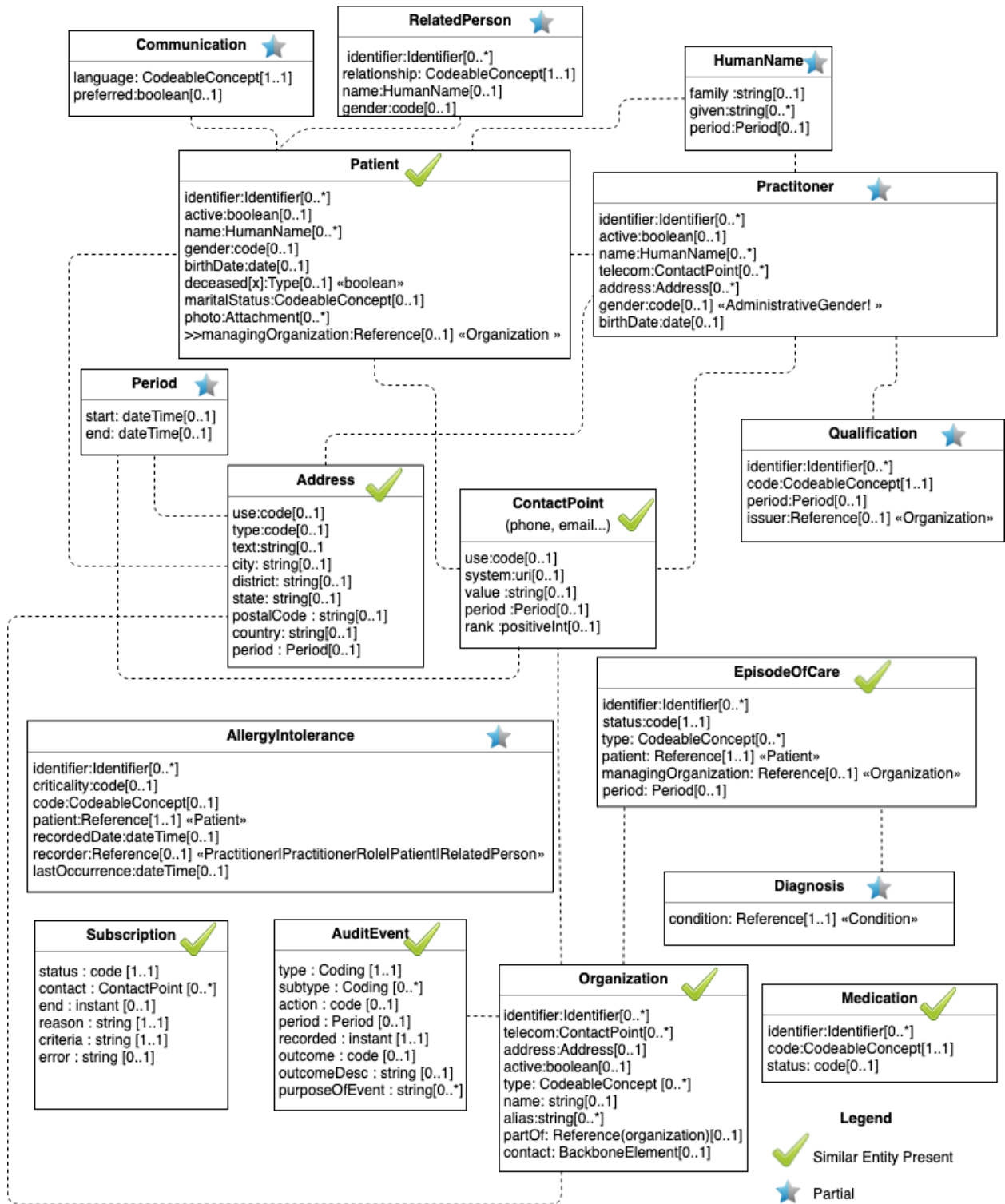


Figure 7 FHIR entities used in our proposed ontology

4.3.5 Step 5 & 6: Defining the attributes and data types

A full definition of all entities and attributes in our ontology is listed in appendix I. The main entities HIC (and subclass HCO, and Practitioner), Client (subclass Patient, and Caregiver), Web User and Episode, all have a unique GUID that identifies them in the system, for the purposes of linking and referencing. All data in the system is associated with one of those four entities. Episode has a HIC_ID and Client_ID to link the owner of the Episode health record with the client receiving care.

As marked on Figure 7, we kept all the entities and attributes that are marked with a check mark. Those marked with half-full stars are partially used or combined into a new entity. “Language” attribute is taken from FHIR’s “communications” entity and is incorporated in Client entity through “service_language” attribute. FHIR “HumanName” attributes are all incorporated through proposed “Client” entity and “name” attribute. We did not break down the “name” entity into smaller attributes such as first name, and surname, because only one agent can write to a shared health record platform i.e. the API. Every API caller is forced to format their requests according to the API method documentations. For example, the API method takes first name, and surname arguments from the caller and writes the full name into the data storage environment. This mechanism reinsures that our proposed “name” attribute is consistent across all records.

FHIR proposed “active” attribute for various entities such as Patient that denotes if a patient is deceased or is inactive for any other reason such as permanently moved out of the health system. However, we omit this attribute in our proposed ontology as it provides redundant information with “end date” attribute. One can simply check if an “end date” is null, to identify an inactive status for a record.

4.3.6 Step 7: Creating instances

One of the characteristics of a good ontology is universal representation i.e. at least one real world instance can be shown to exist (Smith, 2010). We provided a realistic prototypical care scenario in order to find, extract and demonstrate our ontology attributes. In Appendix II: A Representative Instance of the Proposed Ontology, we provide a complete set of instances from our ontology for the prototypical care scenario that was described in 4.3.1.

4.4. Conceptual architecture

In this section we first clarify the functional requirements for the conceptual architecture in terms of actors and use case model. Then we elaborate fully the four tiers of our architecture. Furthermore, in this chapter we explain the registration and authentication of users. Finally, we introduce and describe the available API services.

4.4.1 Actors and Use Case Model

According to Lethbridge and Laganière (Lethbridge & Laganière, 2001), the first step in designing a software system is identifying the user groups, also known as actors. Actors are primarily derived from our proposed ontology and our governance principles. We have three main actors: Health Information Custodian (HIC), Client, Application Developer. Health Information Custodians can be either HealthCare Organizations or Practitioners. Clients can be either Patients or their Caregivers. Figure 8 shows the major use cases for these actors. These use cases or functional requirements are inferred from our proposed ontology (and the motivating scenario that was used to develop it) and governance principles. The actors can:

- View the Episodes
- Register an Episode
- Terminate an Episode
- Update health profile and medications
- View information (basic, health profile, and medications)
- Edit health and medication information
- Leave comments
- Edit basic information

- Access API services
- Registration and authentication

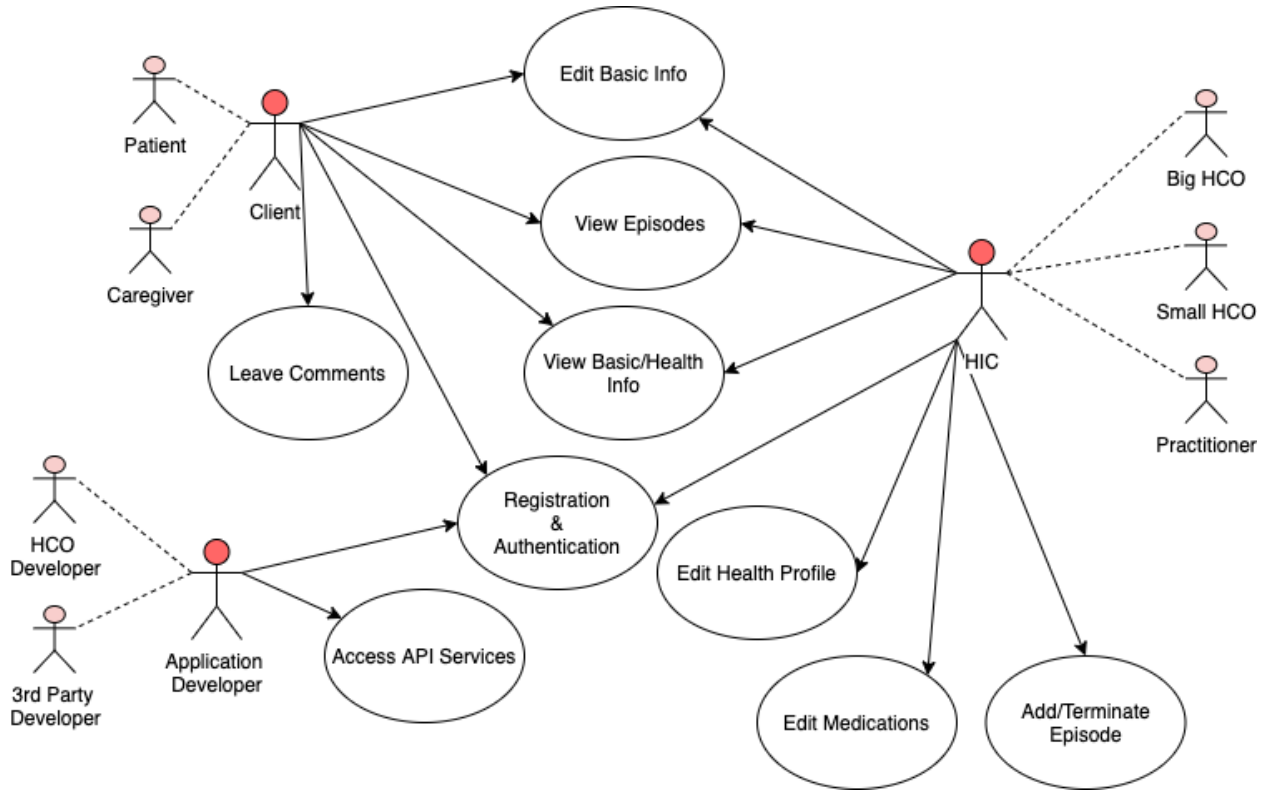


Figure 8 Use Case Diagram

Client

Client as an actor is a human involved in a healthcare service. The Client is not necessarily the receiver of the healthcare services (e.g. a patient). It can also be the caregiver of a patient that somehow has stake in the care delivery. A Client can therefore be someone with a valid health card number or not. We consider Client actor to have two personas of Patient and Caregiver that are determined based on their health card number status and caregiver designation status.

Patient

Patient is a Client who is registered in the healthcare system and has a valid health card number. Even when not actively receiving healthcare, they can still access the patient portal in order to update their profile. The patient as an actor is considered a non-professional entity that needs our proposed portal to be able to access and contribute to the overall system.

Caregiver

Caregiver is a Client that has a caregiver designation. Caregivers may or may not have a valid health card number in the system. A caregiver is designated and introduced by a patient and corresponds to FHIR's RelatedPerson.

HIC

Health Information Custodians (HIC) are the entities that deliver healthcare services to Clients and they have received a Health Information Custodian (HIC) designation from their respective Health Authority (HA). HIC as an actor has three personas: Practitioner, big HCOs and small HCOs.

Practitioner

There are two methods for a practitioner to access the shared health records. They can use their web account to login to the patient portal and view their patients' profiles. This way, they can interact with the record sharing system through designed interfaces for leaving comments, updating patient records such as starting a patient episode, ending an episode, etc. Alternatively, if they have access to an EHR system and that system is already integrated with the integrated health record sharing system, they can do all their view/edit tasks, through their internal EHR system.

Big HCO

Big HCOs such as hospitals, major pharmacies or laboratories, generally have an existing Electronic Health Record (EHR) system. The developers of the EHR systems (e.g. IT departments), can use our proposed API to integrate the shared data within their EHR and also send their data to the API. HCO employees access the health record sharing system through their internal EHR system and present the data in their internal EHR system exactly the same way that they present their internal data. When a HCO employee updates a patient's profile in their internal EHR system, the EHR sends the updates to the API which reinforces a unified format and data type for all the pieces of data it is receiving.

Small HCO

Smaller HCOs such as practitioner offices, small laboratories, boutique pharmacies, physiotherapists etc. are considered small-scale healthcare providers. Most of them have purchased software applications and maintenance packages that allow them to sustain an Electronic Health Record system. We assume that they can negotiate deals with their EHR provider to get their EHR system integrated with the record sharing system. If not, they could still access the patient portal, or they may be able to purchase apps created by healthcare application developers. Users in this category, depending on their existing technology, may fit in the same cohort of users as web users, HCO employees, and/or application users.

Application developer

Application developers may not use the healthcare data directly. They are just making it available to their application users by programming their EHR systems. They need to interact with the API in order to facilitate and maintain the flow of related information into/out of their EHR

system. As a matter of fact, we recognize the application developer as an actor of the proposed framework. We define two personas for the application developer: HCO developer, and 3rd party developer.

HCO Developer

HCO developers are the software application developers that are hired and work for a healthcare organization. Many large healthcare organizations choose to develop their own customized application as opposed to buying something off the shelf. Also, some of the healthcare organizations that buy an off the shelf application, choose to customize or maintain their application through in-house developers. These developers are usually trusted with the organization's sensitive data, or the internal governance policy and data access rules, regulates their access to the sensitive information.

3rd Party Developers

At times, healthcare organizations choose to outsource the development and maintenance of their EHR system. In this case, in order to be able to interact with the record sharing platform, they need to have their third-party developer company facilitate it. The developers in this case need to add extra functionalities and event handlers to their application in order to send requests to the API that either pull data or post. These developers are not considered custodians of Personal Health Information (PHI) according to PHIPPA guidelines. Therefore, they are not to access any PHI. Luckily, the application developers do not need to access PHI in order to develop or maintain EHR systems.

4.4.2 Tiered architecture

Figure 9 Conceptual Architecture Layers depicts the four layers of our proposed conceptual architecture. These layers are inspired by classic multi-tiered software architectures (J2EE) (Alur, Malks, & Crupi, 2003) and the desire for a model-generated / ontology-driven REST API (Bender & Sartipi, 2013). We designed four tiers for our proposed conceptual architecture (Singh, Brydon, Murray, Violleau, & Ramachandran, 2004): client tier, web tier, business tier and Enterprise Information System (EIS) tier.

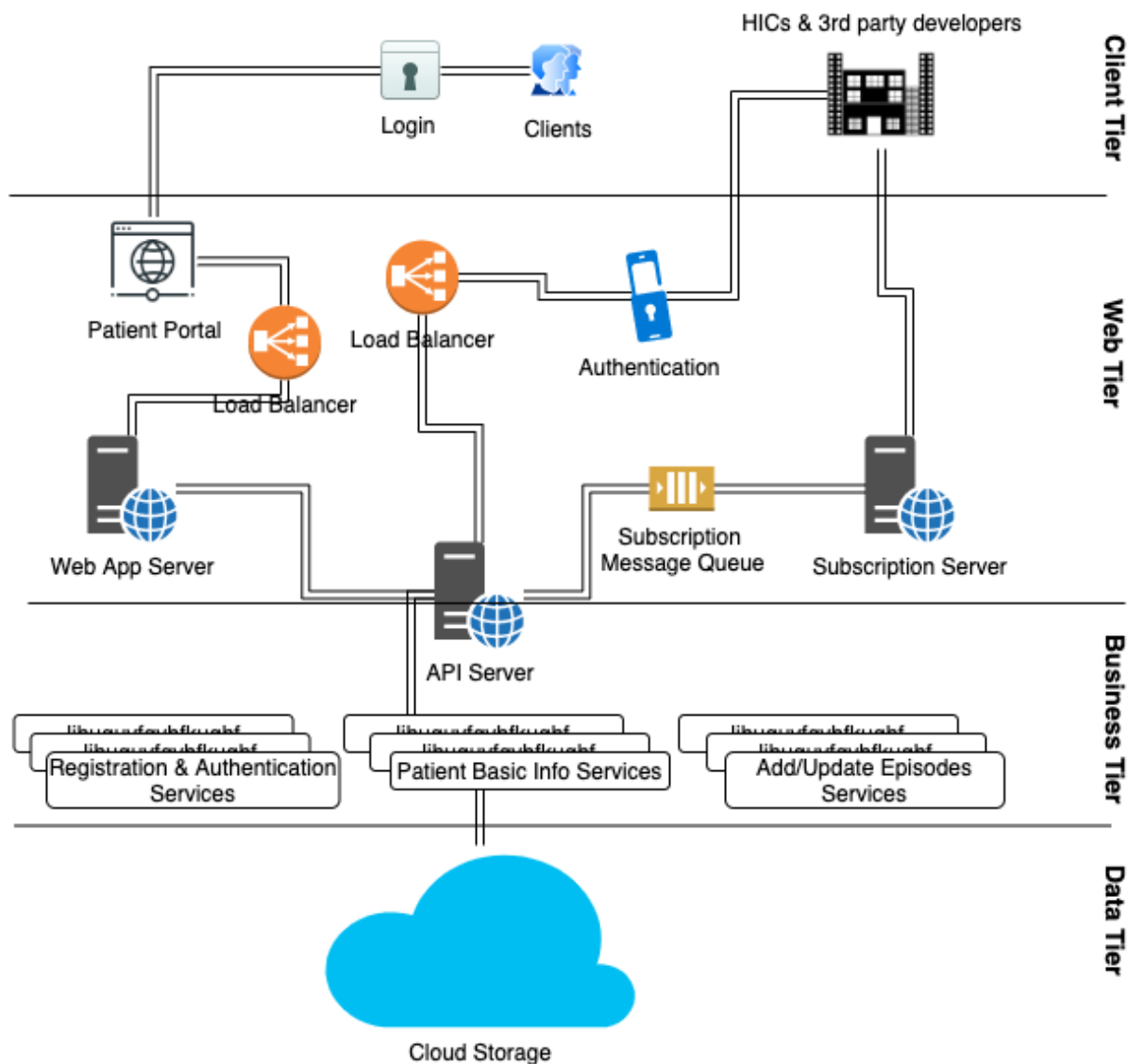


Figure 9 Conceptual Architecture Layers

Client Tier

Our users sit at this tier. User credentials are received at this level to be examined by authentication methods in the Web Tier. While the firewall upstream of the patient portal servers must allow traffic from any origin, the one upstream of the API servers will only allow connections from known whitelisted Health Care Organization (HCO) networks.

Web Tier

This layer comprises the patient portal and its web pages as a front-end GUI for end user interactions. It helps its users format their API requests properly by providing drop-down lists, filters with predefined values. End users like patients can interact with the API through this interface and send their add/update records. In a Model View Control (MVC) concept, this layer would be an equivalent of the view layer.

At the client-facing edge of our deployment, we will deploy independent firewalls, and independent load-balancers to segregate external API traffic from external patient portal traffic. Putting an HTTP load-balancer upstream of the web tier will ensure we can smoothly add new application servers as our load grows, without interruption.

There is a fine line in what is included within the web tier vs. the client tier. While the client tier works out the logic of how the processes are taking place, the web tier takes care of technological realization of those logics. Therefore, the web tier and the client tier work hand in hand in creating the expected functionalities. Web-tier is delivering for Control (in an MVC pattern). Web tier houses the following:

- 1) An application server for the web pages in order to provoke API calls and act as one of the API users.
- 2) Multiple API servers as well as a load balancer to redirect incoming API calls to the server with the lightest load. This would ensure faster transactions.
- 3) A message queueing system to line up update events that need to be delivered to the subscribers of notification delivery system.

- 4) A notification caller server to embed controls and methods of identifying update events and their patients, conflation of multiple updates for one patient, retrieving the stored web hooks, and sending the notification to the web hook URL. Multiple API servers allow us to handle a large request load.

In our proposed conceptual architecture, we have one separate virtual server just for processing notification subscriptions and their delivery, as they can be lagged due to the process dependency on a client's server who is receiving the notification (as this call reaches outside our datacenter and has unpredictable latency). We must dispatch these notifications asynchronously, without holding up an API server's worker thread.

API calls other than the ones originating from the portal, are authenticated using a short-lived API access token previously requested by an HCO (see section 4.4.3). Patient portal sessions use the standard session cookie approach. Note that in our design, authentication of specific accounts is delegated to participating HCOs (we still must authenticate the HCO itself at token-request time), while authorization checks are implicit in every action in the Web and Business tiers. The Web and Business tiers handle authorization checks, ensuring the authenticated principal driving a request is authorized to read/write the target of that request. At implementation, we can pass each incoming request through an authorization-check filter to ensure it has a valid authorization token and security context.

Business Tier

Business tier in an MVC framework, serves as the model layer. This layer embeds the service logics of the proposed conceptual architecture such as:

- Updating an episode/record service: When an update on a patient is received, the system should map and locate the right patient history to append it to. We delve into how the updates can take place in section 4.4.4
- Registration and authentication service which is discussed in further details in 4.4.3.
- Notification subscriptions and delivery service including the use and storage of web hooks and update queuing and releasing mechanism.
- Other services such as patient sharding services. When a patient is added to the system, the API assigns a GUID to that patient. The patient information is then stored at one of the writable databases. The database to write to is selected based on the modulo of GUID on number of writable databases;

The business tier logic can be written to be stateless and pooled and re-used (in the same application container), as well as spread out to multiple application container processes and machines.

Data Tier

Data tier is based on a cloud-based storage model. A cloud-based solution is easily scalable. The cloud-based databases in the data tier are read/written to, by the API, using its service account to authenticate to the Database (DB).

All DB read/write operations should be replicated to a message queue, and from there, written to an append-only audit log in a separate database, by a separate queue-consumer that is authenticated to the DB with a different set of credentials. This ensures that even in the face of a flaw in the API code, it cannot leak credentials to the audit log DB.

4.4.3 Registration and authentication model

Client

Knowing that the health authorities have access to every registered person in the health insurance program and their health card number, we suggest that an individual can sign up with the patient portal by using their health card info. They can receive an online identity from the same place they received their health card. Health card holders can go to their health authority offices and apply to receive a new account with their patient portal. Alternatively, they can apply for a patient portal account online through providing their online banking credentials. Ministry of health can partner with bank systems to authenticate a user's identity.

HIC

As mentioned in 4.2 governance principles, the health authority is assumed to takes care of all registration activities, that is patients as well as HCOs and Practitioners registration. Subsequently, we go through the details of how the initial registration can take place through providing an exemplary Governmental Health Authority i.e. Ontario Ministry of Health (MOH).

An organization can request to register itself as an authorized provider in the region. Assuming that the record sharing platform is owned and managed by the ministry of health (as a Governmental Health Authority GHA), it is easy to access the database of registered health information custodian organizations, as well as physicians' data through collaborations with the college of physicians. Having access to the most up to date records from the ministry of health and college of physicians, we can authenticate a new organization initially by their Business Identification Number (BIN), and a practitioner such as a physician through checking with the college of physicians' records.

Much like credit card processing requests, there would be human intervention and audit/approval trails that involves an auditor's visit to the new HCO site and their IT infrastructure and capabilities. Therefore, After the initial BIN- HCO name and description validation, the record sharing system will follow up with an auditor's visit to the HCO site, in order to assess their IT and security infrastructure. Without this step, bigger healthcare providers in the region would be less willing to participate in this system simply because they do not trust the IT capabilities of small practices and physician offices. Without a thorough audit of the existing security systems within each HCO, we potentially risk unauthorized penetration into the patient's records, if a HCO system gets hacked and their organizational authorization secret (OrgAuthSecret) be compromised by the thieves of information. This risk is mitigated by the fact that this secret is only known to one central participant in the HCO, and never replicated to client devices, the latter only receiving temporary access tokens.

We propose a security system of distributed identity where the healthcare employee identity and authentication is managed by each HCO, and a record sharing platform delegates its trust to identity providers run by each registered HCO. It would be unwieldy for us to manage the thousands of individual practitioner/employee accounts involved. Approaches such as SAML (Cantor, Kemp, Philpott, & Maler, 2005) or OAuth 2.0 (IETF OAuth Working Group) would work well for scenarios involving only web-based usage. However, implementing these would be awkward to support in unattended operations (machine-to-machine backend services) or non-web UIs (desktop applications, native mobile applications, etc.).

Instead, we will introduce another API endpoint intended to let HCO systems request an API authorization token for a specific user session (on-behalf-of a particular user). The EHR

system of a HCO would be presumed to have already authenticated the requesting internal user, using its own preferred means, e.g. Active Directory, 2FA systems, etc. The HCO is not involved in any API traffic after passing-through the API session token back to the requesting user. The proposed API is not authenticating the user itself; it delegates its trust to the HCO. It is only authenticating the HCO server making an API token request.

The API session token is then provided on each API request using a custom header, and validated by the API, e.g.

```
x-auth-user: maza@toh.ca
```

```
x-auth-apitoken: e8ff4526a17345f183975bd85a804102
```

Consequence of such system could be if an EHR system of a HCO leaks its authentication credentials, an attacker could impersonate any user of that HCO (though this does not break the system - it only exposes patient records for the patients that particular HCO was authorized to access). However, with a systematic audit system, the HCO infrastructure is supposed to be strong enough to resist most attacks. Figure 10 HCO Authentication depicts the specific interactions between HCO EHR and the record sharing platform at registration and Figure 11 HCO Employee Authentication Sequence Diagram pictures the authentication of an HCO employee through sequence diagrams.

The record sharing platform should authenticate its clients based on an OAuth authentication system. Once a healthcare organization is registered into the system, they can login by sending a request to the /hco_login endpoint of the API. Then, they would receive a token that

can be used for authenticating their calls. Subsequently, we provide an example that shows how a Healthcare Organization (HCO) can connect to the record sharing platform and get authenticated:

Champlain LHIN has sent notifications to all healthcare providers in the region to inform them about the existence of the patient portal and their API. Therefore, Cham-CCAC as one of the leading home care providers in the region has decided to participate and benefit from this system. Following their decision, Tom Jefferson the manager of applications at Cham-CCAC has arranged to utilize the API through a home-developed extension on their internal EHR system.

Using the API, Cham-CCAC's EHR system is now able to register their organization in the record sharing system. Tom takes care of this task, using their front-end GUI. Diagram below, shows what happens when Tom tries to get Cham-CCAC registered. After he sends the request to the API, the HA auditors check the organization's BIN (Business Identification Number) and their other info in order to validate the legitimacy of the registration request and make sure it is genuine. This validation can take a few days.

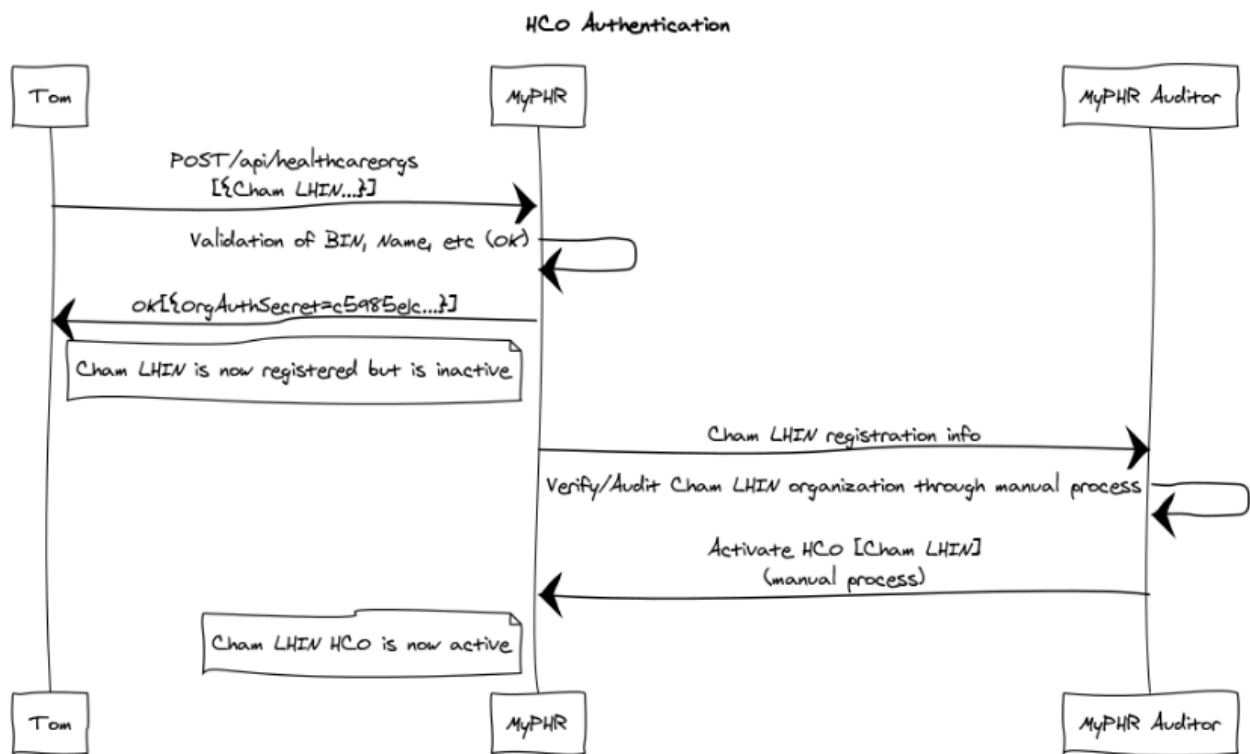


Figure 10 HCO Authentication

Now that Champlain CCAC is successfully registered and has been granted access to the record sharing platform, the employees within Champlain CCAC can benefit from the shared information that is now available to them. Since EHR system developers at CCAC have integrated the API with their application, now the nurses and practitioners at Champlain CCAC can seamlessly access the cross-organizational info. The access levels per employee within CCAC is defined through their internal EHR application that is called CHRIS and would comply with what they have used internally all along.

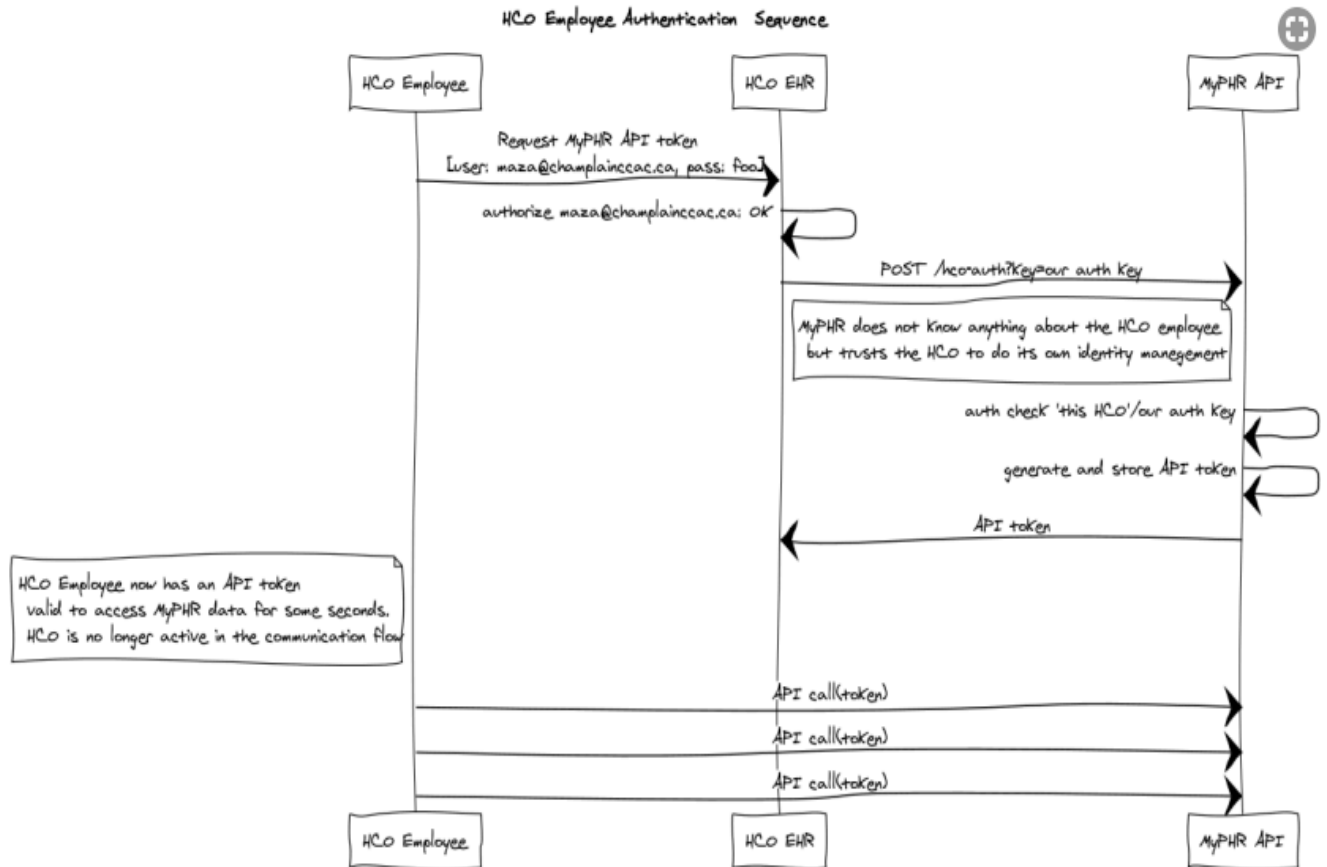


Figure 11 HCO Employee Authentication Sequence Diagram

Since all API actions are tied to a particular API session OAuth token, rate limiting and checking for suspicious access patterns (e.g. same OAuth key used from multiple IPs) are easy to implement. Below, we pinpoint the API call to register a new HCO, the proposed API method and its input/output properties.

Table 6 HCO registration API call details

Method and Path: POST /api/healthcareorgs			
Inputs			
API Parameter	Data Type	Attributes	Notes
HCO	Object	BIN (string) OrgName (string) OrgAddress (string) OrgContactPerson (string) OrgContactNumber (string)	To introduce a HCO to be followed by next audits before activation.
Outputs			
API Parameter	Data Type	Attributes	Notes
status	object	code (int) description (string)	
OrgAuthSecret	string		A shared secret the HCO's systems will use for future authenticated calls (i.e. request API session tokens)
OrgId	string		Assigned Organization ID is guaranteed to be unique (e.g. champlainccac)

Example:

POST /api/healthcareorgs

```
<HCO>
  <HCOName>The Ottawa Hospital</HCOName>
  <BIN>OTT4563728654</BIN>
  <HCOContact>Joe Hunter</HCOContact>
  <HCOContactNumber>6138888888</HCOContactNumber>
  <HCOAddress>100 Smyth Rd.</HCOAddress>
</HCO>
```

Response:

```
<response>
  <status code=200 description=OK />
  <OrgAuthSecret>c5985e1caf624c8a9cb7f67ec3f2200b</OrgAuthSecret>
  <OrgId>theottawahospital</OrgId>
</response>
```

Instead of accessing the shared records through a HCO's internal EHR system, a practitioner can apply for an account with the proposed patient portal by filling the online registration form and indicate the necessary information such as their practice number. An auditor

from the ministry of health (MOH) will then verify their application and may grant an account and access accordingly. Figure 12 Different methods of authentication summarizes how the record sharing platform authenticates various user personas.

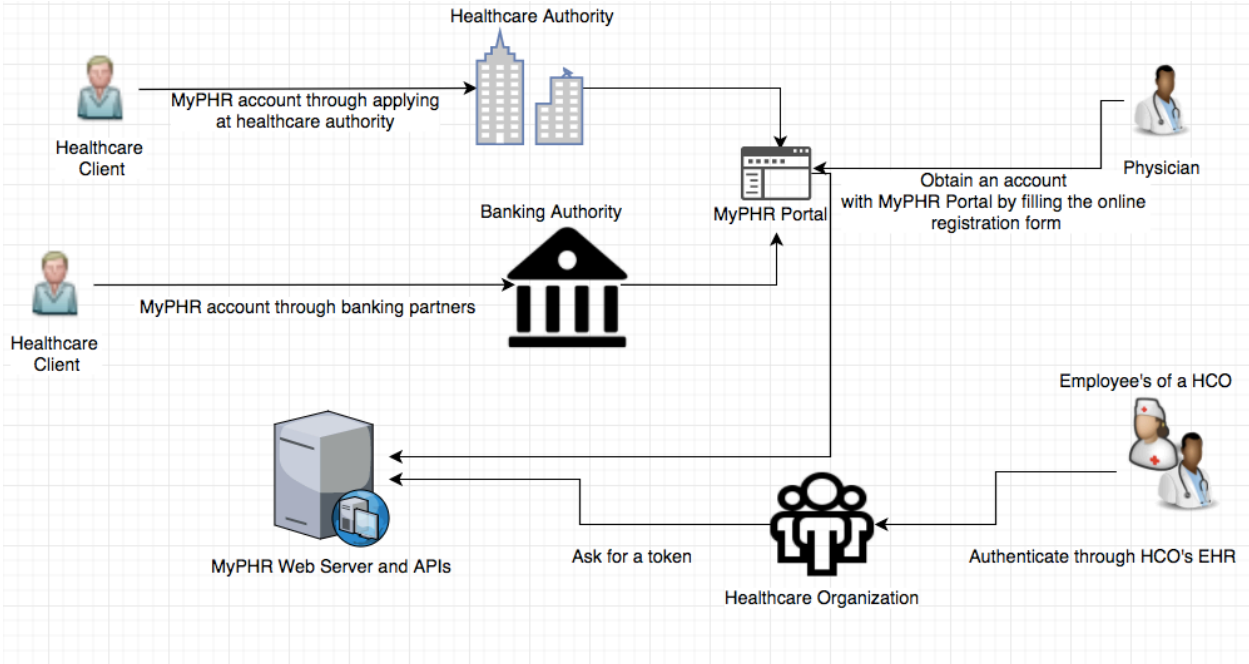


Figure 12 Different methods of authentication

4.4.4 Using API services to Add/Update an Episode

The proposed API has a set of web services that allows HCOs to register a new patient under their care through sending an episode for patient admission. It also enables HCOs to update an existing patient episode with new information as well as marking the end of the episode when discharging a patient. Below we explain how this process is facilitated in our proposed conceptual architecture.

When an HCO takes on a new patient and enters their info in their EHR system, this should trigger a method already written by EHR system developers to post a new episode for this patient to the record sharing platform using the API endpoints for episodes. In other words, by registering

a new episode, the HCO declares that they are admitting a patient. This is how the HCO can enter the patient's system-level circle of care. Below, we see an example of a relayed XML message:

Table 7 Patient registration into the system API call inputs and outputs

POST /api/episodes

Method and path: POST /api/episodes			
Inputs			
API Parameter	Data Type	Attributes	Notes
Patient	Object	HCN (string) firstname (string) surname (string) dob (string) contactNumber (string) residentialAddress (string) emergencyContactName (string) emergencyContactRelation (string) emergencyContactNumber (string)	
CareDetails	Object	primaryDiagnosis (string) PhysicianID careStartDate (DateTime) careEndDate (DateTime)	CareEndDate is optional if unknown.
Outputs			
API Parameter	Data Type	Attributes	Notes
status	object	code (int) description (string)	
Patient	object	id (guid)	
Episode	Object	id (guid)	

```

<Patient>
  <HCN>74637499455</HCN>
  <Firstname>Roya</Firstname>
  <Surname>Juliani</Surname>
  <DOB>1980-01-01</DOB>
  <contactNumber>6134656565</contactNumber>
  <residentialAddress>100 Walkley Rd.</residentialAddress>
  <emergencyContactName>Homa</emergencyContactName>
  <emergencyContactRelation>Juliani</emergencyContactRelation>
  <emergencyContactNumber>5147364758</emergencyContactNumber>
  <primaryDiagnosis>Asthma</primaryDiagnosis>
  <careStartDate>2015-01-01</careStartDate>
  <careEndDate></careEndDate>
</Patient>

```

```

<CareDetails>
  <PrimaryDiagnosis>Asthma</PrimaryDiagnosis>
  <CareStartDate>2015-03-01</CareStartDate>
  <CareEndDate></CareEndDate>
</CareDetails>

```

Response:

```

<response>
  <status code=200 description=OK />
  <Patient id=36CDDA5F9412 />
</response>

```

When an HCO has an update about a patient under their care, they can use the API endpoint designed for updating an episode. This service allows the HCO to format their updates appropriately and post it to the record sharing platform. Below we can see the input and output attributes and an example of the XML message. Example:

Table 8 Update patient record API service

Method and path: POST /api/patients/<patient-guid>/episodes/<episode-guid>			
Inputs			
API Parameter	Data Type	Attributes	Notes
Episode	object	episodeTypeID (int) episodeName (string) episodeValue (string) episode Date (DateTime) username (DateTime)	Username is the HCO's staff completing the event (may be different from the user under who is context the current request is running)
Outputs			
API Parameter	Data Type	Attributes	Notes
status	object	code (int) description (string)	
Event	object	eventId (guid)	The identifier of this particular event; can be used at a later date to update it.

```

</Event>
  <EventTypeID>100001</EventTypeID>
  <EventName>Admission Date </EventName>
  <EventValue> 2015-05-01</EventValue>

```

```
<EventDate>2015-05-01</EventDate>
  <Username>lpeyton033@myorg</Username>
</Event>
```

Response:

```
<response>
  <status code=200 description=OK />
  <Event id=2C282D8E3E6C/>
</response>
```

Using the proposed API endpoints (`/episodes`, `/episodes_by_range`), HCOs can view the history of the care provided to their patients in a desired time range. An episode can be about a new diagnosis, allergy, risk, prescription, or medication dispense. It can also inform us about the practitioners that provide care to a Patient. Although these records do not contain much details, there is enough evidence and contact information provided to guide further inquiries by healthcare professional at a patient's system-level circle of care.

Chapter 5. Case Studies

In this chapter, we report on three use case experiments as case studies to validate the three components of our proposed framework (governance principles, ontology, and conceptual architecture). They are presented in the order that corresponds to the order in which the components are described in chapter 4, not in the chronological order that the case studies were completed.

The initial concept of the framework from our systematic literature review and gap analysis of related work (sections 2.6, and chapter 3) was mainly focused on conceptual architecture but in order to elaborate, that vision was drawn in the subsequent iterations of our research to focus in first on ontology, then governance, before finally completing a detailed conceptual architecture with a prototype implementation of the portal and API. The case study on governance principles was the critical iteration that resulted in the complete high-level understanding in our framework of what it meant to support patient-centered system-level sharing. As a result, the Path2Home (P2H) case study is presented first, followed by the Patient-Centered User Experience that focused on ontology, finishing with the MyPHR Prototype that focused on the Patient Portal and API of the conceptual architecture.

5.1. Path2Home (P2H)

In this section, we report on the case study of the Path2Home application hosted within the NexJ Connected Wellness Platform (referred to as NexJ from here on) (NexJHealth, 2020) that is a commercial software system for cloud-based sharing of health records between collaborating healthcare professionals (NexJ Connected Wellness Platform, 2020). Path2Home application is

based on a project that supports coordination of healthcare within a patient's circle of care for geriatric rehabilitation after discharge from hip surgery. The application is designed to maximize and improve information exchange in a circle of care during care transition. It is noteworthy that Path2Home project and their NexJ application focus on the interactions within a specific circle of care and they did not intend to share information beyond that and at a system-level circle of care.

In this case study, we used our framework and compared it to NexJ application in order to pinpoint what needed to be supported in order to achieve our goal of patient-centered system-level sharing of records. We chose NexJ for this task because they offered a similar architecture to that of our proposed framework. NexJ also proved that a Commercial Health Authority can be a capable HA in governing a system-level health record sharing platform. Although we initially focused on the ontology and conceptual architecture aspects of NexJ, our analysis revealed that the critical element for supporting system-level sharing of health records were governance principles and the right level of details in the health records (ontology).

5.1.1 Overview

P2H is designed to facilitate a smooth patient transition as they navigate after a hip fracture surgery from rehabilitation to home. P2H manages the handoffs between the HCOs and patients in their immediate circle of care. Using P2H, patients are able to track their progress on discharge plans and care transition, make decisions about their needs and health, and have interactions with their healthcare team after their hospital discharge (Backman, et al., 2018).

P2H is designed in a way that caregivers can interact on behalf of the patient. Similarly, HCO employees can interact on behalf of the practitioner. In this case study we try to understand how NexJ as a Commercial Health Authority (CHA) enables the sharing of health records among

its actors. Figure 13 summarizes the actors involved in the P2H project and what they are capable of doing using the NexJ platform.

In terms of our framework, NexJ Health is a system for patient-centered sharing of health records with two main actors: HCO, and the patient. P2H as an HCO uses the NexJ Health system to create and maintain user accounts, healthcare content and modules such as action plans, health library, workbooks, questionnaires, and wellness plans. The application developer also creates and runs reports. Subsequently, we discuss the NexJ elements such as their governance, ontology, and application architecture and how they compare to our proposed framework.

Figure 13 shows a highly abstracted use case diagram for NexJ hosting of P2H. In P2H, HCO includes healthcare employees (staff) who manage healthcare content in the application; as well as the practitioners such as physicians who deliver some form of direct care to patient. Client refers to the healthcare user who is participating in the P2H project i.e. either the geriatric hip surgery rehabilitation patient or their caregivers.

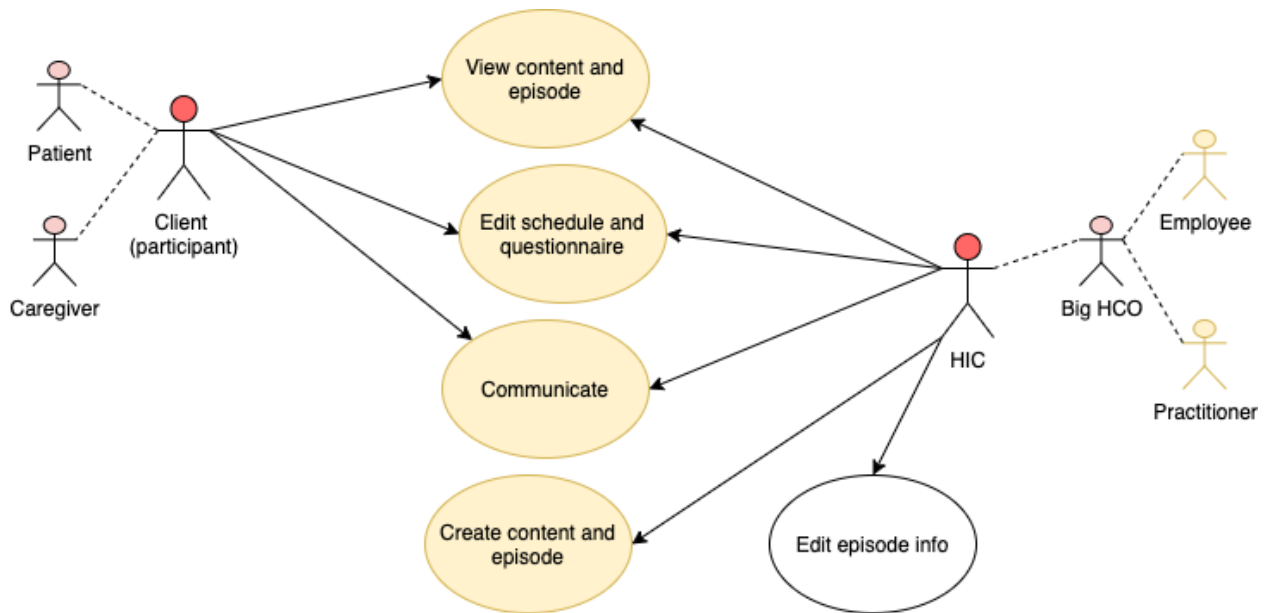


Figure 13 NexJ use case diagram (P2H)

5.1.2 Governance

Authority

Path2Home (P2H) is hosted by a commercial cloud service provider - NexJ Connected Wellness Program. P2H is an application created by Bruyère Continuing Care - a mainly palliative care hospital in Ottawa, Canada. P2H is focused specifically on the hip fracture surgery patient population. P2H connects with other HCOs that are directly within the same circle of care that pertains to the recovery from the hip fracture surgery.

NexJ is the Commercial Health Authority (CHA) who provides the cloud-hosted records sharing. As a commercial health authority, NexJ provides other services to other healthcare providers who may focus on different patient populations. While there may be a shared intersection of patients among all NexJ hosted HCOs, NexJ does not facilitate sharing of health records among its hosted HCOs. Therefore, albeit having the records on the clouds, NexJ is still keeping the information in silos.

Data Principles

As depicted in Figure 13, NexJ provides for two main actors who use the data and draw some value from it: Clients i.e. patients and their caregivers; and HIC HCOs i.e. employees and practitioners. Based on sections 2.2.2, and 4.2.2, below we delve into what is shared with each of these two main actors and where this data is of use.

NexJ is a patient-centered health platform as they allow for the involvement of patients and their caregivers in the care delivery process. The patients and caregivers can be invited to the NexJ platform by an HCO that is in their specific circle of care. In the P2H project, this circle of care is the post-hip surgery population who were discharged from rehabilitation to their home or a convalescent care facility. The HCO is sharing their health-related discharge documents and provides the right access levels for the patients and their caregivers. In addition to viewing their health-related discharge documents, patients are able to communicate with their HCOs, access tailored educational modules related to their specific needs. Furthermore, the patients can view an audit log of the activities on their health records.

By design, patients can only see shared records at the post hip surgery circle of care (CoC) and not at a SLCoC. Similarly, HCOs outside of the hip surgery recovery health outcome cannot access the P2H shared records.

Data Quality and Metadata

In terms of the accuracy, timeliness and credibility of the data, since P2H is cloud-hosted by NexJ, there is immediate access anywhere for everyone. This ensures excellent timeliness and helps credibility and accuracy.

Since the circle of care that P2H focuses on is specific to a significant health outcome, it covers a smaller set of data and stakeholders. The data sharing process is initiated and maintained by HCOs, and they monitor and follow up on their patients' input. P2H has administrators that monitor the process. This contributes to the credibility and accuracy of the shared records, because patients and practitioners can easily correct records and provide comments.

P2H records do not flow automatically from another EHR system. There is rather the human involvement when any record or document needs to be shared. This can potentially hinder consistency between internal HCO EHR systems and what is shared on NexJ platform.

Data Access

The NexJ-hosted HCO can create a sharing space for a specific circle of care and invite other HCOs, the patient, and their caregivers to this space. It is the HCO who decides what to share on that space. This HCO can communicate their efforts with the other healthcare providers, follow up on their patients, and inform and educate their patients through this platform.

NexJ hosts many HCOs like P2H, but there is no sharing of records between them, because they are not concerned with a system-level circle of care. Like our proposed framework, NexJ, as a Health Authority registers HCOs (like P2H) and the HCO is responsible for managing the authorization of healthcare providers to access patient records. However, unlike our framework, NexJ does not register patients. The HCO registers the patients they care for. Physical data storage including data quality checks, privacy, auditing and metadata services are taken care of by NexJ as well.

Security is a top priority for the NexJ platform. Their Connected Wellness platform is hosted in a Tier IV data center and the logical and physical access is meticulously controlled and is limited to highly vetted and verified staff. The data in transit and the stored data is encrypted, hosts are verified by recognized third-party certificate authorities, and all data access to PHI is logged in a ATNA-compliant audit trail (NexJ Health, 2020).

NexJ Connected Wellness required explicit patient consent for any PHI disclosure and the access is limited to those who are specifically invited and given the required credentials. They also have a well-documented procedure for handling any security and privacy exceptions.

In conclusion, it is the HCO who has control over “Control”, “Administration”, and “Access” – the first three pillars discussed in 4.2.4. However, the fourth pillar i.e. the secure hosting is handled by the CHA (NexJ in this case).

5.1.3 Ontology

Figure 14. NexJ object model for P2H is similar in structure to our ontology, but it is much more detailed. It stores and keeps track of every document throughout a Patient’s discharge and rehabilitation from hip surgery. This includes schedules and appointments. On the other hand, P2H’s model is much narrower than what we proposed, since P2H is focused strictly on a specific circle of care i.e. the geriatric rehabilitation hip discharges, whereas our proposed framework is system-level which means any interaction with the healthcare system (medical tests, specialist appointments, prescriptions, etc.).

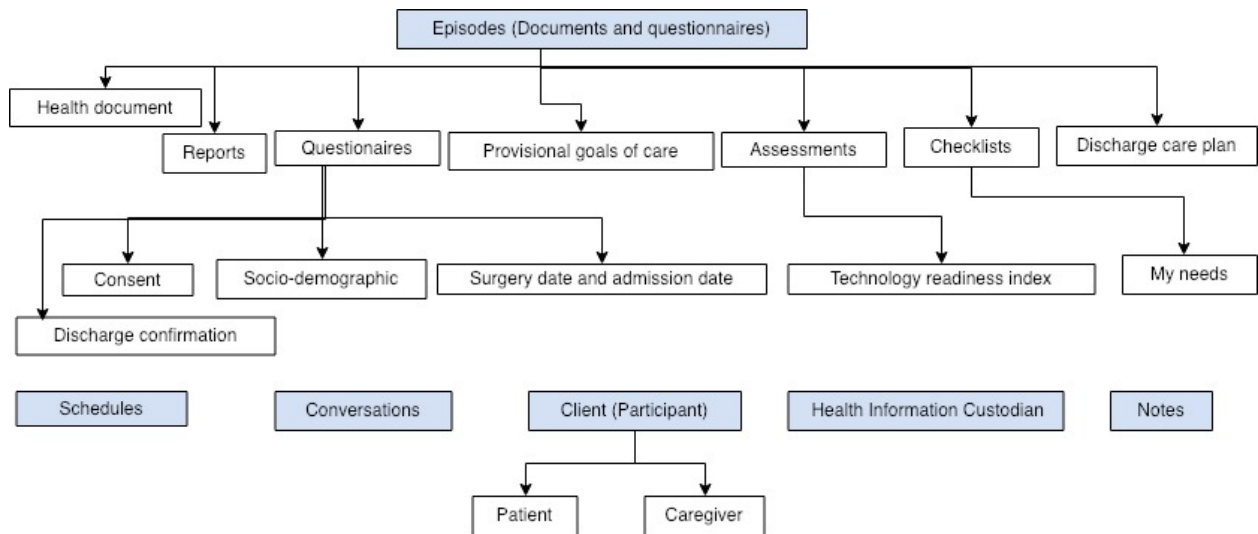


Figure 14. NexJ object model (P2H)

- The P2H object model shows a variety of documents and questionnaires that track progress throughout the discharge and rehabilitation process. Each one of them corresponds to a care episode involving a different healthcare provider
- “Provisional Goals of Care” are the healthcare goals for the patient
- “Conversations” are communications between healthcare providers and patients that are facilitated by the P2H application
- “Notes” keeps information about the care provided or to-be provided to patients.

NexJ provides simple building blocks: form, questionnaire, report that any application can use to customize what data is collected. This allows for any HCO to customize what data they want to record and report on but does not standardize what can be shared. Thus, NexJ’s ontology is more customizable than what we need to be a consistent ontology for all actors in a SLCOC. However, NexJ has good facilities for defining reports.

Furthermore, the documents and questionnaires in P2H are at a level of detail that may not be of interest to other Health Information Custodians in a system-level circle of care. It would be relevant for them to know that there had been a hip surgery and that the patient was still going through rehabilitation, but the details of each of the individual steps in rehabilitation would not be needed from the perspective of our framework.

5.1.4 Architecture

NexJ supports both cloud-hosted web applications (patient portal) and a mobile application. Compared to our proposed conceptual architecture, it offers most of the components except that it does not make its API publicly available. All interactions are through the patient portal. The application is designed to be accessed by human account holders. P2H is a cloud-hosted application. As long as they are connected to the internet, account holders can sign in, add or access information shared with them. Figure 15 shows the conceptual architecture of the NexJ Connected Wellness platform.

Healthcare providers connect with the patient through the NexJ Connected Wellness application. They can display and update their schedule to easily book appointment with other people in the circle of care. They also provide the content for action plans, questionnaires, etc. Patients on the other hand, can view the shared content and communicate their needs and preferences with their healthcare providers.

If NexJ had followed our proposed governance guidelines, they could keep their CoC applications, but have one master patient portal for SLCoC. They could also have HCOs accessing the API (to ensure seamless sharing of EHR into applications and between applications for an HCO) and to have SLCoC interoperability.

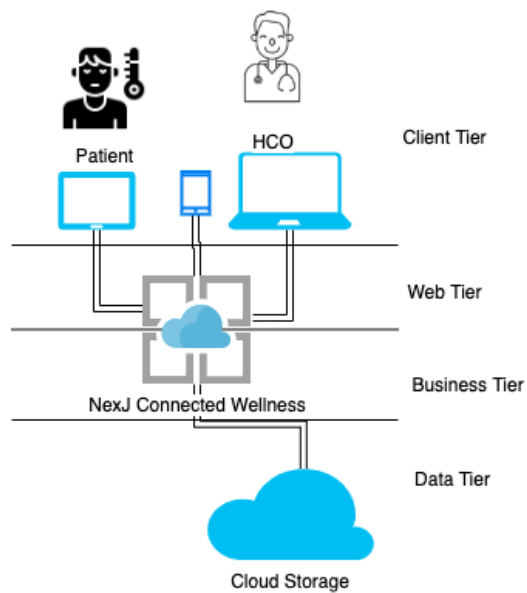


Figure 15 NexJ conceptual architecture

5.1.5 Results

In this case study, we used Path2Home (P2H) application hosted on the NexJ Connected Wellness platform, to demonstrate how our framework can provide guidance on how such a platform could be extended to provide system-level patient-centered records sharing. Based on our framework, there are three possible areas for improvement of the NexJ platform in terms of enabling system-level patient-centered records sharing.

First is the granularity. NexJ focuses on a few types of healthcare services such as hospital discharge, home care admission, hip replacement post operation, etc. and provides very detailed documents in the process. The level of granularity in NexJ is very appropriate for the current users, but not appropriate for sharing with other HCOs in the community that may be treating NexJ patients for other ailments. Our proposed ontology recommends providing a list of healthcare

encounters and some brief details. Our proposed framework's approach leads to a more homogenous stream of records from various healthcare providers at a higher level of granularity. As not all healthcare providers have similar policies on how much data should be shared, our framework focuses on a minimum set of data that most healthcare providers are comfortable sharing.

Second is being able to portray the full picture of a person's healthcare data by enabling a view into the current care of a patient for all HCOs in the system-level circle of care. NexJ works well for the HCOs and only the HCOs registered with NexJ.

Third is about governance and the entity who registers patients. In NexJ approach, the participants a.k.a. patients and their caregivers are registered by the HCO, whereas in our proposed framework the Patients are registered by the Health Authority (HA). When one entity exclusively undertakes the registration responsibility, the odds of duplications and data quality issues are lowered.

NexJ platform has powerful features for sharing data across community providers associated with a single organization. It would be advantageous for NexJ to enable sharing of "system-level" Episodes between the HCOs that it hosts on its platform to create a system-level care. It might make sense for NexJ to ensure patients have visibility to all their healthcare records hosted by NexJ. In order to be a more system-level health authority, NexJ has to accommodate system-level health records sharing and interoperability or become a client of a system-level health records sharing platform. If we assume a system that is developed according to our proposed framework is that system-level health records sharing platform, then NexJ can be a client of a record sharing platform that is developed according to the guidelines of our proposed framework

and leverage our proposed endpoints to send/receive system-level records about the active patients on their platform.

5.2. Patient-Centered User Experience

5.2.1 Overview

A systematic approach is important for analyzing the effectiveness, efficiency, and enjoyable use of a system if we want to be patient-centered (W.Kushniruka, M.Triolab, M.Boryckic, BenSteind, & L.Kannry, 2005). It is also important to identify the representative user personas and scenarios within an ecologically valid environment (Kushniruk, Nohr, Jensen, & Borycki, 2013). In this case study, we examine a representative scenario with regards to Patient persona in order to understand the full life cycle of system level sharing of health records as a patient-centered user experience:

- registration into the system as a patient and the authentication
- viewing information in the current SLCoC
- viewing the complete care history
- editing basic info and caregiver info
- leaving comments

The focus of this case study is to validate that our proposed ontology is sufficient to support the necessary patient experience. It walks through the complete set of use cases for Roya, an active adult under the care of a family physician) in relationship to her SLCoC, complete care history, and audit log of all those in the health care system who have interacted with her. The conceptual architecture is not the focus, but simply assumes a Patient Portal as her “window” into the system-

level sharing of her health records. Similarly, governance is not the focus, but just assumes the typical governance associated with a well-regulated, government-run system. In this case, the Ministry of Health in Ontario, Canada is providing the MyPHR patient portal in which the health records share all relate to services provided through the Ontario Health Insurance Program (OHIP).

As discussed in 1.3, throughout this thesis we have made use of various case studies. Table below summarizes all case studies in this thesis in an attempt to clarify the purpose of each of them and where this case study falls in comparison.

Table 9 Overview of the use cases in this thesis

Section	Persona	Scenario	Purpose
3.1	HCO Employee	Erik Johan	What is missing from a multi-HCO health record sharing platform
4.3.1	Patient	Claire	To satisfy one of the key points in the Noy’s methodology i.e. the use of a candid scenario to motivate and frame our efforts, and to pinpoint the data points in a collaborative care delivery
5.2	Patient	Roya	Validate if the proposed ontology is sufficient to support the necessary patient experience across all the use cases
5.3	Patient	Roya	In order to validate the conceptual architecture can support the use cases; to provide test data for the third-party application developer in order to build a patient portal; to verify FHIR compatibility, and to verify a third-party developer can connect to the proposed API

5.2.2 Governance

Registration and authentication

Through her family physician, Roya has heard about an integrated patient portal that can show her health history from birthdate to present. Client registration involves in-person registration with MOH to verify identity before granting access to MyPHR patient portal. She finds out that she can get an account by proving her identity at one of the many service Ontario branches in town, same places as where she obtained her healthcare card and ID. She receives a temporary password with her account that she needs to change the first time she logs into her MyPHR account. Subsequently, she navigates to MyPHR portal (the portal that is developed in accordance with our proposed framework) by punching in www.MyPHR.com address in her browser's address bar and then she logs in.

She could alternatively sign up with MyPHR portal completely online by proving her identity through one of MyPHR banking partners. By clicking the sign-up button, she gets redirected to a form that asks for her online banking institution. After entering her bank credentials in the bank powered sign-in page, and getting authenticated, she enters her information such as her full name, health card number (HCN), her address, phone number, emergency contact person in order to link her health profile with her banking account. The bank information system is providing the authentication system in this case. Then, she is guided through creating a username and password, security questions, and preferred cell phone number for the MyPHR portal.

On the first login attempt, our patient has to change the temporary password she was given by the Service Ontario office (if that was her preferred way of creating an account). Since MyPHR's patient portal authentication is based on a two-factor authentication system, on top of

username and password she has another authentication step that can be either a security code or answering a security question. She can choose the security option to receive authentication codes on her cell phone number every time she attempts to log in.

Alternatively, she can choose to answer a security question, in which case, she is guided to set up a set of security questions that will randomly be posed at each login attempt. MyPHR validates her info with her HCN and identifies her identity. Finally, she is granted access to the system and gets redirected to the login page.

She punches in the username and password she created and hits the Send Authentication Code button. She is redirected to the authentication code page. Within seconds, she receives an authentication code on her cell phone. She enters the code on the web page and is redirected to her home page. Alternatively, after entering her username and password, she could have clicked on the Answer Security Questions button and get authenticated through her answers.

Therefore, so far in the scenario we needed all the attributes in the Client and Patient entities from our proposed ontology. From the moment Roya signs up for a patient portal account, a new record in the “Web User” entity appears that shows her username, hash of her password, her last login date, the date of her account creation, IDs linking her web account to her patient profile, etc.

The client should accept the terms and conditions of use. As an example, Roya acknowledges that she is responsible to keep her account information confidential and safe. The MOH would not be responsible if her credentials are compromised due to her own negligence. However, she can always ask for a change of password or deactivation of her account.

The gov was not the focus of this case study, we assumed the context is Ontario and the MOH has created a portal for sharing health records. System-level record sharing in MyPHR is compliant with Ontario's PHIPA regulations. Roya understands that her records may be shared among HCOs that fall within her SLCoC. She does not need to provide consent for this sharing of information, as the consent is implicitly given. However, she can revoke that implicit consent at any time.

Roya can only edit her individual data such as name, address, phone number, etc. (see section 4.3.5). She is responsible for accuracy and truthfulness of the data she enters. Every HCO within Roya's system-level circle of care can update her information based on the latest episodes they have had.

HCOs in Roya's system-level circle of care are bound to keep her information confidential and within her system-level circle of care i.e. healthcare professionals that have an active episode of care with her. Once an episode of care is terminated by a healthcare professional, they are no longer able to view the portion of Roya's healthcare that is created by other healthcare providers. They can always keep the portion of information that they have generated. Figure 18 shows an interaction diagram for the critical interactions to illustrate how the system works.

5.2.3 Ontology

In this section, we specifically show what part of the scenario bears information that is encapsulated within each entity of our proposed ontology. The scenario also demonstrates some of the roles of the health authority, specifically when the patient acquires their account information. The health authority (HA) validates the patient's identity and issues an account for her. Although

the HA is not an entity in our ontology, it has a dedicated spot as the entity who governs and maintains the system in our proposed governance principles.

View Basic / Health Info

After she gets her account info and the web address, she goes online to see the portal. In her home page, she finds out that she can connect her smart bracelet to MyPHR portal and see visual graphs of the records that is sent over. Figure 16 shows how such records are displayed on Roya's home page.

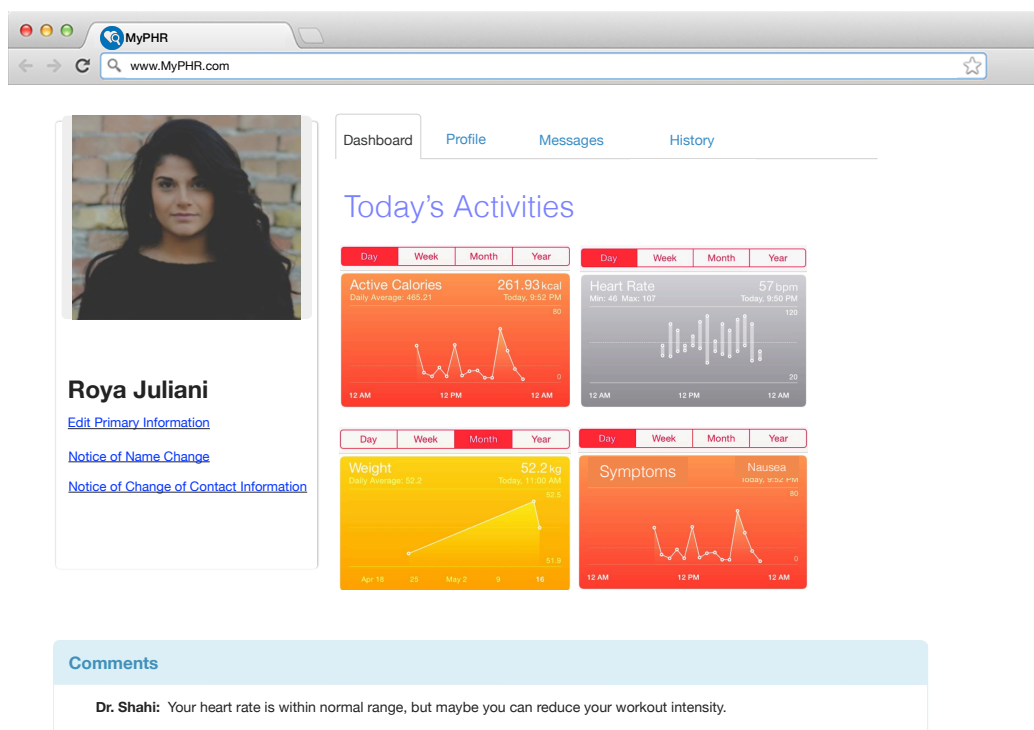


Figure 16 MyPHR portal showing smart device data integration

Roya can see her basic information like her registered name, her address on file, her current family physician, her caregiver information, her health profile info such as list of allergies, advance directives, her dietary regimen, medications, etc.

View Episodes

When Roya clicks on the History tab, she can see a timeline bar as demonstrated in Figure 17 that runs through her entire health records history and includes every care episode she has received from any HCO across her SLCoC. Through the portal, Roya is able to view the dates of previous test and the location of the laboratory. She can also see the history of her past hospitalization. Roya can view the date of her previous visits with each practitioner she has interacted so far, and the contact information of the practitioners.

By clicking on each event on the history tab, she can drill into further details within the selected episode. She can see the tests run and the outcomes achieved. There may be “Episodes” in progress that do not have an “end date” yet. An example is her family physician Dr. Walter Distant that has accepted her as a patient in June 2002 and she has been under his care ever since. Therefore, in the Episodes tab she can see a long running episode with Dr. Walter Distant that is not yet ended.



Figure 17 MyPHR history

Figure 18 visualizes the data interactions that we have explained so far for Roya’s scenario. It focuses specifically on the data interactions among Patient (Roya), HA (Ministry of Health, MOH), and a MyPHR patient portal. Here we can see the most critical records exchanged among these actors and the record sharing platform from the time Roya creates an account until she can see her history on the patient portal. Edit Basic Info and Leave Comments

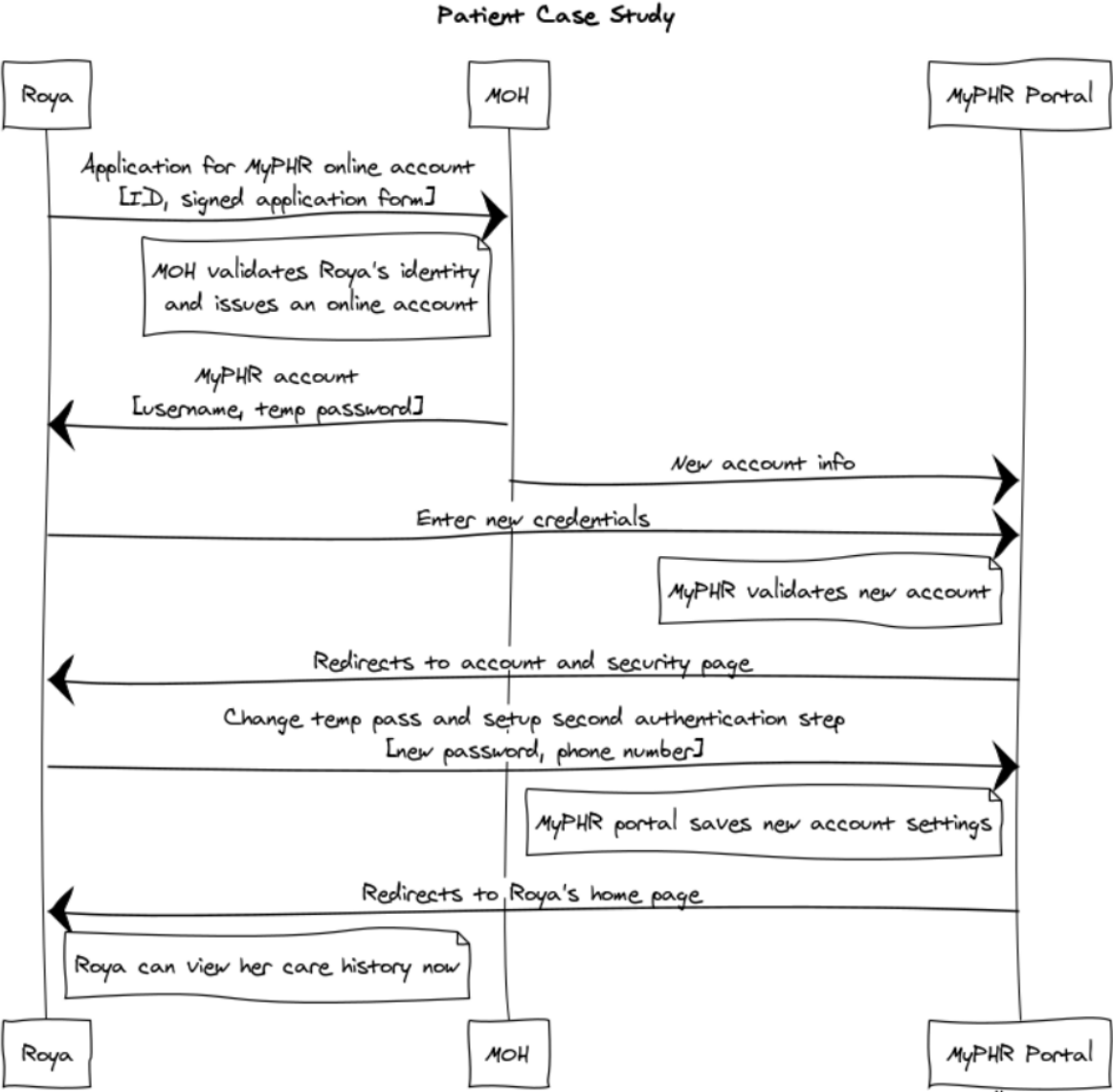


Figure 18 Patient case study interaction diagram

Edit Basic Info

In our proposed framework, patient is recognized as a data entry workforce. Patients can enter/edit their individual info such as their contact information. This can save hours of redundant work and money at multiple care facilities and eventually the healthcare system.

In this sense, Roya can add/end addresses, phone numbers, and her email. She can select/change her preferred service language. She can add a new caregiver, their relationship, and their contact information.

Leave Comments

Patients can also leave comments about their healthcare providers. The regulators are able to view and aggregate these comments, run them through machine learning algorithms and measure their performance metrics (Kowalski, 2017). This can help shorten the periodic healthcare auditing efforts and cut costs on overhead administrative tasks.

Roya can leave comments about her family physician or about her hospitalization episode when she received an appendectomy surgery. She has to select a practitioner, HCO, or an episode that pertains to her comment. Therefore, her comment record on the record sharing platform includes not only the text she enters but also the ID of the HCO/practitioner that the comment pertains to.

5.2.4 Architecture

In this scenario, we did not focus on the architecture component of our framework and we assumed that the proposed conceptual architecture in chapter 4 is providing for the platform that supports the scenario's technical details. However, we demonstrated the patient portal and the

patient experience on the web tier. Figure 19 illustrates our assumptions of the conceptual architecture for our patient scenario. We assume that the platform where our patient is connecting to is talking to an API that is compliant with our proposed framework and the data is store on a cloud storage environment.

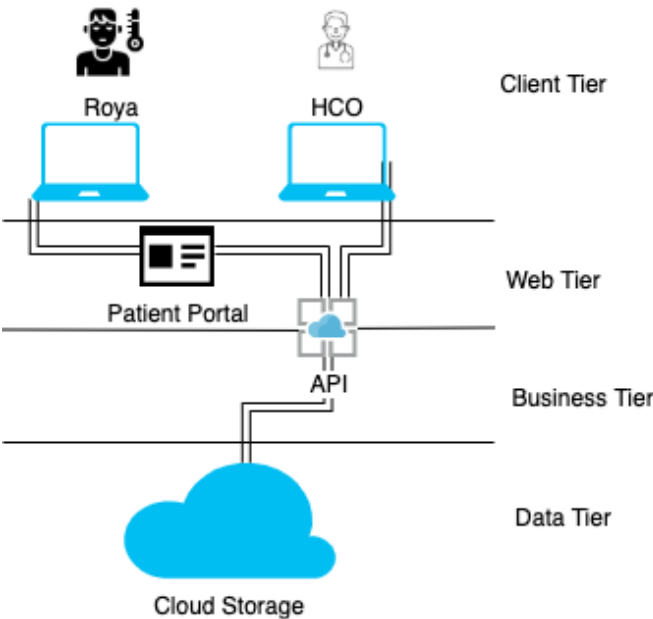


Figure 19 Patient scenario conceptual architecture

5.2.5 Results

Some healthcare providers in Ontario have created patient portals and offer their patient online accounts to view their care history with that specific provider (or allegiance of providers e.g. ClinicalConnect that was introduced in section 2.6.1). The difference between the current practice and our proposed framework is in the cross organizational shared records that is now provided to the patient that can paint a SLCoC picture of the patient’s health records.

Using this scenario, we showed how sharing a minimum data set of health records can be useful for patient and beneficial to the healthcare system while adhering to the health regulation.

This scenario validates that our proposed ontology is sufficient to support our required patient use cases. Below we summarize the entities from our proposed ontology that correspond to Roya's scenario:

- Address: 106 Stonehaven street, K7K 2P8, London, ON, Canada,..
- Audit Event: Last login attempt on 2020-02-09,..
- Caregiver: Claire Maleki, Mother, Born in 1970-01-03, authorized on 2002-01-02,..
- Client: Roya Juliani, Female, Born in 1995-07-11, Preferred language: English,..
- Comment: From Dr. Shahi, "Your heart rate is within the normal range..."..
- Episode: Dynacare, blood test, performed on 2018-11-22, ordered by Dr. Azimi ,..
- HCO : Carling Dynacare, active, 38 Carling Ave. ,..
- Health Profile: Asthma, J45.901, high, started in 2000-09-16,..
- HIC (Health Information Custodian): Dynacare Group, active ,..
- Medication: Inhaled corticosteroid, Z79. 51, started in 2000-10-01,..
- Patient

Patient is the most important entity in the proposed framework. Their data is especially sensitive and subject to many privacy concerns and regulations. Patient is a child of Client entity. Patient includes anyone with a Health Card Number (HCN) whether or not they are actively receiving healthcare. This entity corresponds to FHIR's Patient entity.

We should point out that the proposed framework assumes that the Patients' table in the data storage system is fully loaded by the Health Authority (HA). Patient's consent is implied unless they revoke it. Therefore, no actor can add/remove Patient instances. The Patient entity is very similar to that of FHIR's.

Practitioner

This entity corresponds to the FHIR's Practitioner. In our proposed ontology, we simply add an attribute for specialty inside the Practitioner entity, as opposed to creating an entity for it (like FHIR does).

We established a separate entity for practitioners. One may argue that practitioners could be considered the employees of the family health team or even their own private practice. While this is true, we needed a distinct position for practitioners since the proposed patient portal grants individual web access to practitioners and we need to store the possible communications between practitioners and their patients through comments. We also need to specifically identify the practitioners that are providing care to a patient and those who wrote prescriptions. The patient-practitioner relationship and the duration of their episode is received through the HIC the practitioner belongs to.

- Subscription: Email, Quarterly, active, started in 2019-03-15,..
- Patient: Family physician is Dr. Shahi, living alone, single, DNR, ...
- Practitioner: Dr. Shahi, Family practitioner, Female, DOB 1980-05-04, ...
- Web User: client id: 135436457658, active, last login on 2020-01-19, ...

5.3. MyPHR Prototype

In order to put our proposed MyPHR conceptual architecture to test, we have developed a RESTful API that helps collect and share the records that are formatted in accordance with our proposed ontology. We focused on a patient's overall experience from a functional perspective as opposed to details of user interfaces.

Although, our proposed ontology is mainly expressed in a relational and schema-binding annotation, our prototype records are stored in a No-SQL database (Google Firebase). This speaks to the scalability of our proposed ontology.

Furthermore, a third-party application developer was engaged to build a MyPHR portal prototype based on the patient scenario described in chapter 5.2 and using our API defined in chapter 4.4 (see appendix III) in compliance with the FHIR.

5.3.1 Overview

The MyPHR patient portal and API prototypes include methods to facilitate the Client actions demonstrated in Figure 21 Prototype application Use Case Diagram. The patient portal prototype has methods that sends updates to pull a patient's records from the 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.

The MyPHR portal was developed by a 3rd party developer (Masters Student) who also tested the API and verified its compliance with FHIR. We developed the API and refined it based on feedback from the 3rd party developer. We also implemented the simplified data storage behind the API.

The tools and technologies we employed in order to develop our prototypes are summarized in Figure 20. To develop the data model, we followed our proposed ontology (from section 4.3) and used the OpenAPI framework to program a .swagger file that specifies the application object

model. Through OpenAPI framework, we were able to generate a standardized API backbone and documentation automatically. Using this framework facilitated data model changes; one simply updates the swagger file (see appendix III) and runs the OpenAPI generator in order to update the application models.

The patient portal and the API (what the users interact with) are hosted on the Google cloud. The API event handlers and logic are developed in Python language and using Flask library. GitHub was used for source control and Firebase for permanent cloud storage environment. Figure 20 Prototype application layers summarizes the tools and frameworks we used to develop our prototypes.

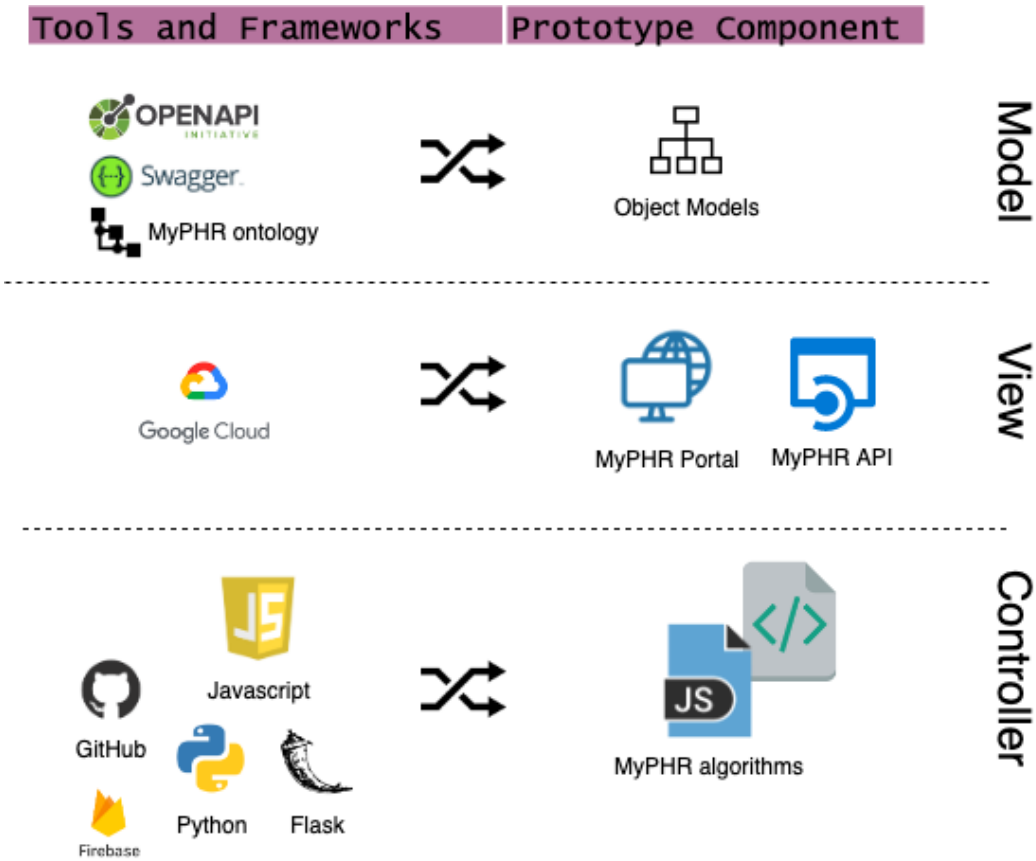


Figure 20 Prototype application layers

5.3.2 Governance

The prototype was based on the case study from section 5.2 and therefore had the same governance principles. Ontario's Ministry of Health (MOH) is the Governmental Health Authority (GHA). We assume that our patient has already gone through the registration process that was laid out in the Patient case study in section 5.2. We also assume that all the HCOs in the scenario have integrated their EHRs, although we simply pre-populated the prototype datastore with the necessary information.

5.3.3 Ontology

Similarly, all the data from case study 5.2 that is in the MyPHR data store is based on our ontology. The data scheme and API object model are generated from a swagger file implementation of the ontology generated by OpenAPI (Appendix III).

5.3.4 Architecture

Actors and Personas

For the purposes of our prototypes, we focused on Client actor and Patient persona, as well as the Application Developer actor and 3rd Party developers. Through our API prototype endpoints, a 3rd party application developer can call and display information without looking at the actual records.

Figure 21 shows the use cases that involve a patient and we focused on, while developing our prototypes. Therefore, through the patient portal, a patient can perform the following tasks:

- Log in and get authenticated

- View basic/health info
 - View service language in their basic information
 - View diet and advance directives within their health profile
 - View their contact information
 - View their active physicians
- Edit basic info
 - Edit service language in their basic information
 - Edit diet and advance directives within their health profile
 - Edit their contact information
 - Edit their caregiver list and the caregiver contact information
- View episodes
- Leave comments

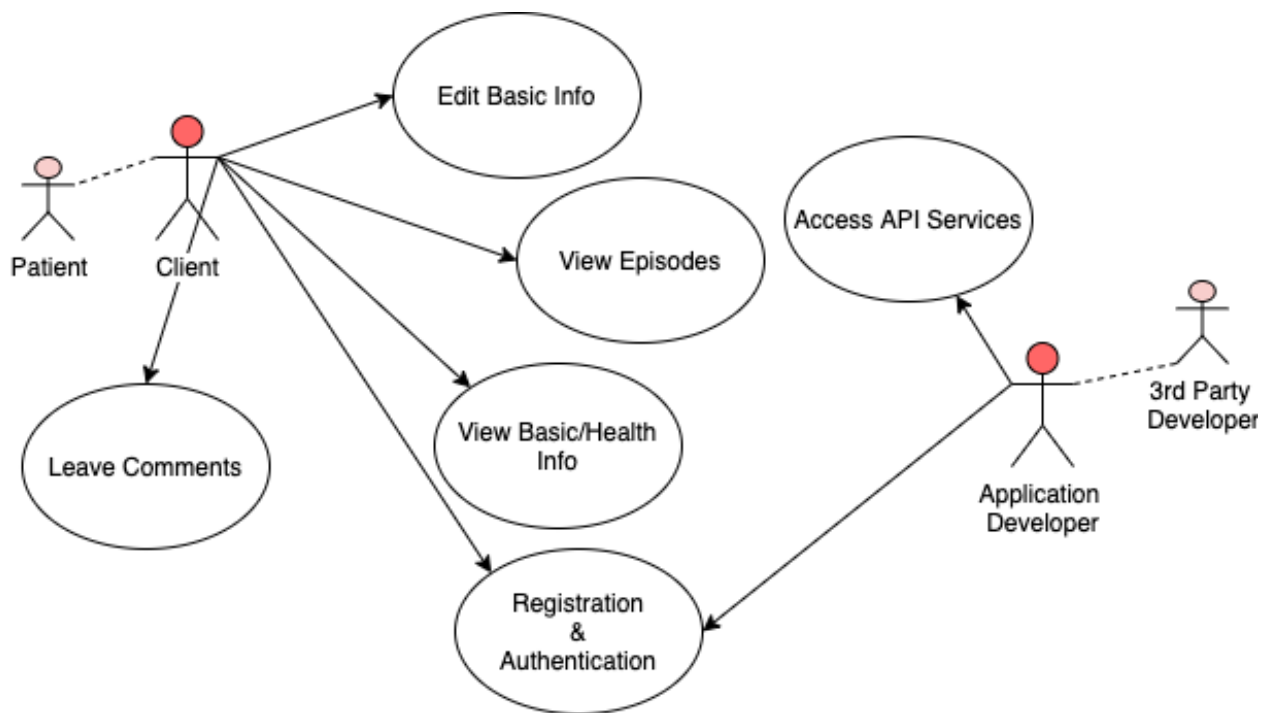


Figure 21 Prototype application Use Case Diagram

Client Tier

Client tier of our prototype entails the users of our record sharing platform i.e. the users of the MyPHR patient portal, and the API callers. Our prototype for MyPHR patient portal is scoped to serve patients, whereas our prototype for MyPHR API is meant to serve the patient portal, and other Electronic Health Record (EHR) systems.

Web tier

MyPHR Portal

[MyPHR Portal](#) is our prototype that serves as a patient endpoint of a patient-centric health records sharing platform. The portal was developed to test the Client Tier of our proposed framework, the role of the 3rd party application developers, and an API client's access to the API services. The portal was developed through collaboration with a master's student (Wenyan Li) for her master's project. From a MyPHR framework point of view, Wenyan took the role of a 3rd – party developer who develop apps that can interact with MyPHR API. The portal is a client of our API prototype. If the third party developed portal can send requests and show responses from the API, we can assume that the API is fulfilling its purpose. Also, our third-party developer compared our API's data model with FHIR and confirmed its conformance.

This patient portal is using React framework and tools such as Google Sign-In and Google Places. The endpoint allows patients to view their health profile, synched activities and episodes, configure alerts as well as add or modify their basic information. The create, read, update, and delete operations are supported by a Python Flask API called MyPHR API. The project was bootstrapped with Create React App. The application is running on Firebase: <https://myphr-portal.firebaseio.com/>

We scoped the portal prototype to a login page, dashboards page, profile page with 5 tabs for different types of patient information, episodes page, and subscription settings page that we called Alerts. Below, we briefly show what is presented in each page and provide screenshots of each page.

1. **Login:** where a patient can login with their HCN and password. Figure 22 shows a screenshot of our prototype for this page.

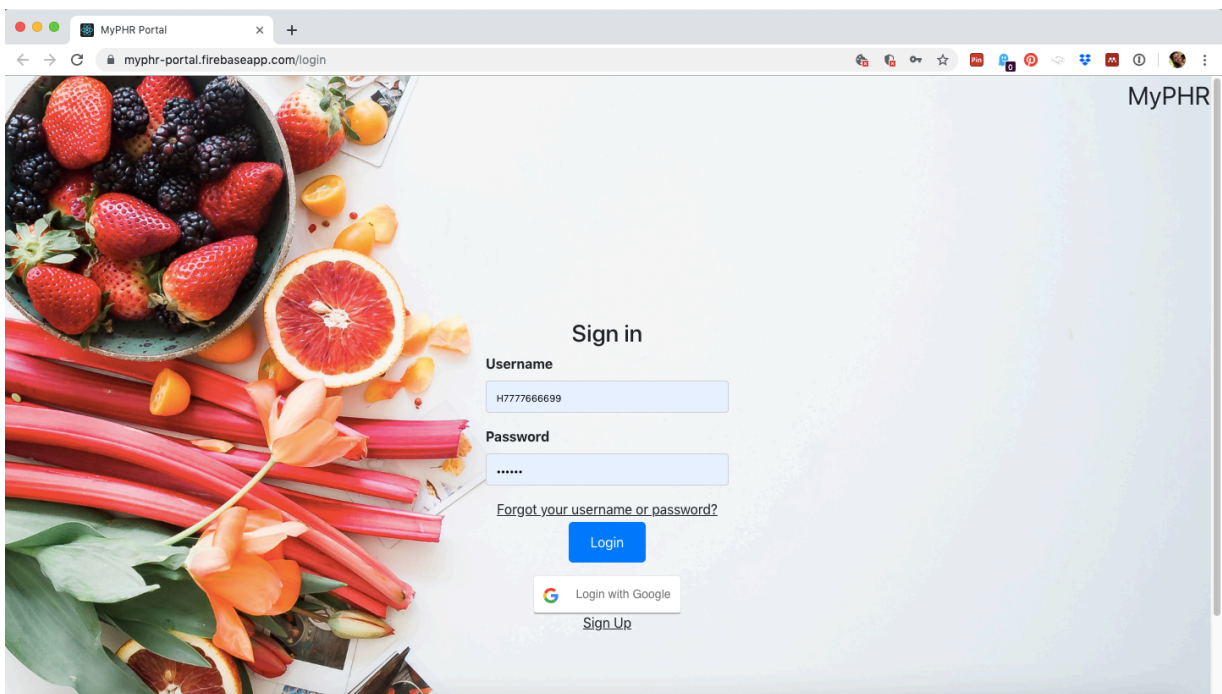


Figure 22 Prototype application Login Page

2. **Dashboard:** where the patient can see a customisable visualization of their records. Here, we assumed that our test patient has connected their personal smart device and can send a stream of activity (movement) records as well as heart rate records. shows a screen shot of this page.

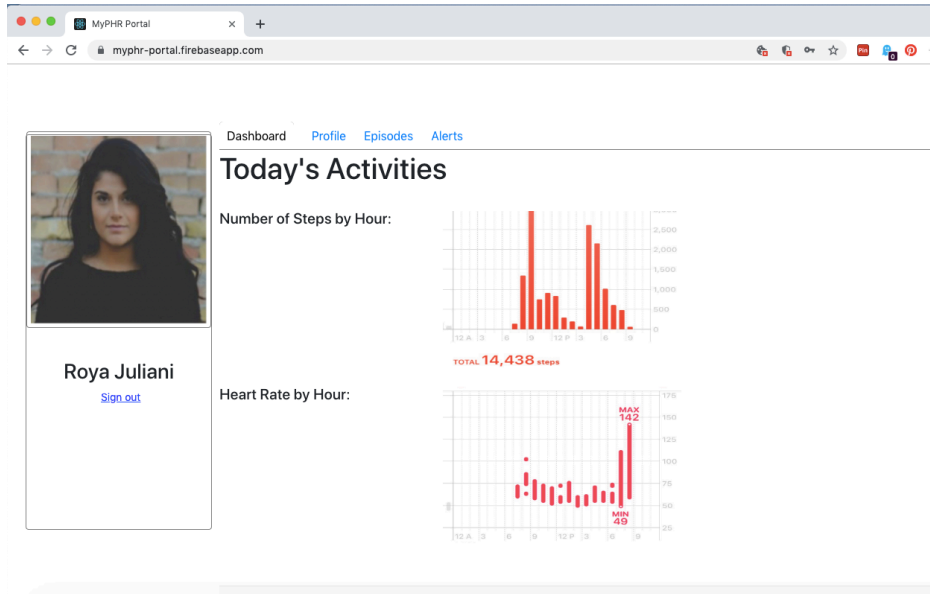


Figure 23 MyPHR Portal Dashboard Page

3. Profile: This page comes with 5 tabs that show different types of patient information. Figure 24 MyPHR Portal Prototype - Profile Page shows a screenshot of this page

- a. Basic info tab shows patient's name basic information such as name, date of birth, their preferred service language and the date of last login. The only piece of data that is modifiable by patient in this page is the service language. The rest are based on patient's registered information in the Health Authority (HA) system.
- b. Health Profile tab is about diet, diagnosis, allergies, risk and safety, and advance directives. Patients can update their dietary regimen, and advance directive information, but the rest is derived from HCO posted episodes.
- c. Contact Info is about a patient's address, phone numbers, and emails. Patients are tasked with keeping their contact info up to date for the whole health care system, just like your driver's license. This tab provides a critical

opportunity for the healthcare system to offload some of their workload and hence cost.

- d. Caregivers displays a patient’s caregiver information. Through this tab, patients can add/edit caregivers and their information. Again, here we can claim healthcare system’s lost opportunity when it comes to enter/update or reconcile patients’ caregiver information and save some money.
- e. Physicians tab shows a list of active physicians for a patient and their contact information.

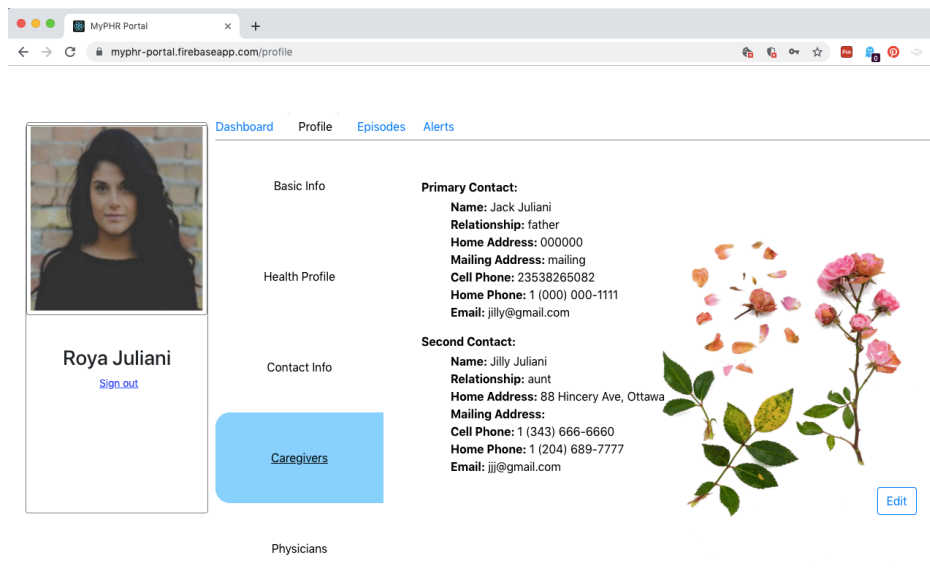


Figure 24 MyPHR Portal Prototype - Profile Page

- 4. Episodes: In this page we see every encounter between the patient and their healthcare providers, the date that encounter happened and a brief description or the name of the physician involved in that encounter in a chronological list. provides a screenshot of this page.

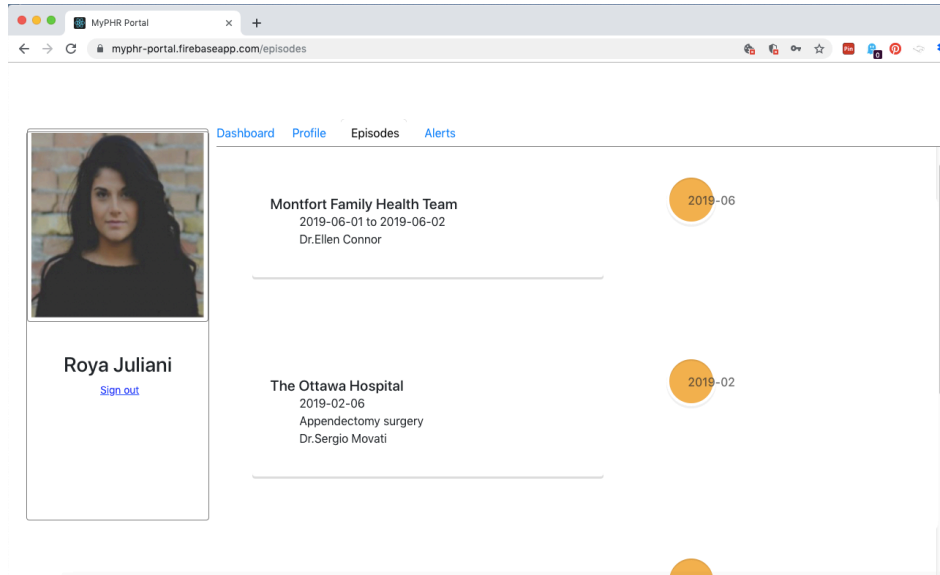


Figure 26 MyPHR Portal - Episodes Page

5. **Alerts:** This page allows patients to set up subscriptions for themselves to receive notifications to receive a summary when an event of interest happens. They can select the channel of message delivery e.g. mail, email, text message. In Figure 25 MyPHR Portal Prototype - Alerts Page we can see a screenshot of this page.

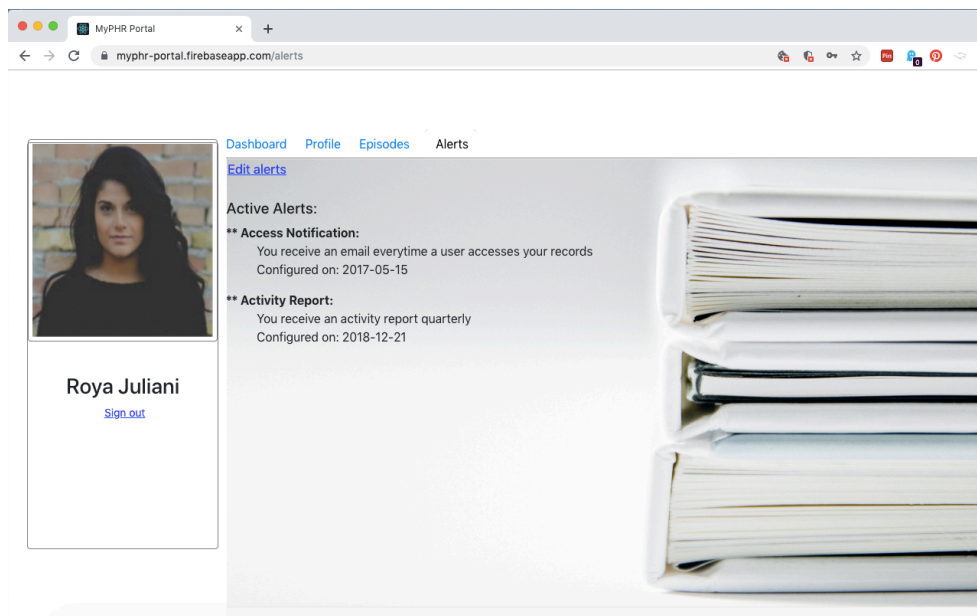


Figure 25 MyPHR Portal Prototype - Alerts Page

Web and Business Tier

Web tier and the business tier together correspond to controller layer of MVC pattern. Based on our proposed MyPHR conceptual architecture, web tier should contain API servers, load balancers, message queues, etc. In our prototypes, we outsource all hosting and server operations to Google Cloud.

Business tier houses our event-handlers and data encapsulation logic. Therefore, our source code in Python and Flask (API source code) and Javascript (developed by the 3rd party developer) translate the business logic into applications. We use the objects that have been created by running our .swagger object model definition language.

Our API prototype spans in both web and business tiers. The API is built upon four components. First is api.py class that receives the API calls and returns the responses to the callers. The api.py calls in methods from controller.py class. In controller.py we translate what is received from the caller into model objects or get data objects from firebase.py and translate them into our model objects. Finally, firebase.py is the Data Access Layer (DAL) that talks to the storage system Google Firebase. Figure 27 summarizes different components of our API prototype.

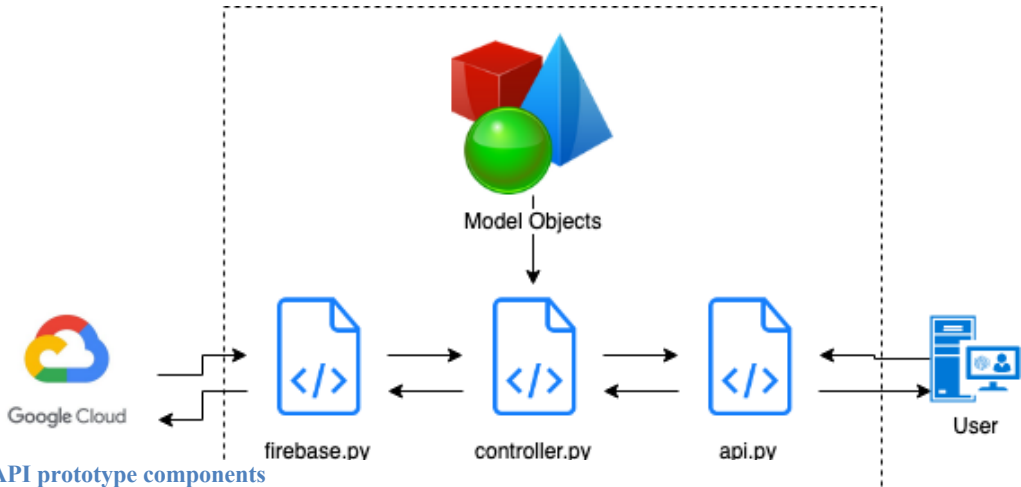


Figure 27 API prototype components

MyPHR API

The API prototype is a web-based application that is written in Python language using Flask library. It includes paths that redirect requests to the correct controllers and dictates a unified data format according to the proposed MyPHR ontology. The full source code of our API is available on GitHub: https://github.com/manaazarm/MyPHR_API

We implemented fourteen paths for our prototype API, of which 8 are implemented by GET methods and 6 by POST methods. The GET methods are designed to pull records from the cloud storage, whereas the POST methods are to add/update records to the cloud storage environment. Below, we explain each end point path, their arguments, response object, and an example of the response object.

Endpoints: GET method

- 1. /login** : Authenticates user based on the provided username and password against what is stored in Firebase in web_user collection.
Arguments: username, password
Response object:
json including: client id, security token, user_id, and user type
Example:

```
{
  "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
  "token": "5c7839bd7f592bf6533f9bd4be3c8cc63d088f4e59a27c65d74284668c6ecc49",
  "user_id": "4cb26605-7a80-4d86-9505-6b8492dab2ce",
  "user_type": "patient"
}
```
- 2. /basic_info**: Provides the basic info that is to be shown in “Profile” page, “Basic Info” tab of the MyPHR portal
Arguments: client_id, user_id, token
Response object: json including: client id, date of birth, first name, surname, gender, health card number, service language, start date of the profile
Example:

```
{
  "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
  "dob": "2000-01-01",
  "firstname": "Roya",

```

```

"gender": "female",
"hcn": "H7777666699",
"last_access_date": "Sat, 01 Jun 2019 04:00:00 GMT",
"service_language": "French",
"start_date": "2001-01-01",
"surname": "Juliani"
}

```

3. **/health_profile**: Provides a summary of the patient’s health that is to be shown on “Profile” page “Health Profile” tab. Please note that this end point only returns the active health profiles i.e. documents without an “end_date”.

Arguments: client_id, token

Response object: json

In response object, please find the “type” key that corresponds to different paragraphs of the “Health Profile” tab e.g. Health Risks, Advance Directives, Dietary Regimen, etc.

Example:

```

{
"client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
"code": "",
"diagnosing_healthcare_provider_id": "",
"health_profile_id": "3b522eaf-9c95-4902-b721-0370ac268531",
"is_activity_impediment": false,
"is_allergy": false,
"is_health_condition": false,
"is_risk_and_safety_issue": true,
"name": "smoker",
"start_date": "Tue, 09 Oct 2018 04:00:00 GMT"
}

```

4. **/contact_info**: Provides all contact information including address(es), phone number(s), and email(s) of a patient to be shown on “Profile” page, “Contact Info” tab.

Arguments: client_id, is_active, token

Response object:

json including addresses, phone numbers, and emails

Example:

```

[
  [
    "addresses",
    [
      {
        "category": "address",
        "city": "Ottawa",
        "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
        "contact_id": "752fb801-6c18-4a90-ad85-68892015dbd4",
        "country": "Canada",
        "healthcare_provider_id": ""
      }
    ]
  ]
]

```

```

        "is_active": true,
        "postal_code": "K3R 1Y8",
        "start_date": "Fri, 01 Mar 2019 05:00:00 GMT",
        "street_name": "Laurier",
        "street_number": "25",
        "street_type": "avenue",
        "type": "home",
        "unit_number": "100"
    }
  ],
  [
    "phone_numbers",
    [
      {
        "category": "phone",
        "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
        "contact_id": "1129d4f4-358d-4706-ac35-3eed0a7a3200",
        "country_code": "1",
        "healthcare_provider_id": "",
        "is_active": true,
        "number": "6134567891",
        "start_date": "Thu, 04 Apr 2019 04:00:00 GMT",
        "type": "cell"
      }
    ]
  ],
  [
    "emails",
    [
      "rji_7676@gmail.com"
    ]
  ]
]

```

5. **/caregiver**: Shows the authorized caregiver information to be put in “Profile” page “Caregiver” tab.

Arguments: client_id, token, is_active

Response object: json

Example:

```

{
  "caregiver_of_client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
  "client_id": "0055756b-5e92-420a-ba60-c16479b9bedc",
  "dob": "Tue, 02 Jun 1964 04:00:00 GMT",
  "firstname": "Jill",
  "gender": "Male",

```

```

    "is_active": true,
    "is_primary_caregiver": true,
    "relationship": "father",
    "service_language": "English",
    "start_date": "Wed, 07 Jun 2017 04:00:00 GMT",
    "surname": "Juliani"
  }

```

6. **/physician:** Shows the physicians who are actively providing care to the patient.

Arguments: `client_id`, `token`

Response object: `json`

Example:

```

{
  "Healthcare_provider_name": "Montfort Family Health Team",
  "Physician name": "Ellen Connor",
  "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
  "episode_id": "23230b0b-3c94-41f9-ac76-a5e5506b6f90",
  "episode_type": "Physician",
  "healthcare_provider_id": "9be40c5a-6df8-4bd1-a306-eb0bf28a7868",
  "is_active": true,
  "physician_id": "7d96a22c-c0e5-4aeb-b208-d26f73028b15",
  "start_date": "Sun, 01 Oct 2017 04:00:00 GMT"
}

```

7. **/episodes:** Shows all healthcare history of the patient to be shown on “Episodes” page

Arguments: `client_id`, `token`

Response object: `json`

Example:

```

{
  "Healthcare_provider_name": "Dynacare",
  "Physician name": "Ellen Connor",
  "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
  "end_date": "Wed, 02 May 2018 04:00:00 GMT",
  "episode_id": "2ff41f15-7249-4752-9cf7-cfa929b9a295",
  "episode_type": "Lab",
  "healthcare_provider_id": "73325fcd-0213-4cff-a515-2f24330c05a7",
  "is_active": false,
  "physician_id": "7d96a22c-c0e5-4aeb-b208-d26f73028b15",
  "start_date": "Wed, 02 May 2018 04:00:00 GMT"
},
{
  "Healthcare_provider_name": "Montfort Family Health Team",
  "Physician name": "Ellen Connor",
  "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
  "episode_id": "23230b0b-3c94-41f9-ac76-a5e5506b6f90",
  "episode_type": "Physician",

```

```

    "healthcare_provider_id": "9be40c5a-6df8-4bd1-a306-eb0bf28a7868",
    "is_active": true,
    "physician_id": "7d96a22c-c0e5-4aeb-b208-d26f73028b15",
    "start_date": "Sun, 01 Oct 2017 04:00:00 GMT"
  },
  {
    "Healthcare_provider_name": "Montfort Family Health Team",
    "Physician name": "Ellen Connor",
    "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
    "end_date": "Fri, 31 May 2019 04:00:00 GMT",
    "episode_id": "99465268-49b5-4367-8d34-23032209002b",
    "episode_type": "Family physician visit",
    "healthcare_provider_id": "9be40c5a-6df8-4bd1-a306-eb0bf28a7868",
    "is_active": false,
    "physician_id": "7d96a22c-c0e5-4aeb-b208-d26f73028b15",
    "start_date": "Sat, 01 Jun 2019 04:00:00 GMT"
  },
  {
    "Healthcare_provider_name": "The Ottawa Hospital",
    "Physician name": "Sergio Movati",
    "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
    "end_date": "Fri, 15 Feb 2019 05:00:00 GMT",
    "episode_id": "8e1ddfea-d522-4d65-9d85-e20a664b5549",
    "episode_type": "hospital",
    "healthcare_provider_id": "c007033a-d6c8-468c-af4b-f559ae637286",
    "is_active": true,
    "physician_id": "be88d99c-e1cb-4684-93e0-72cf81676cf9",
    "reason": "Appendectomy surgery",
    "start_date": "Wed, 06 Feb 2019 05:00:00 GMT"
  }
}

```

8. **/episodes_by_range**: Shows all healthcare history of the patient in a specified date range, to be shown on “Episodes” page

Arguments: `client_id`, `token`, `start_date`, `end_date`

Response object: `json`

Example:

```

{
  "Healthcare_provider_name": "Montfort Family Health Team",
  "Physician name": "Ellen Connor",
  "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
  "episode_id": "23230b0b-3c94-41f9-ac76-a5e5506b6f90",
  "episode_type": "Physician",
  "healthcare_provider_id": "9be40c5a-6df8-4bd1-a306-eb0bf28a7868",
  "is_active": true,
  "physician_id": "7d96a22c-c0e5-4aeb-b208-d26f73028b15",
  "start_date": "Sun, 01 Oct 2017 04:00:00 GMT"
}

```

```

    },
    {
      "Healthcare_provider_name": "Dynacare",
      "Physician name": "Ellen Connor",
      "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
      "end_date": "Wed, 02 May 2018 04:00:00 GMT",
      "episode_id": "2ff41f15-7249-4752-9cf7-cfa929b9a295",
      "episode_type": "Lab",
      "healthcare_provider_id": "73325fcd-0213-4cff-a515-2f24330c05a7",
      "is_active": false,
      "physician_id": "7d96a22c-c0e5-4aeb-b208-d26f73028b15",
      "start_date": "Wed, 02 May 2018 04:00:00 GMT"
    },
    {
      "Healthcare_provider_name": "The Ottawa Hospital",
      "Physician name": "Sergio Movati",
      "client_id": "df39a2a1-c8d1-484e-a5f4-ec6bfd08e345",
      "end_date": "Fri, 15 Feb 2019 05:00:00 GMT",
      "episode_id": "8e1ddfea-d522-4d65-9d85-e20a664b5549",
      "episode_type": "hospital",
      "healthcare_provider_id": "c007033a-d6c8-468c-af4b-f559ae637286",
      "is_active": true,
      "physician_id": "be88d99c-e1cb-4684-93e0-72cf81676cf9",
      "reason": "Appendectomy surgery",
      "start_date": "Wed, 06 Feb 2019 05:00:00 GMT"
    }
  }

```

Endpoints: POST methods

1. **/client/<client_id>/service_language:** To update the patient's service language on the "Profile" page, "Basic Info" tab.
 Arguments: token, service_language
 Response object: Success message
 Example:
 Service language updated successfully :-D
2. **/client/<client_id>/add_diet:** To add a new dietary regimen to the "Profile" page, "Health Profile" tab.
 Arguments: token, diet
 Response object: Success message
 Example:
 Healthy dietary regimen is successfully added!
3. **/client/<client_id>/add_advance_directive:** To add a new advance directive to the "Profile" page, "Health Profile" tab.
 Arguments: token, advance_directive
 Response object: Success message

Example:
DNR advance directive is successfully added!

4. **/client/<client_id>/edit_contact_info:** To update or add a contact on “Profile” page, “Contact Info” tab.

Arguments: token, category, text,contact_type

Category can be any of these values: email, address, phone

Contact type:

- If category = email then contact_type can be “main” or “other”
- If category = address then contact_type can be “home” or “mailing” or “other”
- If category = phone then contact_type can be “home” or “cell”

Response object: Success message

Example:
contact successfully updated!

5. **/client/<client_id>/edit_caregivers:** To update the patient’s service language on the “Profile” page, “Caregivers” tab.

Arguments: token, name, relationship, is_primary

Note: This endpoint requires that both name and relationship parameters be passed in even if one of them is not edited.

Response object: Success message

Example:
Caregiver updated successfully!

6. **/client/<client_id>/edit_caregiver_contacts:** To update or add a contact on “Profile” page, “Caregivers” tab.

Arguments: token, category, text,contact_type, is_primary

Category can be any of these values: email, address, phone

Contact type:

- If category = email then contact_type can be “main” or “other”
- If category = address then contact_type can be “home” or “mailing” or “other”
- If category = phone then contact_type can be “home” or “cell”

Response object: Success message

Example:
contact successfully updated!

Data Tier

Data tier houses the domain model of MyPHR applications and the Google cloud storage a.k.a. Firebase. In an Object-Oriented (OO) world, this layer translates to an object model. We used OpenAPI (OAI, 2019) that is an initiative that provides open and standardized structures for

REST API development. We were able to script the model in Swagger language. Needless to say, this model is a reflection of MyPHR ontology described in section 4.2.

The advantages to using OpenAPI for us was

1. Semi-automated generation of standardized software documentation (OAI, 2018).
Using OpenAPI, we generated documentation for the API as we were writing the Swagger script.
2. Scalability and maintenance tasks can be performed very quickly through a few commands. Data models tend to evolve and/or expire. We needed a structure that is easy and fast when it comes to updates.

Our API model includes two type of components: objects and paths. Objects are the entities that our controller layer will use to encapsulate and store records. Paths are the entities that API uses to route and receive requests. Below, we present a code snippet for each type. The full swagger file is available in Appendix III.

Object Example:

```
Client:
  description: >
    This is the base type with common properties
    between patients and caregivers
  type: object
  properties:
    client_id:
      type: string
    firstname:
      type: string
    surname:
      type: string
    gender:
      type: string
    dob:
      type: string
      format: date
```

```

        service_language:
            type: string
        start_date:
            description: a new client profile may start when they change
names or gender
            type: string
            format: date
        end_date:
            description: a client profile may end when they change names or
gender
            type: string
            format: date

```

Path example:

```

/healthprofiles/{client_id}:
  get:
    summary: gets the health profiles for a client
    operationId: gethealthprofilesforaclient
    parameters:
      - in: path
        name: client_id
        schema:
          type: string
          required: true
    responses:
      '200':
        description: getting the listed Health Profiles for a patient
        content:
          application/json:
            schema:
              type: array
              items:
                $ref: "#/components/schemas/HealthProfile"

```

The object model helps with encapsulation of the shared records into a consistent structure that is going to be stored in a cloud hosted records storage environment. As mentioned before, we chose Google Firebase as the cloud storage environment for our prototype.

5.3.5 Results

This prototype focused on two main goals. First, to validate if third party application developers can connect to this framework and build useful software products or features specifically for patients. This goal was put to test when our portal prototype was developed by our

collaborating master's student. In the end, we were able to use API services in order to share records in the desired format and receive the desired records from the cloud storage environment in real-time.

However, fulfilling our first goal was not an easy and straight forward process and we faced several challenges. We had to loop back to previous stages of our DSR methodology due to the challenges we faced. The first challenge was proper documentation. We had to make sure we had proper documentation in place for the third-party developers. The OpenAPI framework was key in being able to automatically create a lot of our API documentations.

Another challenge we faced was when our third-party developer identified inconsistencies between our proposed ontology and the FHIR published resources. These made us go back to our ontology and update. The inconsistencies were mainly when our ontology and FHIR proposed the same entity concepts but were expressing them differently. Therefore, as DSR methodology puts it, we had to loop from evaluation step back to the design step in order to update our proposed ontology. We aligned our proposed entities and used FHIR attributes when they had the exam same purpose. The ontology we proposed in this thesis reflects the changes.

Our third-party developer was able to use the our eventually well-defined and FHIR compliant API. However, there is still some work to keep our proposed framework compliant as FHIR expands and is updated. Nevertheless, there is also some work in the future on how to integrate an HCO EHRs in practice.

As for our second goal, we aimed at showcasing the tools that can empower patients in taking an active role in their healthcare delivery. Through the prototype web-portal, we presented

how a patient can view every piece of shared information, and also benefit the healthcare system in general by supplying some of their basic information as well as those of their caregivers. Furthermore, this prototype showed how patients can send their share of information in the format that is expected by the record sharing platform.

We faced challenges in regards with usability. We went through multiple rounds of updates with the third party developer in order to streamline the usability and align it with what was laid out in the case study of section 5.2. The result was that the 3rd party developer could build a patient portal. But the actual design of the user experience is another research area on its own. Our third-party developer worked off of PowerPoint mock-ups for understanding the look and feel that we had envisioned.

In this chapter, we evaluate our proposed framework. First, we provide the evaluation and feedback received from a panel of experts who reviewed our proposed framework and the MyPHR Prototype in a structured meeting we organized. Then, we compare our proposed framework with the related work identified in section 2.6 based on our evaluation criteria identified in Section 3.3. Finally, we analyze and discuss assumptions, limitations and potential threats to validity of our research.

6.1. Panel of Experts Review

6.1.1 Overview

We gathered 5 experts introduced in section 6.1.2, in order to have them review our proposed framework and provide feedback. This panel of experts included a general practitioner, a nurse practitioner, two healthcare technology directors, and a healthcare management scholar and thought leader. For the experts to have a thorough understanding of our proposed framework, we walked them through both the three components of our framework (governance principles, ontology and conceptual architecture) as well as a demonstration and review of the implementation of the MyPHR prototype from section 5.3.

6.1.2 Panel of Experts

In order to evaluate our proposed framework and prototype by a small group of clinical-domain experts during scheduled meetings (Agarwal, et al., 2016) (Wright, Aaron, & Sittig, 2017), we contacted and gathered the following individuals:

1. **Chantal Backman:** Assistant Professor at the School of Nursing in Faculty of Health Sciences at the University of Ottawa. Her research is mainly focused on improving the quality, safety and experience of older adults as they navigate the healthcare system. To that effect, she is interested in technologies used for coordinating care among various healthcare providers in a patient's circle of care. Therefore, she has led multiple projects in affiliation with The Ottawa Hospital and Bruyère Hospital that employ information technology in facilitating patient care and navigation through healthcare provider hand-offs.
2. **Jamie Stevens:** Director of Business Intelligence and Performance at Champlain Local Health Integration Network. Jamie is an expert in using data to transform health care business. He has an educational background in commerce and Master of Health Administration. He has 15 years of experience in leading data teams in community care and health integration networks in Ontario.
3. **Paul Boissonneault:** Director, Information Management and Digital Health at Champlain Local Health Integration Network (LHIN). Paul is an expert in information and communications technology and clinical information systems with a demonstrated record of accomplishment and innovation. He is a telecommunication and information systems engineer by profession. Over the last 25 years, as executive leader of information technology departments, he has championed many health electronic infrastructure and information systems deployment projects. He has also led the technology innovation department where they explore various electronic solutions with respect to patient records and care coordination.

4. **Cheryl Netterfield:** Dr. Cheryl Netterfield is a medical doctor with a Residency focused in Family Medicine Residency Program from University of Calgary. She is a physician entrepreneur, Founder and CEO of a health records sharing application called POMMe-Health. She has nearly 30 years of experience in healthcare industry with a demonstrated history of working in the hospital. Furthermore, she has been recognized for her skills in Government, Operational Planning, Team Building, Public Speaking, and Occupational Health.
5. **Craig Kuziemyky:** MacEwan University's Associate Vice-President, Research. His research is focused on developing novel methodological approaches for integrating the diverse information flows and work processes of collaborative healthcare teams. This research will design Internet and Communication Technologies to integrate the different healthcare providers who make complex decisions based on different levels of knowledge while they work at different locations.

6.1.3 Review Session

In order to provide context for the demo, we first gave an overview of our proposed framework and its three major components: ontology, governance and conceptual architecture. Then, we presented our prototypes i.e. the API and a patient portal. 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.

6.1.4 Criterion Ratings and Rubric

Our evaluation rubric listed our evaluation criteria that we laid out in section 3.3. We asked each expert to rate our presented prototype against our evaluation criteria through a 5-level scale with the following values: Not Satisfactory, Below Average, Average, Above Average, Satisfactory. To make the grading task more streamlined, we added a numerical scale (1-10) to our 5-level scale. 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. An example of our evaluation rubric is demonstrated in Table 10.

Table 10 Evaluation Rubric

Your name:			NS ¹		< AVG		AVG		> AVG		S ²	
Domain	Criteria	Main question	1	2	3	4	5	6	7	8	9	10
System-Level Interoperability	Data interoperability	Is sharing of data available across various platforms?										
	Process interoperability	Are we able to align and map processes across the boundaries of organizations?										
	Context interoperability	Is a system capable of operate smoothly across different political/legislative contexts?										
System-Level Quality of Care	Evidence-based	How easy it is to share medical evidence or other processes across different platforms?										
	Right level of details	Does this framework support healthcare workers by providing just the right level of details?										
	Patient-centric	Does it support patient-centric care delivery?										
	Timely	Do users have the means to autonomously access the information in a timely manner?										
	Cost	Are the costs of acquiring the system less than the alternative ways of solving the same problems										
	Health	Does the system under investigation help improve the health of the population? How?										
System-Level Privacy and Confidentiality	Privacy	Does the system provides services in a manner that the sensitive information is kept private and only among the custodians and owners of the data?										
	Regulations compliance	Is the system under review compliant with healthcare regulations in Canada?										

6.1.5 Analysis of Feedback

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.

We classified the comments into 5 themes. In the review session, we presented four aspects to experts: Framework (Governance, Ontology, Architecture), Prototype Usability (user interface demonstration), Demo Data (to illustrate what data would be shared), and Criteria (for structuring feedback from them). Naturally, we wanted to identify and isolate the comments related to each of these aspects. Furthermore, we noticed that some expert feedbacks bore some degree of misunderstanding or communication problems. Therefore, we added a fifth category that encompassed the comments entailing a misunderstanding of a notion.

Table 11 Summary of comment categories

Category	Comment number
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, the experts rated the framework or

prototype 67% of the times “above average”, 19% of the times “average”, and 14% of the times “below average” in terms of addressing patient-centered system-level sharing of health records.

When a criterion was scored with a score variability (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 assumed that the experts had 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 12, experts had consensus on 5 criteria and had divergent opinions on the other six. Based on score averages, the experts scored MyPHR (our prototype) average or above average on all criteria. We colour-coded the Overall Opinions. The color green denotes a positive consensus of the experts on a topic, while red indicates that all experts unanimously found the framework weak on that topic. Yellow shows that the experts had divergent opinions and did not agree.

There was consensus that MyPHR was very strong (> 7.9) on I1-Data Interoperability, Q3-Patient Centric, Q4-Timely, and P2-Regulations compliance, whereas it was merely average (5.0) on I3-context interoperability which was its weakest average score. Although it scored above average on I2-Process Interoperability, P1-Privacy, Q1-Evidence-based, Q2-Right level of details, Q5-Cost and Q6-Health, there was no consensus as some rated it below average and others above average. Arguably, Data Interoperability, Patient-Centric, Timely, and Regulations-Compliant were the easiest to assess objectively, whereas the other criteria are more subjective and open to opinion as to how they should be managed for effective healthcare.

Table 12 Expert scores analysis

Criteria	Criteria CODE	AVG Score	Min Score	Max Score	Overall Opinion
Data interoperability	I1	7.9	6	9.5	consensus
Process interoperability	I2	6.5	4	8	divergent
Context interoperability	I3	5.0	4	6	consensus
Privacy	P1	5.9	4	9.5	divergent
Regulations compliance	P2	8.9	8	9.5	consensus
Evidence-based	Q1	6.0	4	8	divergent
Right level of details	Q2	6.6	4	8	divergent
Patient-centric	Q3	8.7	8	9.5	consensus
Timely	Q4	8.6	7	9.5	consensus
Cost	Q5	6.6	5	9.5	divergent
Health	Q6	6.6	2	8	divergent

Although all our evaluation criteria touched important aspects of the interoperable, patient-centric and successful healthcare platforms, we did not put our focus equally on them. We decided to concentrate more on developing a patient-centric framework that allows all healthcare stakeholders to communicate their records in a timely and more cost-efficient manner. Therefore, not all our proposed evaluation criteria have the same weight for us. We created a three-scale numeric weighting system (1,3,5) based on how influential they were in our research. This weighing system is summarized in Table 13.

Table 13 Weights for Evaluation Criteria

Criteria	Criteria CODE	Weight
Data interoperability	I1	5
Process interoperability	I2	3
Context interoperability	I3	1
Privacy	P1	1
Regulations compliance	P2	5
Evidence-based	Q1	1
Right level of details	Q2	1
Patient-centric	Q3	5
Timely	Q4	5
Cost	Q5	1
Health	Q6	1

Factoring in 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 room for improvement. The proposed framework is perceived to improve the current situation.

6.1.6 Additional Insights

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 records. For example: Diagnoses in reverse chronological, and with a short label/comment

5. Caregiver information was not clear on issues such as the power of attorney for personal care; hierarchy of substitute decision makers; primary care giver
6. The data points that should be editable by the Patients e.g. diet, advanced directives did not match what the physicians expect in the real world.
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 HCOs' visibility on patient records was discussed. Experts suggested to allow HCOs' access to patient records 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, will encounter few technical hurdles, and provide for a platform agnostic approach for sharing records 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 records 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 overall data profiles.

15. The adoption barriers identified by experts were: Financial barriers for HCOs to invest in building the interfaces and rules to submit records 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 records 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 patients 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 records 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 patient level records, 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.

6.2. Comparison to Related Work

In this section we evaluate how our proposed framework addresses each criterion introduced in section 3.3 in comparison to the related work identified in section 2.6. We are using the same evaluation criteria as the ones used in our panel of experts' session. Our analysis is based on what is published in relation to what was demonstrated (and evaluated by our panel of experts) in our MyPHR prototype.

In section 2.4 we categorized current industry practice into three categories of single-HCO, multi-HCO, and HCO-independent and mentioned an example of each category in our related work in section 2.6. We also added three systems of NexJ, ClinicalConnect, and Kjernejournal as they do not completely fit into the aforementioned three categories. These systems have a governance structure that is close to Multi-HCO systems. At the same time, they use technology platforms similar to HCO-independent systems.

6.2.1 Overview

In order to compare our prototype and our proposed framework against the related work from section 2.6, we provided a rubric that is based on the criteria from chapter 3. Table 14 Evaluation rubric, lists the criteria and specifies the precise conditions for each possible value (Acceptable, Partial, Not Available).

Table 14 Evaluation rubric

Domain	Criteria	Rubric	Acceptable (A)	Partial (P)	Not Acceptable (NA)
System-level Interoperability	Data interoperability	Is sharing of patient-specific records available across various platforms at a system-level?	Sharing PHI across a system-level circle of care	Sharing non PHI and/or aggregate records at a system-level	No sharing of data at a system-level; or data is siloes among different circles of care
	Process interoperability	Are we able to align and map processes across the system-level circles of care?	Processes can be automatically and intelligently translated and mapped at a system-level. We reach process interoperability if all healthcare providers share and use a common knowledge.	Allegiance with a group of other healthcare systems is formed and they can all map their processes to each other, or only certain aspects of healthcare can be mapped such as high-level episodes	Not capable of collaborating with other organizations to align their processes with those of other healthcare providers
	Context interoperability	Can we share PHI across a system-level circle of care across different political and legislative context? This is not possible when no process interoperability and no patient matching algorithm is present.	Can share PHI across a system-level circle of care across different political and legislative context. There is a patient-matching algorithm in place, and full process interoperability is available	Can share non-PHI but similar data formats & reports at an aggregate level across a system-level circle of care or multiple political/jurisdiction context. There maybe a patient matching algorithm in place but not at a system-level.	Not concerned with or capable of sharing data at any context outside the boundaries of one organization
System-level Quality of Care	Evidence-based	Is system-level sharing of diagnosis and healthcare evidence analysis available?	System-level analysis of diagnostic information and healthcare evidence is available	When diagnosis information is shared at a system-level or across multiple platforms, but the evidence (i.e. the analysis of all patients' diagnosis at an aggregate level and across all patients) is not available; or cross-organizational evidence is available but not at a system-level	Sharing of diagnosis, medical evidence, or health processes is not available across multiple platform
	Right level of details	Is sharing the right details available in order to know what the other HCOs at a system-level are doing?	The right details are shared at the right level i.e. the system-level in a way that contributes to the improving the experience of providing healthcare	Data is shared at a system level but either not enough or too much detail is shared; Or, the right details are shared at the wrong level i.e. not a system-level	Not the right details and no sharing at a system level; or a standard system-level ontology is not available
	Patient-centric	Are all data shared across the record sharing platform visible and accessible to patients autonomously & easily?	Any shared record across the platform under investigation is visible and accessible to patients in a autonomous manner.	Patients have autonomous access to some shared data	Patients cannot autonomously access any of their shared PHI
	Timely	Is system-level data shared and made available to others in a timely manner?	The platform makes system-level records available to everyone instantly	The platform makes system-level records available to everyone in less than a day	The platform does not share data at a system-level, data is siloed; or it takes longer than 1 day to make records available to everyone
	Cost	How much effort is required for an HCO to publish into the framework and integrate the framework into their system?	There are preexisting mechanisms that can be used to publish data into and integrate with	How to publish the records into and integrate with the record sharing platform is well-defined, but it requires some IT work	It is extremely challenging to integrate and share records with the record sharing platform under investigation at a system-level
	Health	Does the system under investigation help improve the system-level health of the population?	Directly	Indirectly; or not system-level	Not applicable or no support is provided
	System-level Privacy and Confidentiality	Privacy	Does the platform secure system-level sharing of health records in a manner that it ensures PHI is kept confidential and visible only to the system-level circle of care.	The platform allow for the system-level sharing of the health records among all HCOs and patients in a secure manner	Has no known security flaws, but does not secure records at a system-level
Regulations compliant		Is the platform compliant with healthcare regulations in the healthcare system it is being applied to?	When data interoperability is red or yellow i.e. no data is shared, or when the platform is compliant with healthcare regulations in the healthcare system it is being applied to	(Not Applicable)	The platform under investigation is not concerned with the regulatory body mandates

Table 15 Comparison based on the proposed evaluation criteria, shows each of our related works in a column with our framework (MyPHR prototype) in the last column. It lists each of the evaluation criteria from chapter 3 in the rows. Using these criteria, we evaluate our proposed framework as well as each of the systems from our related work in 2.6 according to the rubric in Table 14.

When the subject of a criteria is not available in a system, we gave them a “NA” value with a red color-coding. When a criterion is partially present in a system, we gave them a “P” (for Partial) and a yellow color-coding. Finally, when a criterion is convincingly available within a system, we assigned an “A” (for Available) and color-coded them in green.

MyPHR and Kjernejournal are most effective of all approaches at Data Interoperability, Right Level of Detail, Timely, Privacy and Regulations Compliant. MyPHR is most effective at Timely, since it is real-time anywhere access. But as an established system that requires no extra processing by HCOs, Kjernejournal is the most effective at Cost and Health. All systems struggle with Process Interoperability, Context Operability, and Evidence-based so in that regard MyPHR is current with the state of the art, but more research is needed.

Table 15 Comparison based on the proposed evaluation criteria

Domain	Criteria	CHRIS	Epic	HealthVault	ClinicalConnect	NexJ	Kjernejournal	MyPHR Prototype
System-level Interoperability	Data interoperability	NA	P	A	P	NA	A	A
	Process interoperability	NA	P	P	P	NA	P	P
	Context interoperability	NA	P (similar reports or data format, aggregate)	NA	P (patient matching at a non system-level)	NA	NA	NA
System-level Quality of Care	Evidence-based	NA	P	P	P	NA	P	P
	Right level of details	NA	NA	NA	P	NA	A	A (If we had implemented everything, it would've been green for MyPHR)
	Patient-centric	NA	NA	P	NA	P	A	A
	Timely	NA	NA	A	NA	NA	P	A
	Cost	NA	NA	P	P	P	A (existing mechanism)	P
	Health	P	P	P	P	P	A	P
System-level Privacy and Confidentiality	Privacy	P	P	NA	P	P	A	A (the platform assumes that the HA is taking the required measures to establish a secure platform)
	Regulations compliant	A	A	NA	A	A	A	A

6.2.2 System-Level Interoperability

As mentioned before, our proposed framework benchmarked some of the fundamental technical features of the HCO-independent records sharing platforms like HealthVault, such as the

use of APIs to share and disseminate records. However, what mainly differentiates our proposed framework from the MS HealthVault, is the system-level concept. Also, our ontology helps aligning different processes from different healthcare organizations. Finally, the governance principles and its recognized importance in our framework encourages adoption and participation; something that most HCO-independent systems suffered from. Norway’s Kjernejournal is strong in enabling the records sharing across various health systems and they are governed by their ministry of health which is equivalent to our proposed concept of governmental health authority. However, their ontology is not consistently followed. There is a lot of criticism toward the inconsistency of the information shared from one organization to another (Scandurraa, Jansson, Forsberg-Fransson, & Ålander, 2015). Table 16 summarizes our arguments for system-level interoperability criteria.

Table 16 HCO EMR systems vs. our proposed framework

HCO Category	Data Interoperability	Process Interoperability	Context Interoperability
CHRIS	No. No attempt has been taken towards records sharing.	No. Only within the HCO process interoperability is handled and does not include all actors.	No. There is a single context where the HCO operates.
Epic	Somewhat. is achieved among the participating HCOs only	Somewhat. among participating HCOs only.	Somewhat. having consistent context is a prerequisite to adoption of the system
HealthVault	Yes. Theoretically, all healthcare actors should be able to use these tools to share their records.	Somewhat. Mainly focuses on data interoperability and the technical enablers.	Somewhat. does little towards resolving contextual issues; similar data formats among users of various political contexts paves the path to additional efforts.
ClinicalConnect	Somewhat. ClinicalConnect is a tool for HCOs and does not authorize Patients’ access or input	Somewhat. It does not cover a system-level scope, but provides some matching of processes	Somewhat. Only within a small region (southern Ontario). It requires major development for it to scale to a system-level scope
Kjernejournal	Yes. All actors are able to send and receive data streams at a system-level	Somewhat. mainly for sharing records and does not focus on the workflows in a care collaboration	Somewhat. Governed by a health authority. It does not focus on inter-system collaborations
NexJ	No. keeps the records within care collaboration projects in silos	No. Cannot align processes across the system-level	No. Different care delivery collaborations are siloed from each other
Our Proposed Framework	Yes. All actors are able to send and receive records streams at a system-level	Somewhat. only focusing on processes that are related to the records within proposed ontology	Somewhat. can be implemented at a Canada-wide scale i.e. multiple political contexts (provinces)

CHRIS system makes no attempt towards records sharing outside its boundaries. Process interoperability is only handled within the HCO. Same goes for the context interoperability. There is a single context within which the HCO operates, and that is what concerns the CHRIS system.

The **Epic** system enables full data interoperability among all the participating HCOs. However, systems that have not signed up for an Epic system are excluded, and some of the participating HCOs' records are siloes if they belong to different contextual factors. Similarly, process interoperability could only be achieved among the participating HCOs. Interoperability is only enabled within a single context. Having consistent context is a prerequisite to adoption of the system. For example, Epic users in Sweden are not connected to Epic users in the USA. However, at an aggregate and non-patient-specific level, all the Epic participants could possibly benefit from familiar data formats and reports.

HealthVault theoretically enables all healthcare actors to use its tools to share their records. It focuses on the technical enablers of the record sharing. It does not include a healthcare-specific ontology or a governance structure that can facilitate process or context interoperability. However, if HCOs form allegiance, they could leverage HealthVault offerings to reach process interoperability.

ClinicalConnect is a tool for HCOs and does not authorize Patients' access or their input. We believe this tool excludes one of the most critical actors in a health care delivery process. It is a tool mainly for informing the healthcare professional and does not focus on the workflows in a care delivery collaboration process. ClinicalConnect is only operational within a small region (southern Ontario) and does not cover a full system-level domain. It requires major development for it to scale to a system-level.

Kjernejournal enables all actors to send and receive streams of records at a system-level. As for the process interoperability, it is a tool mainly for sharing records and does not focus on aligning the workflows in shared care delivery collaborations. Governed by a health authority, it does not focus on inter-system collaborations.

Although **NexJ** allows records sharing, it keeps the records within care collaboration projects within a siloed environment. Hence, a true record sharing across the system-level or even outside of that one specific circle of care is not established. It provides process interoperability for the particular care delivery process it is set up for. It is not designed to align processes across a system-level. Although it is governed by a commercial health authority, it is not used well within its system-level. Different care delivery collaborations are siloed from each other.

In a record sharing platform that is developed in accordance with our proposed framework (a compliant system), all actors are able to send and receive records at a system-level. Every interaction in such systems can be captured as an episode, which is the key to the process interoperability across the system-level. The minimum dataset that is our ontology is resulted from what is common practice among all HCOs. This means that a compliant system is only focusing on processes that require the minimum dataset records. Processes that involve records beyond the minimum dataset, are out of our focus. However, our proposed framework can be implemented across Canada and align processes that map to the data entities in our proposed ontology. If established by a federal health authority, there is the possibility of negotiating a federal system-level health ID that is mapped to provincial health IDs. Canada has various political contexts as healthcare is governed at a provincial jurisdiction level. Therefore, we assume that our framework

can partially establish context interoperability with the possibility of negotiating full context interoperability.

6.2.3 System-Level Quality of Care

Here we discuss how each of our systems under study are performing against each of the criteria in the quality of care category:

Evidence-based: In chapter 3 we explained that this criterion is about how a healthcare system can support sharing and dissemination of medical evidence across different healthcare systems. It is quite obvious that a system that does not support any records sharing outside its boundaries, such as CHRIS system, would not perform well on this criterion. The multi-HCO systems (e.g. Epic system) tend to do better here, as they normally support sharing of records and some evidence (such as past diagnosis) across the participating HCOs. However, like data interoperability, sharing of the evidence is limited among the participating HCOs.

HCO-independent systems such as HealthVault have the technical capacity to share medical evidence. However, they have not yet had much luck in user adoption. Systems like Kjernejournal are covering a small scope of information, and they do not tend to dive deep in evidence-based medicine apart from sharing the diagnosis per patient. A record sharing platform that follows our framework also does not fully support evidence-based medicine, as it is intended to enable the sharing of a minimum dataset (proposed ontology) which is not very comprehensive when it comes to sharing of clinical evidence. Our framework does however help sharing of the diagnosis information at a system-level.

Right level of details: this criterion refers to the quantity of the available records on a platform. Too little is not useful, and too much is overwhelming. Single-HCO systems naturally have a good balance in the amount of available records, because every piece of available information is relevant to their organization, and they do not receive anything beyond their organization. Multi-HCO systems are usually the organizations of the same type. For example, a handful of hospitals that all buy an Epic system. In this sense, any shared records from external sources is in the same field of work. However, when we talk about the right details, we are also looking at a delivering those details at a system-level. This is where Epic falls short.

HealthVault allows the flow of any information they can get. This tends to create a pool of diverse records with no standard ontology for all HCOs to follow. The variety of available information can in fact overwhelm the stakeholders. Kjernejournal (Larsen, Arnesen, & Svarlien, 2018) focuses on a small subset of information, and same goes with the proposed framework. These systems are designed to cover a wide range of shallow information. Wide in the sense that records from different health disciplines are gathered (e.g. dental and physiotherapy), and narrow in the sense that there is no depth to stored information. For example, no patient chart information is shared, but at a high level, the dates of admission and the general purpose of the admission is available.

Health records sharing systems such as ClinicalConnect system (explained in 2.6.1) focus on a subset of information too. The information is not as shallow as what we recommend, but it is not as wide neither. In this system, a good depth of information is shared in certain topics. Evidence sharing is particularly an area of interest in this system (HNHB LHIN, 2011).

Patient-Centric: A patient-centric platform involves and empowers the patient to participate in their care delivery and informs them of any the records that is shared about them. ClinicalConnect, Single-HCO, and multi-HCO systems are all designed for the healthcare providers. Therefore, they do not authorize patients on their platforms. HCO-independent systems, Journalen, and Kjernejournal all give the patients access to their platforms. A compliant record-sharing framework also enables the patients to use the records sharing platform. It distinguishes the patient as a key actor in the system that needs to be considered throughout the development of any records sharing platform. NexJ is not fully patient-centric as they only make some and not all shared records available to patients.

Timely: This criterion investigates if the system under review presents records in a timely manner. CHRIS and Epic systems are practically operational systems and the healthcare records are available to users almost as soon as they are generated. However, HealthVault, ClinicalConnect, and Kjernejournal have not yet been able to deliver the information in real time. Kjernejournal has made numerous updates to their system since inception and is expected to increase the speed of data availability through the roll out of APIs (Norwegian E-Health, 2019). Our framework provides guidelines and solutions that can support a platform with real-time information availability through the use of our proposed API and automated updates from various EMR systems into a compliant platform. If a compliant platform is not fully meeting this criterion, it will not be a question of technology readiness, but is a factor of the industry practice and procedures.

Cost: Here we are looking for new avenues of savings introduced by a healthcare information system. Does the new system automate, eliminate, defer certain procedures that can

save money without sacrificing the quality of care? The savings can come in the form of the required initial investment, and/or elimination of duplicate tasks at a system-level.

By allowing the sharing of already entered records, both multi-HCO (Epic) and HCO-independent (HealthVault) systems address the problem of the man-hours spent in entering duplicate information. They relieve the staff from entering certain information that can be found in other healthcare providers' systems. However, our framework takes this advantage one step further by broadening records sharing scope to a system-level space.

CHRIS and Epic systems spend considerable man-hours on medication reconciliation, and reconciliation of patient contact information or their caregivers. A compliant platform can shift some of this workload to the patients themselves. By allowing and empowering patients in a system that follows our proposed framework, the patients can take some of the data entry burden off of healthcare organizations shoulders. For example, patients can be tasked with keeping their contact information current; much like what we see in municipal practice of updating addresses on drivers' licences.

Furthermore, we can achieve savings by elimination of duplicate tests/procedures ordered. Single-HCO, multi-HCO systems can potentially miss such an opportunity, simply due to not being able to access information about the tests/procedures ordered by other counterparts in the industry. In a system-level health records sharing practice (such as MyPHR), all healthcare providers can have access to the patient history including past tests and procedures. Such system also facilitates quick access to the points of contacts with various healthcare providers in a patient's care history, saving the working hours spent on chasing the past healthcare teams.

Moreover, we need to look at the cost of acquiring the system in comparison with the status quo practice. For multi-HCO solutions such as Epic, the participants should basically scrap their existing information systems in favor of capitalizing on a new system that is also acquired by their industry counterparts. According to the US office of the national coordinator for health information technology, purchasing and installing an EHR system would cost on average between 30'000 USD to 58'000 USD for a 5-year period per physician (Fleming, Culler, McCorkle, Becker, & Ballard, 2011), depending on the Software as a Service (SaaS) or on-premise solution types (The Office of the National Coordinator for Health Information Technology (ONC), 2014):

Table 17 Estimated cost of an EHR system

	On-Premise			SaaS		
	Initial Investment	Annual Fee	5-Year TCO ¹	Initial Investment	Annual Fee	5-Year TCO ¹
Estimated AVG Cost (in Thousands USD)	33	4	48	26	8	58

In comparison, the cost of integrating an existing system with an API such as one based on FHIR (similar to our guidelines) is estimated to be lower than acquiring a whole new system (Tyndall & Tyndall, 2018). Our framework guides setting up a system where existing EHR systems can be integrated with a centralized record sharing platform.

Health: This criterion examines how a system contributes to improving the health of the population. Studies have shown that use of EHR and team-based care have a positive impact on disease prevention and population health improvement (Briss, 2015). Based on this fact, we analyze each of the systems under our investigation.

¹ Total Cost of Ownership (TCO)

Every EHR system has a degree of contribution in improving the health population. However, when a system also supports multi-HCO team-based care, they would have a greater impact. However, team collaboration in a single-HCO system does not go beyond the boundaries of a single HCO. While multi-HCO systems encourage team-based care to some extent, a fully compliant platform can facilitate team-based care at a system-level, hence achieving higher impacts on population health. HealthVault struggled with user adoption which lead to the same results as multi-HCO system i.e. not covering the entire healthcare system. Our governance principles and the role of health authority in enforcing the use of a single health records sharing platform, addresses the short comings of the HCO-independent systems.

6.2.4 System-Level Privacy and Confidentiality

Privacy

When we talk about privacy, we should consider a scope to which the health records are kept private. Based on our proposed framework, sharing of health records at a system-level circle of care (SLCoC) is the ideal scope. In other words, the health records should be able to flow freely but kept private within HCOs and their patient in a SLCoC.

The single-HCO systems are too cautious towards the use of cutting-edge technology for sharing healthcare records. In order to avoid any privacy breaches, most single-HCOs choose to limit records sharing attempts. When a collaboration between different HCOs is required, for example, to deliver a shared care or to perform an investigation, the records are shared through email, secure cloud-based file storage/sharing systems like SkyDrive, or a simple fax.

Multi-HCOs, ClinicalConnect, and NexJ are a step further than single-HCOs, in that they keep records flowing but private among a few HCOs. Commercial HCO-independent platforms

such as HealthVault have no mandate on keeping the records private at a SLCoC and their scope of privacy varies among the agreements that their subscribers form. In other words, if an HCO who is subscribed to HealthVault platform decides to share their records with a massage therapy clinic that is not recognized as a legal Health Information Custodian, HealthVault as the commercial health authority can allow this record sharing. Therefore, a non-HIC access to PHI can be granted. We consider this a privacy flaw.

Regulation Compliance

The regulation compliance criterion investigates the privacy assurance and the regulations compliance in accordance with the contextual regulations where the platform is being implemented. ClinicalConnect is the first stride towards multi-system information sharing and is delivering their platform in a very secure manner that is compliant with the healthcare regulations in Canada and Ontario. Systems such as Kjernejournal, Journalen, and the HCO-independent platforms do not offer a universal framework. Those systems cannot easily fit into Canada's healthcare governance structure, as an example. However, all but HealthVault are compliant with the regulatory context that they are siloed into. HealthVault on the other hand is a commercial HA that will enable the data sharing among its clients as long as they all agree with each other. This means that a non-HIC entity that can reach an agreement with some HCOs can gain access to the shared health records, albeit this access being non-compliant with the regulations.

6.3. Assumptions, Limitations, and Threats to Validity

6.3.1 Assumptions

In this thesis we assume that any Health Authority (HA) that adopts our framework has the financial and technical means to develop and support and safeguard an information architecture

for patient-centered system-level sharing of health records in compliance with appropriate standards, regulations and laws. We also assume that such an HA has the legal and moral authority to ensure adoption, registration and participation of all relevant HCOs and patients within the health system it controls based on our governance guidelines.

We also made the assumption that all healthcare providers are able to invest the resources that it takes for connecting their existing EHR systems to a cloud-based record sharing platform. Also, for the healthcare providers who outsource the development and maintenance of their EHR systems to the third party EHR developers, we assume that they are willing to integrate their software with a compliant system.

6.3.2 Limitations

This thesis represents early research on the viability of our approach and following design science research methodology we have simply prototyped in a lab setting how the framework can be followed under different scenarios. More case studies with different systems in different health jurisdictions are needed. These case studies should move to real trials outside the lab, that validate the degree to which our framework can help guide deployment of record-sharing to support SLCoCs.

More work is also needed to follow through on all the details needed for a fully functional deployed system. For example, our system articulated basic role-based access control at the level of episodes and other entities. However, in practice there may be a need to have more fine-grained attribute level control access control as identified during our panel of experts' review session. Similarly, more work is needed to ensure there is enough detail in the audit trail to support monitoring and reporting for privacy compliance. Our experts were interested in being able to

obscure certain patient attributes from certain healthcare providers or actors in a system-level circle of care, usually as per a patient's request. Our proposed ontology that was the basis for the data model in our API prototype, lacked the extra metadata layer that could make such functionality available.

6.3.3 Threats to validity

The major threat to validity is that because we adopted the DSR methodology, our framework is an early research. Therefore, we can only show that our framework is potentially viable. We have only tried our proposed framework in a few limited situations with the exception of the Path2home case study. Path2Home represented a real situation but, even that was an analysis of a trial application using our framework, not an actual system. The other case studies were based on personas and representative scenarios. While this is acceptable for an early DSR research, it is quite possible that serious flaws will appear in practice with our proposed framework. Therefore, more comprehensive and methodological case studies are needed including building and deploying a real system.

We have performed most of the work and analysis by ourselves. Therefore, it is not clear if others can duplicate the same results. We did, however take some steps to mitigate this threat. We had a third party developer use and work with our prototype API and received useful feedback on how to improve the API as a result. And, we did have a panel of experts, with extensive practical experience, review our framework in a systematic in order to assess the validity and viability of our approach.

Finally, any healthcare electronic system is developed to ultimately assist the delivery of the healthcare to the patient. Although we indicated that our proposed framework indirectly has

the potential to contribute to the improvement of the health of the population in section 6.2.3, we should admit that other approaches especially the ones we mentioned in our related work are already deployed and currently have positive impacts on the health of the population.

7.1. Conclusion

We started this research by identifying gaps in healthcare service delivery when it comes to service hand offs and continuity of care among various healthcare providers. Motivated by our previous relevant work experience in the Canadian healthcare industry, we conducted a systematic literature review in order to document the problems, to find where the gaps were, and to find relevant efforts taken by others to mitigate or eliminate the gaps.

We identified that these problems originated from a lack of a system-level record sharing platform, fragmented healthcare delivery, poor healthcare interoperability, and patient dissatisfaction linked to a missing patient-centered perspective in the design of health information systems.

We introduced a framework that guides the deployment of system-level health record sharing platforms that are accessible by patients autonomously. We introduced a framework with three main components: governance principles, ontology, and a conceptual architecture.

Our framework incorporates principles, technology design and best practices from around the world, especially the health record sharing systems identified in our related work. The most important concept that we introduced in our framework is the System-Level Circle of Care (SLCoC). Through our proposed framework, different healthcare providers from different HCOs working with different circle-of-care teams can share and update the information that is defined in our proposed ontology. This information is presented in a common language that is easy to comprehend by all parties. Our ontology is grounded in a popular standard HL7 FHIR. Our

proposed API ensures common semantic access point for record sharing. Furthermore, based on our governance model, the proposed system should be governed and audited by a health authority; be it a governmental health authority (such as the ministry of health in Ontario) or a commercial health authority (such as Kaiser Permanente in the US).

Most importantly we validated our framework through a representative set of user scenarios to ensure a patient-centric approach and the building of a prototype by a third-party developer. We evaluated our framework and prototypes through a panel of experts as well as a set of evaluation criteria that were drawn from a related and proven body of knowledge.

7.2. Future Work

7.2.1 Metadata Component

After our panel of experts review session and the feedbacks we received, we recognized the need to add a metadata component to our proposed ontology. This metadata component should address attribute-level privacy concerns; when we need to isolate a specific piece of information and treat it differently. For example, when a patient is requesting to keep their past mental diagnosis private to their psychotherapist but allowing the rest of their information to be shared with all healthcare providers in their system-level circle of care. A more in-depth development process for a metadata component is considered to be a future work for our research. An example of the metadata structure is as follows:

```
{  
  "entity": {  
    "name": "some name",  
    "description": "some description",
```

```
"attributes":[
  {
    "name":"some name",
    "data_type": "some data type",
    "private": false,
    "description":"some description"
  }
]
}
```

7.2.2 Security

In our proposed framework, we assumed that any handling of health records is done in a secure manner. However, apart from the client authentication, we did not discuss or provide recommendations on what security features there should be (for records storage, as an example) and how they should be implemented. While it is one of the most important aspects of a healthcare information system, we chose to focus on other aspects for this thesis. Information systems security is a domain that has been and continues to be researched and developed extensively. Therefore, future work should develop best practices and technologies relevant to security for our framework.

7.2.3 Cost analysis

In section 6.2.3 we provided a simplistic indication on how much setting up a health record sharing platform could cost. However, as a future work, a thorough study of the costing of our proposed framework and all its components should be performed.

7.2.4 Smart device integration

One of the suggestions that our experts (from the panel of experts review session) were interested in, was the integration of personal smart devices with the rest of professional health records. We presented some previous work in this regard in section 4.3.2 and we recommended the use of smart device data in our proposed framework. Another future work revolves around a solution for gathering, storing, and integrating such stream of data with our proposed framework.

7.2.5 System-level patient-matching algorithm

The presence of system-level patient matching across HCOs or even across separate health systems (from different countries) is critical to a complete approach to system-level health record sharing. As it stands right now, most EMR systems implement their own siloed system of patient identification. While there have been some small-scale cross-EMR patient matching attempts, there is no universal patient identification system or algorithm that can identify and track a patient across a healthcare system. Future work should address this.

REFERENCES

- IETF OAuth Working Group. (n.d.). *OAuth 2.0*. Retrieved from OAuth: <https://oauth.net/2/>
- Adam, T., & Savigny, D. d. (2012, October). Systems thinking for strengthening health systems in LMICs: need for a paradigm shift. *Health Policy and Planning, 27*(4), iv1-iv3.
- Agarwal, S., LeFevre, A. E., Lee, J., L'Engle, K., Mehl, G., Sinha, C., & Labrique, A. (2016). Guidelines for reporting of health interventions using mobile phones: mobile health (mHealth) evidence reporting and assessment (mERA) checklist. *the bmj, 352*-362.
- Alexandru, A., & Coardos, D. (2016). *Big Data in Healthcare and Medical Applications in Romania*. Bucharest: National Institute for Research and Development in Informatics (ICI Bucharest).
- Alur, D., Malks, D., & Crupi, J. (2003). *Core J2EE Patterns Best Practices and Design Strategies* (Second ed.). Prentice Hall.
- An architectural design for self-reporting e-health systems. (2019). *Software Engineering in Healthcare*. Montreal.
- Aniche, M., Bavota, G., Treude, C., Gerosa, M. A., & Deursen, A. v. (2018). Code smells for Model-View-Controller architectures. *Empirical Software Engineering, 2121*–2157.
- Antoniou, G., & Harmelen, F. v. (2008). *A Semantic Web Primer* (Vol. 2). Cambridge, Massachusetts, USA: Massachusetts Institute of Technology.
- Armstrong, S. (2017, May 2). Patient access to health records: striving for the Swedish ideal. *BMJ, 357*.
- Austin, L. M. (2006). Reviewing pipeda: Control, privacy and the limits of fair information practices. *Canadian Business Law Journal, 44*(1), 21-53.
- Azarm, M., & Peyton, L. (2018). An Ontology for a Patient-Centric Healthcare Interoperability Framework. *IEEE/ACM International Workshop on Software Engineering in Healthcare Systems (SEHS)*. Gothenburg, Sweden: IEEE Xplore.
- Azarm, M., Kuziemy, C., & Peyton, L. (2015). A Review of Cross Organizational Healthcare Data Sharing. *The 5th International Conference on Current and Future Trends of Information and Communication Technologies in Healthcare (ICTH-2015)*. 63, pp. 425-432. Berlin: Elsevier.
- Azarm, M., Peyton, L., Backman, C., & Kuziemy, C. (2017). Breaking the Healthcare Interoperability Barrier by Empowering and Engaging Actors in the Healthcare System. *Procedia Computer Science. 113*, pp. 326-333. Lund, Sweden: Elsevier.

- Backman, C., Harley, A., Peyton, L., Kuziemy, C., Jay Mercer, M. A., Schmidt, S., . . . Gravel, D. (2018). Development of a Path to Home Mobile App for the Geriatric Rehabilitation Program at Bruyère Continuing Care: Protocol for User-Centered Design and Feasibility Testing Studies. *JMIR Research Protocol*, 7(9).
- Beardwood, J., & Kerr, J. (2005). Coming soon to a health sector near you: an advance look at the new Ontario Personal Health Information Protection Act (PHIPA): part II. *Healthcare quarterly*, 8(1), pp. 76-83.
- Bender, D., & Sartipi, K. (2013). HL7 FHIR: An Agile and RESTful approach to healthcare information exchange. *Proceedings of the 26th IEEE International Symposium on Computer-Based Medical Systems*. Porto, Portugal: IEEE.
- Benson, T., & Grieve, G. (2016). *Principles of Health Interoperability SNOMED CT, HL7 and FHIR* (Third ed.). (T. Benson, Ed.) London, UK: Springer.
- Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The Triple Aim: Care, Health, And Cost. *Health Affairs*, 27(3).
- Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med*, 573-576.
- Briss, P. A. (2015, January 8). Exploring better links between clinics and communities to improve population health. *Preventing Chronic Disease*, 12(E03).
- Canada Health Infoway. (n.d.). *Interoperable EHRs*. Retrieved February 12, 2017, from Canada Health Infoway: <https://www.infoway-inforoute.ca/en/solutions/electronic-health-records/interoperable-ehr>
- Cantor, S., Kemp, J., Philpott, R., & Maler, E. (2005, March 15). *Assertions and Protocols for the OASIS Security Assertion Markup Language (SAML) V2.0*. Retrieved from OASIS-OPEN: <https://docs.oasis-open.org/security/saml/v2.0/saml-core-2.0-os.pdf>
- Cars, T., Wettermark, B., Malmstrom, R., Ekeving, G., Vikstrom, B., Bergman, U., . . . Gustafsson, L. (2013). Extraction of Electronic Health Record Data in a Hospital Setting: Comparison of Automatic and Semi-Automatic Methods Using Anti-TNF Therapy as Model. *Basic & Clinical Pharmacology & Toxicology*, 112, 329-400.
- Casellas, N. (2011). Methodologies, Tools and Languages for Ontology Design. In *Legal Ontology Engineering: Methodologies, Modelling Trends, and the Ontology of Professional Judicial Knowledge, Law, Governance and Technology* (pp. 57-107). Springer Science+Business Media.
- Cassel, D., Tsiolis, A., Peytchev, V., Escher, T., Thuesen, J., Hansen, J., & Michalski, C. (2009). *US Patent No. US20050071195A1*.
- Cavoukian, A. (2004). *A Guide to the Personal Health Information Protection Act*. Ontario Information and Privacy Commissioner . Toronto, Canada: IPC.

- Cavoukian, A., & Emam, K. E. (2011, June). *Dispelling the Myths Surrounding De-identification: Anonymization Remains a Strong Tool for Protecting Privacy*. Retrieved July 2019, from Future of Privacy Forum: <https://fpf.org/wp-content/uploads/2011/07/Dispelling%20the%20Myths%20Surrounding%20De-identification%20Anonymization%20Remains%20a%20Strong%20Tool%20for%20Protecting%20Privacy.pdf>
- Champion, C., Kuziemsy, C., Affleck, E., & Alvarez, G. G. (2019). A system approach for modeling health information complexity. *International Journal of Information Management*, 343-354.
- CIHI. (2011). *Learning From the Best: Benchmarking Canada's Health System*. Canadian Institute for Health Information.
- Collen, M. F., & Ball, M. J. (2015). *The History of Medical Informatics in the United States*. Baltimore, MD, USA: Springer-Verlag London.
- Costa, A. P., Poss, J. W., Peirce, T., & Hirdes, J. P. (2012). Acute care inpatients with long-term delayed-discharge: evidence from a Canadian health region. *BMC Health Services Research*.
- Cristani, M., & Cuel, R. (2005). A Survey on Ontology Creation Methodologies. *Int'l Journal on Semantic Web & Information Systems*, 1(2).
- D. Hardt, E. (2012). *The OAuth 2.0 Authorization Framework*. Internet Engineering Task Force (IETF).
- De Freitas Dias, T. F., Alves, D., & Felipe, J. C. (2014). Method for the Mapping between Health Terminologies aiming Systems Interoperability. *014 IEEE 16th International Conference on e-Health Networking, Applications and Services (Healthcom)* (pp. 353-357). IEEE.
- Dinov, I. D. (2016). Methodological challenges and analytic opportunities for modeling and interpreting Big Healthcare Data. *GigaScience*, 5(1).
- Dixon, B., Vreeman, D., & Grannis, S. (2014). The long road to semantic interoperability in support of public health: Experiences from two states. *Journal of biomedical informatics*, 49, 3-8.
- Do, N. V., Barnhill, R., Heermann-Do, K. A., Salzman, K. L., & Gimbel, R. W. (2011, March). The military health system's personal health record pilot with Microsoft HealthVault and Google Health. *ournal of the American Medical Informatics Association*, 18(2), 118-124.
- Donga, X., Samavia, R., & Topaloglou, T. (2015). COC: An Ontology for Capturing Semantics of Circle of Care. *Procedia Computer Science*. 63, pp. 589-594. Elsevier.
- El Emam, K. (2010). The inadvertent disclosure of personal health information through peer-to-peer file sharing programs. *ournal of the American Medical Informatics Association*, 17(2).

- El Emam, K., Jabouri, S., Sams, S., Drouet, Y., & Power, M. (2010, October). Evaluating common de-identification heuristics for personal health information. *Journal of medical internet research*, 8(4).
- El Emam, K., Jonker, E., Arbuckle, L., & Malin, B. (2011). "A Systematic Review of Re-Identification Attacks on Health Data (Re-Identification Attacks on Health Data)." 6, no. 12 (2011): 1-12. *PLoS ONE*, 6(12), 1-12.
- Faulkner, J. R., Dvorak, C. D., Weisberger, B. M., Campbell, J. L., Escher, T. W., Gage, D. L., . . . Sidney, M. D. (2009). *US Patent No. US20090216562A1*.
- FHIR Ontology Module*. (2020, July 9). Retrieved from HL7.org/fhir: <http://hl7.org/fhir/2016sep/ontology-module.html>
- Fleming, N. S., Culler, S. D., McCorkle, R., Becker, E. R., & Ballard, D. J. (2011). The Financial And Nonfinancial Costs Of Implementing Electronic Health Records In Primary Care Practices. *Health Information Technology*, 481-489.
- Friedman, A., Howard, J., Shaw, E. K., Cohen, D. J., Shahidi, L., & Ferrante, J. M. (2016, January). Facilitators and Barriers to Care Coordination in Patient-centered Medical Homes (PCMHs) from Coordinators' Perspectives. *JABFM*, 29(1), 90-101.
- Gay, V., & Leijdekkers, P. (2015, November). Bringing Health and Fitness Data Together for Connected Health Care: Mobile Apps as Enablers of Interoperability. *Journal of Medical Internet Research (JMIR)*, 17(11).
- Gaynor, M., Yu, F., Andrus, C. H., Bradner, S., & Rawn, J. (2014, March). A generalframeworkforinteroperabilitywith applicationstohealthcare. *Health PolicyandTechnology*, 3(1), 3-12.
- Gerring, J. (2006). *Case Study Research : Principles and Practices*. Cambridge University Press.
- Government of Ontario. (2020). *Personal Health Information Protection Act, Schedule A*. Ontario.ca.
- Grüninger, M., & Fox, M. S. (1995). Methodologies for the Design and Evaluation of Ontologies. *IJCAI-95*. Montreal.
- Gregor, S., Müller, O., & Seidel, S. (2013). Reflection, abstraction, and theorizing in design and development research. *Proceedings of European Conference on Information Systems*, (p. 74). Utrecht, The Netherlands: ECIS.
- Hägglund, M. (2017, 10 30). *How Sweden is giving all citizens access to their electronic health records*. Retrieved 10 2, 2018, from Future Health Index: <https://www.futurehealthindex.com/2017/10/30/access-electronic-health-records/>
- Hancock, D. R., & Algozzine, B. (2006). *Doing Case Study Research*. New York: Teachers College Press.

- Haux, R. (2006). Health information systems : past, present, future. *International journal of medical informatics* , 75(3), 268-281.
- Health Canada. (2007, December 07). *Canada's Health Infostructure*. Retrieved February 12, 2017, from Health Canada: <http://www.hc-sc.gc.ca/hcs-sss/ehealth-esante/infostructure/index-eng.php>
- Health Level 7 International. (2017). *HL7/ASTM Implementation Guide for CDA® R2 -Continuity of Care Document (CCD®) Release 1*. Retrieved 11 13, 2017, from HL7.org: http://www.hl7.org/implement/standards/product_brief.cfm?product_id=6
- Health Standards. (2020). *Health Standards Organization*. Retrieved September 25, 2013, from Hospice Palliative and End-of-Life Services: <https://healthstandards.org/standard/palliative/>
- Hevner, A. R., & Chatterjee, S. (2015). Design Science Research in Information Systems. *Association for Information Systems (AIS)*.
- HL7. (2019, July). *HL7 FHIR current build*. Retrieved from Health Level 7: <http://build.fhir.org/>
- HL7. (2020, May). *Resource Index*. Retrieved from HL7 FHIR: <https://www.hl7.org/fhir/resourcelist.html>
- HL7 Community. (n.d.). *FHIR Documentation*. Retrieved November 2017, from HL7.org: <http://www.hl7.org/implement/standards/fhir/documentation.html>
- HL7 International. (2007). *HL7 Implementation Guide: CDA Release 2 – Continuity of Care Document (CCD)*. Health Level Seven International.
- HNHB LHIN. (2011, May). *Integration in the HNHB LHIN*. Retrieved November 10, 2014, from Hamilton Niagara Haldimand Brant LHIN: <http://www.hnhblhin.on.ca/accountability/integration.aspx>
- International Health Level Seven. (2017). *Introduction to HL7 Standards*. Retrieved 11 13, 2017, from hl7.org: <http://www.hl7.org/implement/standards/index.cfm?ref=nav>
- Jha, A. K., DesRoches, C. M., Campbell, E. G., Donelan, K., Rao, S. R., Ferris, T. G., . . . Blumenthal, D. (2009). Use of Electronic Health Records in U.S. Hospitals. *The New England Journal of Medicine*, 1628-1638.
- Jothia, N., Rashidb, N. A., & Husain, W. (2015). Data Mining in Healthcare – A Review. *The Third Information Systems International Conference* (pp. 306-313). Procedia Computer Science.
- Khatri, V., & Brown, C. V. (2010, January). Designing Data Governance. *Communications of ACM*, 53(1), 148-152.

- Kierkegaard, P. (2015). Governance structures impact on eHealth. *Health Policy and Technology*, 4, 39-46.
- Kim, J., & Chung, K.-Y. (2014). Ontology-based healthcare context information model to implement ubiquitous environment. *Multimedia Tools and Applications*, 71(2), 873–888.
- Kish, L. J., & Topol, E. J. (2015, September). Unpatients—why patients should own their medical data. *Nature Biotechnology*, 33(9), 921-924.
- Knublauch, H., Fergerson, R. W., Noy, N. F., & Musen, M. A. (2004). The Protégé OWL plugin: An open development environment for semantic web applications. *n International Semantic Web Conference* (pp. 229-243). Berlin: Springer.
- Koppel, R., & Lehmann, C. U. (2014). Implications of an emerging EHR monoculture for hospitals and healthcare systems. *Journal of Informatics in Health and Biomedicine JAMIA*, 465–471.
- Kowalski, R. (2017). Patients’ written reviews as a resource for public healthcare management in England. *Procedia Computer Science*. 113, pp. 545-550. Lund: Elsevier.
- Krasner, G. E., & Pope, S. T. (1988). *A Description of the Model-View-Controller User Interface Paradigm in the Smalltalk-80 System*. Mountain View, CA: ParcPlace Systems.
- Kushniruk, A., Nohr, C., Jensen, S., & Borycki, E. M. (2013). From Usability Testing to Clinical Simulations: Bringing Context into the Design and Evaluation of Usable and Safe Health Information Technologies. *Yearbook of medical informatics*, 22(1), 78-85.
- Kuziemsky, C. (2013). Interoperability, A Multi-Tiered Perspective on Healthcare. In M. Ángel Sicilia, & P. Balazote, *Interoperability in Healthcare Information Systems Standards Management and Technology*. IGI Global.
- Kuziemsky, C., & Peyton, L. (2016). A framework for understanding process interoperability and health information technology. *Health Policy and Technology*, 196-203.
- Kuziemsky, C., Monkman, H., Peterson, C., Weber, J., Borycki, E. M., Adams, S., & Collins, S. (2014, August 15). Big Data in Healthcare – Defining the Digital Persona through User Contexts from the Micro to the Macro. *Yearbook of Medical Informatics*, 9(1), 82-89.
- Larsen, B. A., Arnesen, E. N., & Svarlien, A. B. (2018). *Critical health information (alert information) in the Summary Care Record*. Oslo, Norway: Norwegian Directorate of eHealth .
- Leff, A., & Rayfield, J. (2001). Web-application development using the Model/View/Controller design pattern. *Fifth IEEE International Enterprise Distributed Object Computing Conference*. Seattle, WA, USA: IEEE.
- Leiba, B. (2012, February). OAuth Web Authorization Protocol. *IEEE Internet Computing*, 16(1), 74 - 77.

- Lenat, D., & Guha, R. (1990). Cyc: A midterm report. *AI magazine*, 11(3), 32-59.
- LeRouge, C., Ma, J., Sneha, S., & Tolle, K. (2013). User profiles and personas in the design and development of consumer health technologies. *international journal of medical informatics*, 8(2), 251-268.
- Lethbridge, T. C., & Laganier, R. (2001). *Object-Oriented Software Engineering*. McGraw-Hill Education.
- Local Health Integration Network. (2011, August 9). *Online patient records enhancing care for 2 million Ontarians*. Retrieved November 10, 2014, from <http://www.hnhblhin.on.ca/goalsandachievements/value/ehealth/eHealthinHNHBLHIN/ClinicalConnect.aspx>
- Lopez, D. M., & Blobel, B. G. (2009). A development framework for semantically interoperable health information systems. *international journal of medical informatics*, 83-103.
- Luchenski, S., Reed, J., Marston, C., Papoutsis, C., Majeed, A., & Bell, D. (2013, August). Patient and Public Views on Electronic Health Records and Their Uses in the United Kingdom: Cross-Sectional Survey. *Journal of medical Internet research*, 15(8).
- Macedo, M., & Isaías, P. (2013). Standards Related to Interoperability in EHR & HS. In M. Á. Sicilia, & P. Balazote, *Interoperability in Healthcare Information Systems Standards Management and Technology* (pp. 19-44). IGI Global.
- Madore, O. (2005, May 17). *Parliament of Canada*. Retrieved February 11, 2017, from <http://www.lop.parl.gc.ca/content/lop/researchpublications/944-e.pdf>: <http://www.lop.parl.gc.ca/content/lop/researchpublications/944-e.pdf>
- Mandel, J. C., Kreda, D. A., Mandl, K. D., Kohane, I. S., & Ramoni, R. B. (2016). SMART on FHIR: a standards-based, interoperable apps platform for electronic health records. *Journal of the American Medical Informatics Association*, 23(5), 899-908.
- Mandel, K. D., Mandel, J. C., & Kohane, I. S. (2015, July). Driving Innovation in Health Systems through an Apps-Based Information Economy. *Cell Systems*, 1(1), 8-13.
- Marcotte, L., Kirtane, J., Lynn, J., & McKethan, A. (2014). Integrating Health Information Technology to Achieve Seamless Care Transitions. *Journal of Patient Safety*.
- Ministry of Health and Social Affairs. (2011). *National eHealth-the Strategy for Accessible and Secure Information in Health and Social Care*. Sweden: Edita.
- Newfoundland and Labrador Centre for Health Information. (2015). *Benefit Evaluation of the PEI Clinical Information System*. Newfoundland and Labrador Centre for Health Information.
- NexJ Connected Wellness Platform. (2020). *NexJ Health*. Retrieved Feb 2019, from <https://www.nexjhealth.com/>

- NexJ Health. (2020). *Privacy and Security*. Retrieved from NexJHealth: <https://www.nexjhealth.com/solutions/nexj-connected-wellness/privacy-security/>
- NexJHealth. (2020). Retrieved from <https://www.nexjhealth.com/>
- Norwegian E-Health. (2019). *The Norwegian Summary Care Record*. Retrieved from Direktoratet for e-helse: <https://ehelse.no/opplaering/kjernejournal/hva-er-kjernejournal#English%3A%20The%20Norwegian%20Summary%20Care%20Record>
- Noy, N. F., & McGuinness, D. L. (2001). *Ontology Development 101: A Guide to Creating Your First Ontology*. Stanford University, Knowledge Systems Laboratory Tech report KSL-01-05. Palo Alto: Stanford University.
- OAI. (2018, October). *OpenAPI-Specification*. Retrieved August 2019, from GitHub: <https://github.com/OAI/OpenAPI-Specification>
- OAI. (2019). *About*. Retrieved August 2019, from Open API Initiative: <https://www.openapis.org/about>
- Ontario Association of Community Care Access Centres. (2016). *Connecting Care: OACCAC's eHealth Assets*. Government of Ontario.
- Otto, B. (2011, August). Data Governance. *Business & Information Systems Engineering*, 3(4), 241–244.
- Oyeyemi, A., & Scott, P. (2018). Interoperability in health and social care: organisational issues are the biggest challenge. *Journal of Innovation in Health Informatics*, 25(3), 196-198.
- Payne, E. (2019, March 15). *Ontario begins dismantling local health integration system*. Retrieved from Ottawa Citizen: <https://ottawacitizen.com/news/politics/ontario-begins-dismantling-local-health-integration-system>
- Porter, K. (2017, April 25). *Ontario set to begin shifting home care responsibilities*. Retrieved from CBC News: <https://www.cbc.ca/news/canada/ottawa/ontario-home-care-ccac-lhin-1.4082732>
- Pruitt, J. S., & Adlin, T. (2006). *The Persona Lifecycle: Keeping People in Mind Throughout Product Design*. San Francisco, California, USA: Morgan Kaufmann Publishers .
- Quanjel, T., Spreeuwenberg, M. D., Struijs, J. N., & Baan, C. A. (2019, May). Substituting hospital-based outpatient cardiology care: The impact on quality, health and costs. *Plus One*, 14(5).
- Radwin, L. E., Castonguay, D., Keenan, C. B., & Hermann, C. (2016). An Expanded Theoretical Framework of Care Coordination Across Transitions in Care Settings. *Journal of Nursing Care Quality*, 31(3), 269–274.

- Sanchez-Caro, A., Soguero-Ruiz, C., Mora-Jimenez, I., Lechuga, L., Ramos-Lopez, J., Garcia-Alberola, A., . . . Rojo-Alvarez, J. L. (2014). Towards Semantic Interoperability for Cardiovascular Risk Stratification into the Electronic Health Records Using Archetypes and SNOMED-CT. *Computing in Cardiology*, 497-500.
- Scandurra, I., Jansson, A., Forsberg-Fransson, M.-L., & Ålander, T. (2015). Is ‘patient’s online access to health records’ a good reform? – Opinions from Swedish healthcare professionals differ. *Conference on ENTERprise Information Systems / International Conference on Project MANagement / Conference on Health and Social Care Information Systems and Technologies, CENTERIS / ProjMAN / HCist 2015* (pp. 964 – 968). Procedia Computer Science.
- Sikka, R., Morath, J. M., & Leape, L. (2015). The Quadruple Aim: care, health, cost, and meaning in work. *The BMJ*, 608-610.
- Singh, I., Brydon, S., Murray, G., Violleau, T., & Ramachandran, V. (2004). *Designing Web Services with the J2EE 1.4 Platform: JAX-RPC, XML Services, and Clients*. Pearson Education.
- Siriwardena, P., & Peacock, M. (2014). *Advanced API security securing APIs with OAuth 2.0, OpenID Connect, JWS, and JWE*. New York: friends of ED/Apress.
- Smith, B. &. (2010). Ontological realism: A methodology for coordinated evolution of scientific ontologies. *Applied Ontology*, 5(3-4), 139–188.
- Spil, T., & Klein, R. (2014). Personal Health Records Success; Why Google Health failed and what does that mean for Microsoft HealthVault? *47th International Conference on System Science*. Hawaii.
- Sterman, J. D. (2011, October). Learning from Evidence in a Complex World. *American Journal of Public Health*, online resource <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2005.066043>.
- Sunyaev, A., Kaletsch, A., & Krcmar, H. (2011). Comparative Evaluation of Google Health API vs. Microsoft Healthvault API. *Proceedings of the Third International Conference on Health Informatics (HealthInf 2010)* (pp. 195-201). Valencia, Spain: SSRN.
- Tapuria, A., Kalra, D., & Kobayashi, S. (2013). Contribution of Clinical Archetypes, and the Challenges, towards Achieving Semantic Interoperability for EHRs. *Health Informatics Research*, 19(4), 286-292.
- The Norwegian Directorate of eHealth. (2016, 09 28). *Kjernejournal for safer healthcare*. Retrieved 03 27, 2017, from [helsenorge.no: https://helsenorge.no/kjernejournal/kjernejournal-for-safer-healthcare#What-does-kjernejournal-contain?](https://helsenorge.no/kjernejournal/kjernejournal-for-safer-healthcare#What-does-kjernejournal-contain?)

- The Office of the National Coordinator for Health Information Technology (ONC). (2014). *How much is this going to cost me?* Retrieved 2019, from <https://www.healthit.gov/faq/how-much-going-cost-me>
- Tove Sorenson, M. A. (2016). Developing and implementing patients' full-scale electronic access to their health records. *European Federation for Medical Informatics*.
- Tu, K., Klein-Geltink, J., Mitiku, T., Mihai, C., & Martin, J. (2010). De-identification of primary care electronic medical records free-text data in Ontario, Canada. *BMC Medical Informatics and Decision Making*, 10(35).
- Tyndall, T., & Tyndall, A. (2018). HIR Healthcare Directories: Adopting Shared Interfaces to Achieve Interoperable Medical Device Data Integration. *PHealth 2018* (pp. 181-184). IOS Press.
- V.Eikey, E., Reddy, M. C., & Kuziemy, C. (2015, October). Examining the role of collaboration in studies of health information technologies in biomedical informatics: A systematic review of 25 years of research. *Journal of Biomedical Informatics*, 57, 263-277.
- Vaishnavi , V., & Kuechler , W. (2015). *Design science research methods and patterns : Innovating information and communication technology* (Second ed.).
- Vida, M., Lupse, O., Gomoi, V., Stoicu-Tivadar, L., Stoicu-Tivadar, V., & Bernad, E. (2014). Using web services to support the interoperability between healthcare information systems and CDS systems. *CEAI*, 16(1), 106-113.
- W.Kushniruka, A., M.Triolab, M., M.Boryckic, E., BenSteind, & L.Kannry, J. (2005). Technology induced error and usability: The relationship between usability problems and prescription errors when using a handheld application. *International Journal of Medical Informatics*, 74(8), 519-526.
- Weber-Jahnke, J. H., Price, M., & Williams, J. (2013). Software engineering in health care: Is it really different? And how to gain impact. *2013 5th International Workshop on Software Engineering in Health Care (SEHC)* (pp. 1-4). San Francisco, California : ACM Digital Library.
- Webster, P. (2017). Growing use of integrated e-health systems. *CMAJ*, 1075-1076.
- World Health Organization. (2019, 07 17). *Health Systems*. Retrieved from WHO: https://www.who.int/topics/health_systems/en/
- Wright, A., Aaron, S., & Sittig, D. F. (2017). Testing electronic health records in the “production” environment: an essential step in the journey to a safe and effective health care system. *Journal of the American Medical Informatics Association*, 24(1), 188-192.
- Yin, R. K. (2017). *Case Study Research and Applications: Design and Methods*. Los Angeles, USA: Sage.

Appendix I: Entities and Attributes in the Proposed Ontology

In this section we provide a detailed list of all the entities and attributes (including their data types). We briefly describe each entity and attribute and when applicable, list the possible values. The entities are listed in an alphabetical order, while the attributes follow a DBA's logical order i.e. starting with ID attributes, and end with date attributes when possible.

Address: for address entity, we recommend the following attributes and data types:

- **id** (GUID): Unique identifier of the record
- **use** (string (enum)): possible values: home | work | temp | old | billing - purpose of this address
- **type** (string (enum)): possible values: postal | physical | both
- **text** (string): Text representation of the address
- **line** (string): Street name, number, direction & P.O. Box etc.
- **city** (string): Name of city, town etc.
- **district** (string): District name or county
- **state** (string): Sub-unit of country
- **postal_code** (string): Postal code for area
- **country** (string)
- **start_date** (datetime): the date the address takes effect
- **end_date** (datetime): the date when the address is no longer valid

Audit_Event

- **id**: GUID

- **user_id**, GUID
- **hic_id**, GUID
- **type**: string (enum)
audit log used | patient record (created/read/updated/deleted) | user authentication has been attempted | data exported | data imported
- **subtype**: string (enum)
Application Start | Application Stop | Login | Logout | Audit Recording Stopped | Audit | Recording Started | Object Security Attributes Changed | Security Roles Changed | User security Attributes Changed
- **action**: string
create | read/view/print | update | delete | execute
- **outcome**: string
succeeded | failed
- **date**: datetime

Caregiver: inherits from Client entity. attributes other than those inherited from Client entity are listed below:

- **relationship**: string
the caregiver's relationship to the patient
- **primary**: Boolean
identifies the primary caregiver in case there are more than one
- **start_date**: datetime
the date the caregiver is selected
- **end_date**: datetime

the date when the caregiver is no longer valid

Client: this parent entity includes the following attributes:

- **id:** GUID
- **name:** string
human name in the format of first name + [one space] + last name
- **gender:** string (enum)
female | male | queer
- **hcn:** string
health card number
- **service_language:** string (enum)
english | french
- **contact_point:** Contact_Point
- **address:** Address
- **photo:** binary
- **active:** Boolean
- **dob:** datetime

Comment

- **id:** GUID
- **user_id:** GUID
- **subject_client_id:** GUID
id of the client that the comment is about
- **subject_hic_id:** GUID

id of the HIC that the comment is about

- **text:** string

comment text

- **date:** datetime

Contact Point: includes the following attributes:

- **id** (GUID): Unique identifier of the record
- **system** (string (enum)): phone | fax | email | pager | url | sms | other
- **value** (string): The actual contact point details
- **use** (string (enum)): home | work | temp | old | mobile - purpose of this contact point
- **rank** (string): Specify preferred order of use (1 = highest)
- **start_date** (datetime): the date the contact point takes effect
- **end_date** (datetime): the date when the contact point is no longer valid

Episode

- **id:** GUID

- **client_id:** GUID

- **hic_id:** GUID

the ID of the HIC that is providing healthcare services

- **status:** string (enum)

planned | waitlist | active | on-hold | finished | cancelled | entered-in-error

- **episode_type:** string

e.g. Prescription Dispense, Hospital Stay, Tests

- **comments:** string

free text field for extra information

- **start_date**: datetime
- **end_date**: datetime

HCO: We store the basic information such as name, contact information such as address and phone number, Business Identification Number (BIN), and of course the type of the organization that can be hospital, pharmacy, Family Health Team (FHT), laboratory, community care providers, clinic, and smaller practices with a EHR system. Attributes that HCOs share apart from the ones they inherit from HIC entity are as follows:

- **bin**: string
Business Identification Number

Health_Profile

- **id**: GUID
- **client_id**: GUID
- **name**: string
title of the condition/diagnosis/allergy
- **code**: string
code that identifies this profile
- **code_system**: string
coding system title for the medication code
- **diagnosing_hic_id**: GUID
- **criticality**: string (enum)
low | high | unable to assess

- **type:** string (enum)
allergy | intolerance | diagnosis | condition
- **start_date:** datetime
- **end_date:** datetime

HIC: As a parent to HCOs and Practitioners, HIC entity has the following attributes:

- **id:** GUID
Unique identifier of the HCO
- **type:** string
Kind of organization
- **name:** string
Name used for the organization
- **alias:** string
A list of alternate names that the organization is known as, or was known as in the past
- **contact_point:** Contact Point
A contact detail for the organization
- **address:** Address
An address for the organization
- **partOf :** GUID
The ID of the HCO of which this HCO forms a part
- **start_date:** datetime
the date the contact point takes effect
- **end_date:** datetime
the date when the contact point is no longer valid

Medication

- **id:** GUID
- **name:** string
- **code:** string
code that identifies this medication
- **code_system:** string
coding system title for the medication code
- **client_id:** GUID
- **prescribing_hic_id:** GUID
- **dispensing_hic_id:** GUID
- **manufacturer:** string
name of the medication manufacturer
- **health_profile_id:** GUID
reference to Health_Profile entity that this medication was prescribed for
- **start_date:** datetime
- **end_date:** datetime

Patient: Patient's attributes other than those inherited from Client entity are listed below:

- **family_physician_id:** GUID
the practitioner id of the patient's family physician.
- **living_arrangement:** string
the living arrangements of the patient: alone | with spouse/partner | with other family |
retirement home | roommates

- **marital_status**: string (enum)
legal marriage status: single | married | divorced | common law | widowed
- **dietary_regimen**: list<string>
list of patient's dietary regimen
- **advance_directives**: list<string>
list of patient's advance directives

Practitioner: we recommend the following attributes

- **license_number**: string
Practitioner's Licence Number
- **qualification**: string
Practitioner's specialty or other qualification
- **gender**: string (enum)
male | female | other | unknown
- **dob**: datetime
The date on which the practitioner or practitioner was born
- **photo**: binary

Subscription

- **id**: GUID
- **client_id**: GUID
- **hic_id**: GUID
- **status**: string
subscription status: requested | active | error | off
- **contact**: Contact_Point

the address where the subscription material should be sent to

- **frequency:** string (enum)
daily | weekly | monthly | quarterly | annually
- **number_in_frequency:** string
hour number, day of week number, day of month number, day of quarter number, day of year number
- **channel_type:** string (enum)
sms | email | web socket | rest-hook
- **reason:** string
why this subscription was created
- **criteria:** string
rule for server push
- **error:** string
latest error note
- **start:** datetime
when the subscription starts
- **end:** datetime
when the subscription should end

Web-User

- **use_id:** GUID
- **client_id:** GUID
- **hic_id:** GUID
- **status:** string

- **role:** string

the role category that the user belongs to, based on governance structure

- **username:** string
- **password_hash:** string
- **last_login_date:** datetime
- **start_date:** datetime
- **end_date:** datetime

Appendix II: A Representative Instance of the Proposed Ontology

Based on section 4.3.6 and following Noy’s methodology development process, in step 7 we had to provide a complete instance of the proposed ontology. The table below provides a representative instance that entails specific values for each of the proposed entities and attributes.

Attributes and data types	Instance Values
Address id: GUID use : string (enum) type : string (enum) text : string line : string city : string district: string state : string postal_code: string country: string start_date: datetime end_date: datetime	da657ff1c05446798bb498744a72033f home physical 110 marzipan street, H7T 2G3, London, ON, Canada 110 marzipan London Kista Ontario H7T 2G3 Canada 2010-03-08 null
Contact Point id: GUID system: string (enum) value : string use: string (enum) rank: string start_date: datetime end_date: datetime	4e5fc9818cf8488f85d19a13ddf80f06 Telephone 6477555555 Home 1 2010-03-15 null
HIC id: GUID type : string name : string alias : string contact_point: Contact Point address : Address partOf : GUID start_date: datetime end_date: datetime	e3351f0e9dbe44799ab996d76cb25fe4 Hospital The Ottawa Hospital TOH { 72b9e8f89a7046fb8c9cd, telephone,6134444444, work,1, 2018-01-01 } {8cf8488f85d19a13ddf8ed,work,mailing, P.O. box 15, 1 Carling,Ottawa,...} null 2018-01-01 null
Client id: GUID name: string gender: string (enum) dob: datetime hcn: string service_language: string contact_point : Contact_Point address: Address photo : binary	c1fccc2b4344a1e82bac60eec448796 Claire Larsson female 1934-11-01 H777999766 English {444e8f89a7046fb8c9cd, telephone,6134444444, home,1, 2018-01-01 } {222488f85d19a13ddf8ed,home,mailing, 333 ulong, 1 Carling,Ottawa,...} UUU

active : boolean	True
Subscription id: GUID status: string contact: Contact_Point start: datetime end : datetime frequency: string (enum) number_in_frequency: string channel_type: string (enum) reason : string criteria : string error : string	s3fcccc2b4344a1e82bac60ecc448796 active {444e8f89a7046fb8c9cd, email,tt@gmail.com,1, 2018-01-01} 2019-03-05 2019-12-31 Quarterly 1 Email Lob lob When a record is accessed Null
Audit_Event id: GUID user_id, GUID hic_id, GUID date: datetime type : string (enum) subtype : string (enum) action : string outcome : string	8c8b25155ba34e728b70770ce2d103da d3a41e8ae38443ac8823f7426d773b76 null 2019-01-09 user authentication has been attempted login execute succeeded
Comment id: GUID user_id: GUID subject_client_id: GUID subject_hic_id: GUID date: datetime text: string	c053b8427eac4b06b272cd7e50e06540 c7e95ef968d54be49e13021e07293ffb null e3351f0e9dbe44799ab996d76cb25fe4 2019-05-22 Good job!
Web-User use_id: GUID client_id: GUID hic_id: GUID status: string last_login_date: datetime start_date: datetime end_date: datetime username: string password_hash: string role: string	c053b8427eac4b06b272cd7e50e06540 c1fcccc2b4344a1e82bac60ecc448796 null active 2019-07-31 2018-01-01 Null Clairl Hjlasiufaebga iniakujfo ;aukghf vaillkhjvo;aeihgaieughvbadoufjkhvno;sd.jfgh patient
Health_Profile id: GUID client_id: GUID name: string code: string code_system: string start_date: datetime end_date: datetime diagnosing_hic_id: GUID criticality: string (enum) type: string (enum)	b9d4b743-54c9-42a1-83d4-c8ffef2419c 4f3e7c62-7063-49d9-a2c6-0a5960565fbd Pet Allergy C056T ICD010 2010-01-01 NULL b4b41d6d-c9b6-42c3-bf01-99b6fe032149 high Allergy
Medication id: GUID name: string code: string code_system: string	1c1df098-593c-40ac-9a8f-0f3d8fd5e8f7 Antihistamine T45.0X1 ICD10

client_id: GUID prescribing_hic_id: GUID dispensing_hic_id: GUID manufacturer: string start_date: datetime end_date: datetime health_profile_id: GUID	4f3e7c62-7063-49d9-a2c6-0a5960565fbd 4f3e7c62-7063-49d9-a2c6-0a5960565fbd 6a1c186d-210a-4a1d-99df-f825cef4 99d9-a2c6-0a5960565fbd 6a1c186d Best Med Co 2016-11-15 2017-04-10 49d9-a2c6-0a5960565fbd 6a1c186d
Episode id: GUID client_id: GUID hic_id: GUID status: string (enum) episode_type: string comments: string start_date: datetime end_date: datetime	05adb66c-6c2d-40d4-8b09-220ebed41550 4f3e7c62-7063-49d9-a2c6-0a5960565fbd 1ccfc976-4c62-47ca-8948-dabbb0f0446d Inactive practitioner visit hip fracture, referral to specialist 2017-02-02 2017-02-02
Patient family_physician_id: GUID living_arrangement: string marital_status: string (enum) dietary_regimen: list<string> advance_directives: list<string>	b4b41d6d-c9b6-42c3-bf01-99b6fe032149 Alone Single Null DNR
Practitioner license_number: string fht_id: GUID qualification: string gender: string (enum) dob: datetime photo: binary	84658Y63899 1ccfc976-4c62-47ca-8948-dabbb0f0446d Family Practitioner Female 1980-01-01 <some xml>
Caregiver relationship: string primary: Boolean start_date: datetime end_date: datetime	Daughter True 1999-01-01 null

Appendix III: Data Model of the API Prototype

In this appendix, we present how we modeled our proposed ontology for our API prototype.

We used OpenAPI and the swagger notation in order to specify our data model.

MyPHR based API Prototype

```
openapi: '3.0.0'
info:
  title: MyPHR API
  description: >
    This API provides means to collect and disseminate data (proposed in
    MyPHR ontology) from
    healthcare clients and providers
  version: "0.0.1"
servers:
  - url: http://localhost
    description: default server

paths:

  /patients:
    post:
      summary: creates a new patient object
      operationId: createpatient
      requestBody:
        required: true
        content:
          application/json:
            schema:
              $ref: "#/components/schemas/Patient"
      responses:
        '201':
          description: created

  /patients/{client_id}:
    get:
      summary: gets a patient by ID
      operationId: getpatientinfo
      parameters:
        - in: path
          name: client_id
          schema:
            type: string
            required: true
      responses:
        '200':
          description: one patient object
          content:
            application/json:
              schema:
```

```

        $ref: "#/components/schemas/Patient"
patch:
  summary: add/modify patient info
  operationId: editpatientinfo
  parameters:
    - in: path
      name: client_id
      schema:
        type: string
      required: true
  requestBody:
    required: false
    content:
      application/json:
        schema:
          $ref: "#/components/schemas/Patient"
  responses:
    '201':
      description: patient info modified

/addresses/{client_id}:
get:
  summary: gets the active addresses for a client
  operationId: getaddressesforaclient
  parameters:
    - in: path
      name: client_id
      schema:
        type: string
      required: true
  responses:
    '200':
      description: getting the listed addresses for a patient
      content:
        application/json:
          schema:
            type: array
            items:
              $ref: "#/components/schemas/Address"
post:
  summary: add/modify addresses
  operationId: editaddressesforaclient
  parameters:
    - in: path
      name: client_id
      schema:
        type: string
      required: true
  requestBody:
    required: true
    content:
      application/json:
        schema:
          $ref: "#/components/schemas/Address"
  responses:
    '201':
      description: addresses modified
/phonenumbers/{client_id}:

```

```

get:
  summary: gets the active phonenumber for a client
  operationId: getphonenumberforaclient
  parameters:
    - in: path
      name: client_id
      schema:
        type: string
      required: true
  responses:
    '200':
      description: getting the listed phonenumber for a patient
      content:
        application/json:
          schema:
            type: array
            items:
              $ref: "#/components/schemas/PhoneNumber"
post:
  summary: add/modify phonenumber
  operationId: editphonenumberforaclient
  parameters:
    - in: path
      name: client_id
      schema:
        type: string
      required: true
  requestBody:
    required: false
    content:
      application/json:
        schema:
          $ref: "#/components/schemas/PhoneNumber"
  responses:
    '201':
      description: phonenumber modified

/caregivers:
  post:
    summary: creates a new caregiver object
    operationId: createcaregiver
    requestBody:
      required: true
      content:
        application/json:
          schema:
            $ref: "#/components/schemas/Caregiver"
    responses:
      '201':
        description: created
/caregivers/{client_id}:
  get:
    summary: gets a caregiver by ID
    operationId: getcaregiverinfo
    parameters:
      - in: path
        name: client_id
        schema:

```

```

        type: string
        required: true
    responses:
      '200':
        description: one care giver object
        content:
          application/json:
            schema:
              $ref: "#/components/schemas/Caregiver"
/hco:
  get:
    summary: List all HCOs
    operationId: listHCOs
    responses:
      '200':
        description: array of results
        content:
          application/json:
            schema:
              type: array
              items:
                $ref: "#/components/schemas/HCO"

/comments:
  post:
    summary: creates a new comment
    operationId: postcomment
    requestBody:
      required: true
      content:
        application/json:
          schema:
            $ref: "#/components/schemas/Comment"
    responses:
      '201':
        description: comment posted
/comments/{subject_healthcare_provider_id}:
  get:
    summary: gets the comments for a healthcare provider by ID
    operationId: getcommentforhco
    parameters:
      - in: path
        name: subject_healthcare_provider_id
        schema:
          type: string
          required: true
    responses:
      '200':
        description: comments for this HCO
        content:
          application/json:
            schema:
              type: array
              items:
                $ref: "#/components/schemas/Comment"

/medications/{client_id}:
  get:

```

```

summary: gets the medications for a client
operationId: getmedicationsforaclient
parameters:
  - in: path
    name: client_id
    schema:
      type: string
    required: true
responses:
  '200':
    description: getting the listed medications for a patient
    content:
      application/json:
        schema:
          type: array
          items:
            $ref: "#/components/schemas/Medication"
post:
summary: creates a new medication
operationId: postmedication
parameters:
  - in: path
    name: client_id
    schema:
      type: string
    required: true
requestBody:
  required: true
  content:
    application/json:
      schema:
        $ref: "#/components/schemas/Medication"
responses:
  '201':
    description: medication posted
/healthprofiles/{client_id}:
get:
summary: gets the health profiles for a client
operationId: gethealthprofilesforaclient
parameters:
  - in: path
    name: client_id
    schema:
      type: string
    required: true
responses:
  '200':
    description: getting the listed Health Profiles for a patient
    content:
      application/json:
        schema:
          type: array
          items:
            $ref: "#/components/schemas/HealthProfile"
post:
summary: creates a new healthprofile
operationId: posthealthprofile
parameters:

```

```

- in: path
  name: client_id
  schema:
    type: string
    required: true
requestBody:
  required: true
  content:
    application/json:
      schema:
        $ref: "#/components/schemas/HealthProfile"
responses:
  '201':
    description: health profile posted
/episodes/{client_id}:
get:
  summary: gets the episodes for a client
  operationId: getepisodesforaclient
  parameters:
    - in: path
      name: client_id
      schema:
        type: string
        required: true
  responses:
    '200':
      description: getting the listed episodes for a patient
      content:
        application/json:
          schema:
            type: array
            items:
              $ref: "#/components/schemas/Episode"
post:
  summary: add an episode
  operationId: addepisodeforaclient
  parameters:
    - in: path
      name: client_id
      schema:
        type: string
        required: true
  requestBody:
    required: false
  content:
    application/json:
      schema:
        $ref: "#/components/schemas/Episode"
  responses:
    '201':
      description: episode added

schemas:
  GenderType:
    type: string
    enum:
      - female

```

- male
- unknown
- nonbinary

ServiceLanguage:

- type: string
- enum:
 - en
 - fr

OrganizationType:

- type: string
- enum:
 - Hospital
 - Community care provider
 - Physician
 - Family Health Team
 - Pharmacy
 - Laboratory
 - Chiropractice
 - Physiotherapy centre

NotificationType:

- type: string
- enum:
 - patient episodes
 - addresses
 - phone number
 - web access
 - comment added

DietaryRegimen:

- type: object
- properties:
 - dietary_regimen_id:
 - type: string
 - start_date:
 - type: string
 - format: date
 - end_date:
 - type: string
 - format: date

Client:

- description: >
 - This is the base type with common properties between patients and caregivers
- type: object
- properties:
 - client_id:
 - type: string
 - firstname:
 - type: string
 - surname:
 - type: string
 - gender:
 - type: string
 - dob:

```

    type: string
    format: date
  service_language:
    type: string
  start_date:
    description: a new client profile may start when they change names
or gender
    type: string
    format: date
  end_date:
    description: a client profile may end when they change names or
gender
    type: string
    format: date

```

```

Patient:
  description: >
    a person with a health card number
    that is the subject of the records
  allOf:
    - $ref: '#/components/schemas/Client'
    - type: object
      properties:
        health_card_number:
          type: string
        active_primary_physician_id:
          type: string
        dietary_regimen:
          description: the dietary aversions, restrictions, or
preferences
          type: array
          items:
            $ref: '#/components/schemas/DietaryRegimen'
        advance_directives:
          type: array
          items:
            type: string

```

```

Caregiver:
  allOf:
    - $ref: '#/components/schemas/Client'
    - type: object
      description: >
        a healthcare client that helps with a patient's
        activities of daily living
      properties:
        relationship:
          type: string
          description: who the caregiver is to patient
        is_active:
          type: boolean
        is_primary_caregiver:
          type: boolean
        caregiver_of_client_id:
          type: string

```

```

HIC:
  description: >

```

```

    a registered provider with HIC designation
    offering healthcare services
type: object
properties:
  healthcare_provider_id:
    type: string
  name:
    type: string
  start_date:
    type: string
    format: date
  end_date:
    type: string
    format: date

HCO:
  allOf:
    - $ref: '#/components/schemas/HIC'
    - type: object
      description: >
        a business entity that provides healthcare services
        and has at least one electronic health record system
      properties:
        bin:
          type: string
          description: the business identification number
        organization_type:
          type: string

Physician:
  allOf:
    - $ref: '#/components/schemas/HIC'
    - type: object
      description: >
        a physician regardless of their employment arrangement,
        hired by hospital or hired by their own practice
      properties:
        firstname:
          type: string
        surname:
          type: string
        specialty:
          type: string
        license_number:
          type: string
        license_date:
          type: string
          format: date

HealthProfile:
  type: object
  properties:
    health_profile_id:
      type: string
    client_id:
      type: string
    name:
      type: string

```

```
code:
  type: string
start_date:
  type: string
  format: date
end_date:
  type: string
  format: date
diagnosing_healthcare_provider_id:
  type: string
is_activity_impediment:
  type: boolean
is_risk_and_safety_issue:
  type: boolean
is_allergy:
  type: boolean
is_health_condition:
  type: boolean
```

```
Medication:
  type: object
  properties:
    medication_id:
      type: string
    name:
      type: string
    icd_code:
      type: string
    client_id:
      type: string
    prescribing_healthcare_provider_id:
      type: string
    start_date:
      type: string
      format: date
    end_date:
      type: string
      format: date
    last_reconciliation_date:
      type: string
      format: date
    condition_prescribed_for_id:
      type: string
```

```
WebUser:
  type: object
  properties:
    user_id:
      type: string
    client_id:
      type: string
    healthcare_provider_id:
      type: string
    status:
      type: string
    created_date:
      type: string
      format: date
```

```

    type:
      type: string
    hcn:
      type: string
    password:
      type: string

Comment:
  type: object
  properties:
    comment_id:
      type: string
    user_id:
      type: string
    subject_healthcare_provider_id:
      type: string
    subject_client_id:
      type: string
    comment_date:
      type: string
      format: date
    comment_text:
      type: string

Episode:
  type: object
  properties:
    episode_id:
      type: string
    client_id:
      type: string
    healthcare_provider_id:
      type: string
    start_date:
      type: string
      format: date
    end_date:
      type: string
      format: date
    is_active:
      type: string
    episode_type:
      type: string
    physician_id:
      type: string

Address:
  type: object
  properties:
    address_id:
      type: string
    address_type:
      description: e.g. mailing, home, temporary etc.
      type: string
    client_id:
      type: string
    healthcare_provider_id:
      type: string

```

```
is_active:
  type: boolean
start_date:
  type: string
  format: date
end_date:
  type: string
  format: date
country:
  type: string
city:
  type: string
street_type:
  type: string
street_number:
  type: string
street_name:
  type: string
unit_number:
  type: string
postal_code:
  type: string
```

```
PhoneNumber:
  type: object
  properties:
    phone_num_id:
      type: string
    client_id:
      type: string
    healthcare_provider_id:
      type: string
    is_active:
      type: boolean
    start_date:
      type: string
      format: date
    end_date:
      type: string
      format: date
    country_code:
      type: string
    number:
      type: string
    type:
      type: string
```

```
AuditTrail:
  type: object
  properties:
    audit_id:
      type: string
    user_id:
      type: string
    healthcare_provider_id:
      type: string
    is_web_access:
      type: boolean
```

```
is_api_access:
  type: boolean
access_date:
  type: string
  format: date
accessed_client_id:
  type: string
```

```
Notification:
  type: object
  properties:
    subscription_id:
      type: string
    user_id:
      type: string
    healthcare_provider_id:
      type: string
    notification_type:
      $ref: "#/components/schemas/NotificationType"
    subscription_start_date:
      type: string
      format: date
    subscription_end_date:
      type: string
      format: date
```