

An Ontology for a Patient-Centric Healthcare Interoperability Framework

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ABSTRACT*

Healthcare clients are increasingly interested to be involved and informed of their healthcare delivery and status [1] [2]. They need to be able to access, view, and analyze their health data easily and securely. Clients need one single gateway to their medical records. Some healthcare providers are creating portals for their clients to flow some data for them to view [3]. In addition, clients can request a portion of their health data in paper format from their healthcare providers by filling in forms and manually submitting their requests. But, this is not sufficient for the average healthcare client. There is a need for a platform independent tool that can automatically gather and combine a client's health information from the various providers in their circle of care and provide the information securely and electronically without inconveniencing the client with multiple requests and sharing agreements [4]. Healthcare providers can also benefit from such a tool in the sense of gaining insights from their colleagues' efforts automatically and without starting a separate quest for each piece of information. In this paper we propose framework and toolset that can provide a secure single point of access to a client's full picture of their personal health information. In particular, we delve into one of the key components of our framework which is our proposed ontology.

KEYWORDS

Healthcare applications, patient centric, healthcare integration, healthcare API, Healthcare ontology

INTRODUCTION

With the prevalence of Application Programming Interfaces (API) and web services over the past decade, many businesses attempt to utilize them to share and transfer their data [4] [5]. Many significant companies in

the software industry have attempted to develop healthcare APIs [6]. However, the healthcare industry in Canada still stays within the traditional data management space i.e. ad-hoc or fax-based sharing of information across organizations. There is a need for a healthcare data-sharing framework that considers the limitations of professional practice in this industry such as the very conservative outlook on the privacy and protection of personal health information. In order to help the adoption of such a framework, a unified, well defined, and specific ontology is of the utmost importance.

BACKGROUND

Healthcare standards and ontologies

For data 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 [7]. Terminology standardization is essential to successful information systems integration from different organizations.

Often developed by a panel of domain experts, an 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 [8].

Health Level 7 (HL7)

The normalization and standardization of electronic health data is a key driver in healthcare collaborations and integration of systems. HL7 is an organization that creates standards for packaging healthcare data for exchange, management, sharing, retrieval and integration purposes. HL7 is followed and adopted internationally [9]. HL7 does

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not develop software but develop guidelines and standards for integrating software suits in a healthcare setting.

Many of the modern EHRs rely heavily on the standards and formats laid out in the HL7 standards and APIs. HL7 has the famous vision of “A world in which everyone can securely access and use the right health data when and where they need it” [10]. HL7 standards are grouped into the following categories [11]:

- 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

HL7 Fast Healthcare Interoperability Resources Specification (FHIR®) is a standards framework for exchange of electronic health data among systems. It supports both central patient care systems and more distributed environments where data 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, etc. [12]

Web services and APIs

A 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.

An Application Programming Interface (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 for API designs [10].

FHIR is a combination of HL7 products and latest web standards and RESTful practices in order to facilitate adoption of integrated healthcare practices across various

healthcare providers globally [13]. 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. FHIR provides a REST API to set and modify resources with functions such as create, read, update, delete, search, etc. and provides detailed guidelines as to how to send the requests and read responses from the API.

Ontology Development Methodologies

There are various ontology methodologies in the body of literature [15]. 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 [15]. 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.

Then TOVE methodology was introduced in 1995 by Grüninger and Fox who described 5 steps in defining an ontology: 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; and 5) Putting the developed ontology to test by proving its completeness against the defined questions [16].

In 2001, Noy and McGuinness presented their ontology development methodology. This is the methodology we adopted and hence we delve into it in the following section.

HL7 Ontology Development Methodology

An ontology is a formal representation of the entities defined in a domain. Ontologies are usually defined to: establish a unified understanding of the information structure among all stakeholders; make the entities reusable; clarify the assumptions; make a distinction between domain information and operational information; Analyze domain knowledge

HL7 recommends a simple and general methodology to guide ontology development in a healthcare setting. They specify a sequence of steps but leave the developers to follow whatever order they see fit in following them. The following steps are laid out in the HL7 ontology development methodology [14]:

- 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.

- Reusing the existing ontologies: this methodology recommends to search for similar ontologies that have been developed already and try to reuse them. This would help interoperability among different systems.
- Providing a list of relevant terminology in the domain: this makes it easier for the users to understand and adopt the ontology
- 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.
- Defining the attributes of the entities defined in the previous step
- Defining the data types of the attributes defined the previous step
- Creating instances for the defined entities

PROPOSED ONTOLOGY

At a high level, the proposed framework (MyPHR) is composed of a web portal (MyPHR web application) a set of web service APIs, and a data storage system [15]. HCO employees use internal applications that leverage the APIs. Other stakeholders use mobile apps developed by healthcare app developers that leverage the APIs. The architecture is designed to serve variety of users from patients to HCO employees. The proposed application architecture takes a typical data-centric cloud-based architecture and extends it with appropriate security mechanisms and user registrations for healthcare, and a common meta-data ontology, and a systematic approach to governance. In order to elevate the chances of adoption of our proposed framework [16], we developed an ontology and metadata model.

Our metadata model and ontology defines the data entities and their attributes that flow through our proposed framework. It characterizes the data that stakeholders need access to and would be required to provide. We developed this ontology manually [17] and started our ontology development process by building a model of care processes and identified what each persona needed from the others and the whole system. In order to define our proposed ontology, we followed the ontology development methodology [14] by Noy and McGuinness recommended by HL7. We selected this methodology because it guides the ontology development process in seven simple steps and is recommended by one of the largest standard setting organizations in healthcare domain i.e. HL7. In the following sections, we describe the development phases of our proposed ontology.

Step 1: Defining the domain and scope

The domain of the proposed ontology and metadata model is healthcare electronic data sharing and collaboration. This ontology defines the minimum necessary pieces of information that most healthcare providers are willing to share with each other. We use this ontology to format the data that flows in the proposed architecture and to define the objects and classes in the proposed API. Through this ontology, the shared data would be consistent and uniform.

The proposed ontology can be used in any data sharing effort within a healthcare setting anywhere in the world. The information in the ontology describes patients, various healthcare providers and their interactions with their clients, physicians and their interactions with their patients. It also provides information on a form of communication between healthcare service providers and clients (i.e. comments). Some of the types of questions that the information in the ontology provide answers to are:

- When did I last receive my tetanus shot?
- What are my upcoming medical appointments? And when are they scheduled for?
- Who is the primary care provider of my client?
- Who is the primary caregiver for my client?
- What's my patient's current address?
- What were the past medical conditions of my patient?
- What risk factors is my patient exposed to?

Step 2: Reusing the existing ontologies

The HL7 vocabulary policy recommends the use of existing relevant vocabulary. A 2014 research publication in Korea has identified seven categories for their healthcare context information model [18]. The categories are: Individual Data, Medical Data, Auxiliary Data, Location Data, Device Data, Activity Data, and Environment Data. Individual data includes attributes such as name, age, and other information describing a patient's profile. Medical data includes information about history of diseases, symptoms, examination and vital metrics such as blood pressure, blood sugar, weight, etc. Auxiliary data include biological data analysis and management, and exercise and nutrition consulting services. Location data describes the indoor/outdoor location. Device data include the device-specific data from smart phones, medical detectors, etc. Activity data describes states of one's activity levels such as sedentary, walk, run, etc. Finally, environment data focuses on environment variable such as temperature, humidity, illumination, etc.

In our proposed ontology, we adopt the vocabulary for Individual data that matched to what we want to describe in that category. We break down the medical data into medications, and health profile, hence we introduce new vocabulary there. Finally, since getting a shared view of one's medical appointment is a new concept, we introduce our own vocabulary there as well.

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

Apart from what we identified as the entities of the proposed system, subsequently, we describe some of the relevant terminology in healthcare domain and their descriptions.

- Activity Impediments: an obstacle or difficulty that hinders one's progress in motion, daily activities of living, etc.
- Advance Directives: 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.
- Family Physician: a client'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: the actions taken to improve one's physical and/or mental health or prevent negative conditions especially through providing medical services.
- Home Care Services: a healthcare service that's provided within someone's place of residence
- 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 is 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

Step 4: Defining the entities and their relative hierarchy

Subsequently we name and describe every entity that we propose for our ontology.

Addresses: In our proposed ontology, we suggest an entity that captures the addresses for all the other entities. Therefore, healthcare providers and clients are linked with this entity.

Phone Numbers: Similarly, we propose an entity for phone numbers. This entity can include multiple phone numbers for various other entities if applicable.

HealthCare Organizations (HCO): Healthcare organizations are the big healthcare providers that provide service through a well established organization, such as hospitals, community care access centres, pharmacy, laboratory, etc.

Physicians: We established a separate entity for physicians. One may argue that physicians could be considered employees of a family health team or their practice as the business they belong to, and hence the HCO entity would cover them. However, we needed a distinct position for physicians since MyPHR application grants individual web access to physicians and we need to store the possible communications between physicians and their patients through comments. The patient-physician relationship and the duration of their episode is received through the HCO the physician belongs to.

Healthcare Provider: Since HCOs and physicians' actions have a lot in common, we decided to create a parent entity that both HCO and physician entities inherit from. A healthcare provider 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

Episodes: This entity captures the encounters between patients and the HCOs or patients and physicians. An HCO can register an episode with a patient and set the start date of the episode. When a new patient is added in an HCO's EHR system under a physician's care, a method gets triggered to register this new patient for that specific physician/HCO. Once the HCO-patient episode ends, the HCO must send the according end date immediately through the API methods.

Medications: This entity describes the medications prescribed by a healthcare provider for a patient. For credibility reasons, only a healthcare provider can add a

new record for this entity and the clients are not allowed to edit this information.

Health Profiles: Similar to medications, a health profile provides ways of describing a patient situation. It can be a health condition, allergy, risk and safety issue, or an activity impediment. Again, for credibility reasons, we only allow the diagnosing healthcare provider to add or terminate a health profile record.

Patients: Patient is the most important entity in MyPHR framework. Their data is especially sensitive and subject to many privacy concerns and regulations. In order to comply with these regulations and concerns, we pinpoint the very specific attributes that are gathered through various personas and flow on MyPHR architecture.

The proposed metadata model gives an understanding of the patient's trajectory through the health system and clues to where they can get more information, should the need arise. Hence, it would not include details such as procedures done during a hospital stay. We arrived at this model by building a model of care processes and identified what each persona needed from the others and the system as a whole. The scenario below paints a realistic but fictitious picture of the current care processes in Ontario, where we concluded the proposed metadata model.

Our model of care highlighta data interoperability issues such as a patient's dietary restrictions and hospital stay not being readily available when their care is transitioned from one healthcare provider to another, and there are process interoperability issues that prevent integration of providers to support collaborative care delivery, and finally there are contextual factors in terms of the change in e.g. a patient's living situation changing from private home to retirement home to convalescent care home [19].

Clients: We suggest that we can fit patients and caregivers under a parent entity called clients. Patient and caregivers have many similar attributes and can do similar functions. A client can:

- Add addresses
- Add phone numbers
- End addresses
- End phone numbers

Caregivers: Caregivers are individuals who provide care to patients and are trusted with patient's PHI information through the consent form that the patient signs. They inherit most of the attributes from the parent entity –clients.

Web users: web users are patients and physicians with access to the MyPHR web 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 users entity is therefore related to patients and physicians entities. Each web user may have a physician ID or a patient ID associated with it.

Comments: We defined a separate entity for comments that may be written by a MyPHR web user. These comments can 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. Having applied natural language processing techniques, they determined that there is a great potential for an automated and accurate performance measurement [20].

Audit trails: Another entity that we designed to be part of MyPHR ontology is an audit trail. We foresee that this information is going to be useful for privacy audits and even in case of potential investigations for privacy breeches. This way we keep logs on every OAuth request, any web access and we can generate access reports and monitor the requests for any potential breach. We can set up unauthorized access rules and generate reports that meet those patterns.

Notification Subscription: One of the services that MyPHR framework offers is subscription to certain events within one's circle of care and responsibilities. Physicians, HCOs, and patients can set up subscriptions through the web portal or API web service to receive notifications when certain events happen.

Step 5 & 6 & 7: Defining the attributes and data types and creating instances

We summarize the last three steps of the ontology development methodology in Table 1.

Table 1 Proposed ontology attributes, data types, and example instances

Attributes and data types	Instance Values
Addresses	
Address ID: GUID	74ab42ad-11e6-40ff-879c-1b4365056e7c
Client ID: GUID	4f3e7c62-7063-49d9-a2c6-0a5960565fbd
Healthcare Provider ID: GUID	NULL
Is Active: boolean	Yes
Start Date: DateTime	2004-04-09
End Date: DateTime	NULL
Country: string	Canada
City: string	Ottawa
Street Type: string	Street

Street Name: string Street Number: string Unit Number: string Postal Code: string Residence Type	Elgin 111 NULL J7J 7J7 Private dwelling
Phone Numbers Phone Num ID: GUID Client ID: GUID Healthcare Provider ID: GUID Is Active: boolean Start Date: DateTime End Date: DateTime Country Code: int Number: int	3db95096-37b2-4061-9eee-80a0b5d6249e 4f3e7c62-7063-49d9-a2c6-0a5960565fbd NULL Yes 2000-01-09 NULL 1 6138888888
Healthcare Providers (Children: HCOs and physicians) Healthcare Provider ID: GUID Name: string	1ccfc976-4c62-47ca-8948-dabbb0f0446d Dynacare
HealthCare Organizations Business Identification Number, long Organization Type, List<string>	9654KJH6789 Pharmacy
Physicians Licence Number, string Family Health Team ID, GUID Specialty, string	84658Y63899 b4b41d6d-c9b6-42c3-bf01-99b6fe032149 General Practitioner
Clients (Children: Patients and Caregivers) Client ID: GUID Name: string Gender: string DOB: DateTime Living Arrangement Service Language: string	4f3e7c62-7063-49d9-a2c6-0a5960565fbd Roya Juliani Female 1987-03-25 Alone English
Patients Primary Physician ID: GUID Dietary Regimen: list<string> Advance Directives: list<string>	b4b41d6d-c9b6-42c3-bf01-99b6fe032149 Vegetarian DNR
Caregivers Relationship: string Is Active: boolean Is Primary Care Giver: Boolean	Mother Yes Yes
Episodes Episode ID, GUID Client ID, GUID Healthcare Provider ID, GUID Start Date, DateTime End Date, DateTime Status, string Episode Type, string; e.g. [Prescription Dispense, Hospital Stay, Tests]	05adb66c-6c2d-40d4-8b09-220ebed41550 4f3e7c62-7063-49d9-a2c6-0a5960565fbd 1ccfc976-4c62-47ca-8948-dabbb0f0446d 2015-05-08 2015-05-08 Ended Prescription Dispense
Medications Medication ID: GUID Name: string ICD Code: string Client ID: GUID Prescribing Healthcare Provider ID: GUID Start Date: DateTime End Date: DateTime Last Reconciliation Date: DateTime Condition Prescribed for ID: GUID	1c1df098-593c-40ac-9a8f-0f3d8fd5e8f7 Antihistamine 2015-05-08 to 2015-08-02 4f3e7c62-7063-49d9-a2c6-0a5960565fbd 6a1c186d-210a-4a1d-99df-f825cef40eb3 2017-01-01 NULL 2016-11-15 to 2017-04-10 Arm Fracture
Health Profiles Health Profile ID: GUID Client ID: GUID	b9d4b743-54c9-42a1-83d4-c8ffef2419c 4f3e7c62-7063-49d9-a2c6-0a5960565fbd

Name: string Code: string Start Date: DateTime End Date: DateTime Diagnosing Healthcare Provider ID: GUID Is Activity Impediment: boolean Is Risk and Safety Issue: boolean Is Allergy: boolean Is Health Condition: Boolean	Pet Allergy C056T 2010-01-01 NULL b4b41d6d-c9b6-42c3-bf01-99b6fe032149 0 0 1 0
Web users User ID, GUID Client ID, GUID HCO ID, GUID Status, string Last Login Date, DateTime	5b549b86-6019-4bf4-add2-a3060b2abd0f 4f3e7c62-7063-49d9-a2c6-0a5960565fbd NULL Active 2018-01-05
Comments Comment ID, GUID User ID, GUID Subject Patient ID, GUID Subject Physician ID, GUID Subject HCO ID, GUID Subject FHT ID, GUID Date, DateTime Comment Text, string	4604d842-45ed-4aff-b5f1-0447131938de 5b549b86-6019-4bf4-add2-a3060b2abd0f NULL b4b41d6d-c9b6-42c3-bf01-99b6fe032149 NULL NULL 2018-01-05 Dr. O'Connor is amazing!
Audit trails Audit Log ID, GUID User ID, GUID HCO ID, GUID Is Web Access, Boolean Is API Access, Boolean Date, DateTime	2b7a17c7-fe66-427b-87be-1e2fd5211f55 5b549b86-6019-4bf4-add2-a3060b2abd0f NULL Yes No 2018-01-05
Notification Subscription Subscription ID, GUID User ID, GUID: the user subscribed HCO ID, GUID Notification Type ID, GUID Notification Type, string: Patient Episodes, Medications, Allergies, Address Subscription Start Date, DateTime Subscription End Date, DateTime	598f8b58-da2b-48c9-8b42-05d9f44af7ea 01dc2d3d-9b3a-45ef-9e6c-babe34609806 NULL 2899b233-81cf-45b2-9cad-0bcafec5e0b0 Patient Episodes 2009-05-04 NULL

DISCUSSIONS

According to Toronto Virtual Enterprise (TOVE), the methodology creation should start by demonstrating 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 [21]. We initiated our ontology development process by a scenario that models a healthcare delivery in Ontario and highlights the interoperability issues in current practice. We laid out a set of questions that the ontology can provide answers to and we described the entities, their attributes, and the reasoning on why we included them in our proposed ontology.

One of the characteristics of a good ontology is universal representation i.e. at least one real world instance can be shown to exist [22]. We provided a

fictitious but realistic example for the ontology attributes. Furthermore, the MyPHR framework includes a web portal and API that applies the proposed ontology. MyPHR toolset is to be tested through focus groups for another level of evaluation, which provides user feedbacks. Receiving feedback from people who have used the ontology [22] or the products of it is considered of value.

Finally, our proposed ontology focuses on the critical entities that we determined 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. This is to balance out the current conservative practice of not sharing any information in order to not risk a personal health information breach [23].

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