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DEVELOPMENT OF AN INTEGRATED SERVICE MODEL TO ACHIEVE PERSONAL HEALTH LIBRARIES FOR CONSUMERS

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DEVELOPMENT OF AN INTEGRATED SERVICE MODEL
TO ACHIEVE PERSONAL HEALTH LIBRARIES FOR CONSUMERS

By
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A REPORT

Submitted in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

In Medical Informatics

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Abstract

This concept paper establishes the framework for additional research regarding how medical records are stored and shared. Health Information Technology is rapidly developing, and one large barrier to true interoperability is data silos. This integrated service model proposes using Health Record Banks (HRB) to store and share data, while using open source applications to limit costs and create opportunities for the consumer to be at the center of their own medical records. This includes the authorization phase, in which patients will be able to seamlessly allow access to their records for clinicians they choose. This conceptual framework includes using eXist data base, PHP servers, applications, and testing mobile health apps using Ionic framework to transmit patient data in between multiple organizations using both FHIR and C-CDA standards. If this framework is used to its potential, there could be significant increases in transition of care, personalized medicine, and population health management, which will ultimately lead to better health outcomes for the population. Furthermore, this framework was designed to work on the back end of existing EHR's, so there would not be additional data entry for clinical or administrative staff. The use of public libraries was also examined as a means of accessibility for those who did not have smart phones or personal computers.

I. Introduction

As Health Information Technology (HIT) continues to advance and play a larger role in healthcare, the industry is now capturing more valuable data than ever before. However, this data cannot be used to its full potential if it is trapped in proprietary silos. Apple's CEO, Tim Cook, was recently quoted stating "healthcare is an enormous opportunity" [1]. Companies like Apple and Amazon are both investing large amounts of resources into HIT because the value of health information is significant. However, who does that information really belong to? The patient is the one paying for the service, however, in today's healthcare environment the healthcare facility is the one that has the rights to their data. This is one of the largest contributing factors to health data silos. No one wants to give up their information for free. Some of the largest advancements that have been made in interoperability are due to the government creating financial incentives for things like Electronic Health Records (EHR), data sharing, patient direct messaging, and public health reporting. These incentives were all created by Centers for Medicare and Medicaid Services (CMS), under the Meaningful Use (MU) program. CMS continues to lead change in the healthcare industry due to their status as the largest payer within the U.S. [2]. As CMS guides the paradigm shift in healthcare from fee-for-service, to a more value-based reimbursement system, now is an ideal time for additional changes to be made in the industry. Patients now have more healthcare options than ever in urban areas, and they can begin to select only professionals or organizations that meet their needs. The healthcare consumers are the missing factor for driving the healthcare data industry. As healthcare data standards have made significant advancements in the last five years, true interoperability is becoming more conceivable. Fast Health Interoperability Resources (FHIR) has gained a lot of momentum, and all the major EHR vendors are incorporating this standard in

their products. This standard, coupled with Substitutable Medical Applications, Reusable Technologies (SMART) is simple and based more around standard webservice that the IT industry has used for the last decade [3]. The Consolidated Clinical Document Architecture (C-CDA) is another widely used standard within the clinical and behavioral sectors and will be incorporated in the Health Record Bank (HRB) framework. With these advancements, the industry only lacks financial motivation to truly move towards interoperability that would create seamless care coordination and create ideal healthcare communication between providers and organizations.

a. Background

Health Information Exchanges (HIE) attempt to create networks of data sharing, and sufficiently support areas like population health with higher reporting channels to state and national data exchanges [4]. However, HIE's have also been driven by MU, and not the consumers themselves. HIE's are still subject to collaboration with proprietary healthcare organizations for transition of care. Consumers actually have the ability to make healthcare providers compete for their business by providing quality care at reasonable prices and allowing them to be in control of their own healthcare data. In order for this to happen, consumers will need to be more informed and take a more proactive role in their healthcare choices, focusing on the above attributes [5]. With current HIE and HRB data sharing models continuing to encounter interoperability issues, an alternative solution must be implemented.

b. Problem Statement

Imagine a healthcare environment where there is no emergent faxing of documents for patient treatment, or where services are not delayed by weeks just for the exchange of pre-

surgical records. This could be a reality with the integrated service model that is being proposed in this study. Although the technological advancements to create true interoperability exist, the healthcare industry lacks the financial motivation to quickly make this a reality. Healthcare interoperability would greatly enhance the timeliness of care and could lead to better health outcomes [6]. One large barrier to interoperability is the current state of HIT data, and its proprietary nature for storage. Using a centralized HRB, patients would regain control of their health data and healthcare organizations would have to ensure their systems could communicate with the HRB, thus enforcing certain Application Program Interface (API) standards that would drive interoperability.

c. Methodology

In order for the healthcare paradigm shift to impact HIT data, there needs to be a centralized storage facility(s), and accessibility to that data by the patients themselves. HRB's provide this structure and are an extremely intuitive alternative to HIE's. Using FHIR/C-CDA, a HRB can be the centralized storage entity, while health care professionals or organizations will need to query the HRB to obtain patient data. This will only occur if the patient authorizes the sharing of their data, using an authorization system like Oauth2. Oauth2 is an authorization framework that is ideal for integration between mobile applications, and cloud-based services [7]. The HRB model can provide a health data structure that can support the large data sets, and will be less expensive, simpler, and more secure than other data sharing options [8]. Equally as important as the consumers driving this data change, is the accessibility for the patients. To ensure that all patients have the opportunity to access their health records, it is critical to choose an alternative access point that is not only abundant, but also trustworthy. The public library can serve as an intermediary to the public and their health records. Public libraries are useful

because 95.6% percent of Americans live within their service area [9]. This makes library's ideal for use within a healthcare data structure, since that framework is already present.

Furthermore, public libraries have the public's trust and confidence as a source of information finding assistance, and access to resources like the internet [10]. While most Americans these days have smart phones and various devices, it's important to remember that some of the countries demographic may not be tech savvy, and librarians can serve as intermediaries for patients that require extra assistance.

d. Objectives

The main objective of the project is to have a centralized HRB within each community that transmits the Agonaut Project's data points to requested healthcare organizations via FHIR or C-CDA, while incorporating a simple and seamless authorization process for the patients. The Agonaut project is a private sector endeavor that continues to work through interoperability issues, with the goal of open standards for sharing health information [11]. It is extremely relevant to this project because the open standards used in the project are ideal for using mobile apps to share data with EHR's. The integrated service model project uses PHP programming language for the server and the application. The data will be stored using the eXist data base format which stores data in extensible markup language (XML). The HRB would also allow the patients to query their own data using web services protocols. This patient driven initiative follows recent legislation aimed towards improving patient access to health data, culminating in the 21st Cures Act passed in December 2016. This would increase patient involvement, which could have large benefits on patient's healthcare decisions, and further their understanding on personal health decisions [11]. This is a conceptual study for a more technical future projects that will use mobile health applications built with Ionic to pull data from wearable health devices

from Misfit, Fitbit, and iOS to test the compatibility and plausibility under this framework. Ionic is a unique framework because it uses Apache Cordova to build apps that can operate on either iOS or Android and is not reliant on platform specific API's [12]. If the integrated service model is fully implemented using the open source applications chosen within this study, the system could easily be incorporated within any healthcare organization and provide opportunities for healthcare developers to build on this model's success, as technology continues to advances.

II. Related Work

a. Literature Review

The benefit of aggregated health data is extremely apparent in the predictive analytics field. Predictive risk algorithms used in clinical settings have been proven to improve outcomes and provide valuable data for clinicians to use for both individual patient care, and population health [13]. Manuel *et al.* [14] discusses predictive risk algorithms for population health management and focuses on stroke risk. It is noted that increased amounts of data for population health leads to more accurate estimates of disease risk, and higher calibration of risk algorithms. Although HIE's also have the potential to seamlessly share health data, they involve proprietary vendors working through interoperability issues with not only the state or federal entities, but also other proprietary entities. Thornewill *et al.* noted that HRB's offer a unique solution to the complex business aspects of data sharing by placing the consumer at the center of the model [15]. The study also noted that not just one HRB would be sufficient, but a network of HRB's that were administered by non-profit organizations would be relatively low cost and ensure portability of patient data [15]. The major software achievement needed for this concept paper is mapping between FHIR and C-CDA. This is necessary for the different data sets to be pulled

and pushed through the data base as requested by each individual healthcare entity. Although FHIR is very popular right now for mobile applications, C-CDA is a reliable clinical data standard that is still being used by many healthcare facilities for clinical and behavioral data.

With more personalized health data than ever before, clinicians have more tools for treating patients than ever before. As interoperability continues to improve, treatment plans no longer need to be “one size fits all”. Using concepts like personalized medicine, healthcare providers can look at the full scope of their specific patient’s condition down to their genetics. The clinician is then able to make personalized care plans based on concrete clinical decision support systems, and care algorithms [16]. Katsios *et al.* examined the personalized medicine concept for not only disease treatments, but also prevention. Using Bio-Markers for certain diseases like cancer and diabetes, Katsios proposed identifying those high-risk patients before diseases set in and creating preventative interventions to protect those patients. While conducting the disease treatment phase, personalized medicine can also be used as a barrier to adverse drug effects. Katsios notes that unlike the pharmaceutical industry of the past that would wait for the patient’s feedback on their reaction to drugs, clinicians can use pharmacogenomics to identify certain enzymes that will react adversely with some drugs and can model their treatment plan towards drugs that have less of an adverse opportunity per specific patient. Personalized medicine will continue to get increasingly powerful with additional health data being aggregated and analyzed. The proposed structure of this project will help achieve this goal by increasing data aggregation without increasing clinical workload.

Another critical aspect of effective healthcare delivery is transition of care. This piece of the patient care model is particularly difficult to accomplish efficiently if health care entities cannot communicate with one another and see the patient’s longitudinal health record [17].

Davis *et al.* examined care transition between two hospitals, two outpatient primary care clinics, and one state ran program. The study concluded that communication between all the entities was a major deficiency, particularly when caring for patients who had complex sociological requirements [17]. The study even noted that care for patients was “chaotic” when dealing with transitions, which are critical to patient outcomes. The study concluded that care fragmentation and communication barriers are major areas for improvement in current transition of care processes. The integrated service model proposed in this study would help resolve both of these problems by making patient care plans viewable by all clinical stakeholders and enabling a much more efficient transition of care.

b. Project Novelty

This project is unique because of the potential solutions that it offers to an industry that is on the cusp of wielding massive amounts of health data to improve population health management, personalized medicine, transition of care, and overall patient outcomes. This entire framework utilizes open source software, which essentially removes the proprietary stakeholders from the patients/customers data, which is a known barrier for achieving true interoperability.

III. System Design and Implementation

a. Resources

Using the XML structured database, eXist, API’s will be able to call for patient data using C-CDA or FHIR standards. This will be accomplished using a PHP server and PHP web application. The API requests will be routed to the HRB where patients/consumers data will be stored. These requests will only be granted if the patient authorizes access through Oauth2. The exception to this authorization process will be in emergent situations. The patient data points

identified in the Agonaut Project will be the standard for this conceptual model. They include: Patient name / Sex / Date of birth / Race / Ethnicity / Preferred language, smoking status, problems, medications, medication allergies, laboratory test(s), laboratory value(s)/result(s), vital signs – height, weight, blood pressure, BMI, Care plan field(s), including goals and instructions, procedures, care team member(s), and documents relating to a patient. The patients themselves will also have accessibility to their data via a modified C-CDA viewer that will be based on SSL/TLS using web services. Public library access will be available to those that don't have other means. See figure 1 for visual depiction.

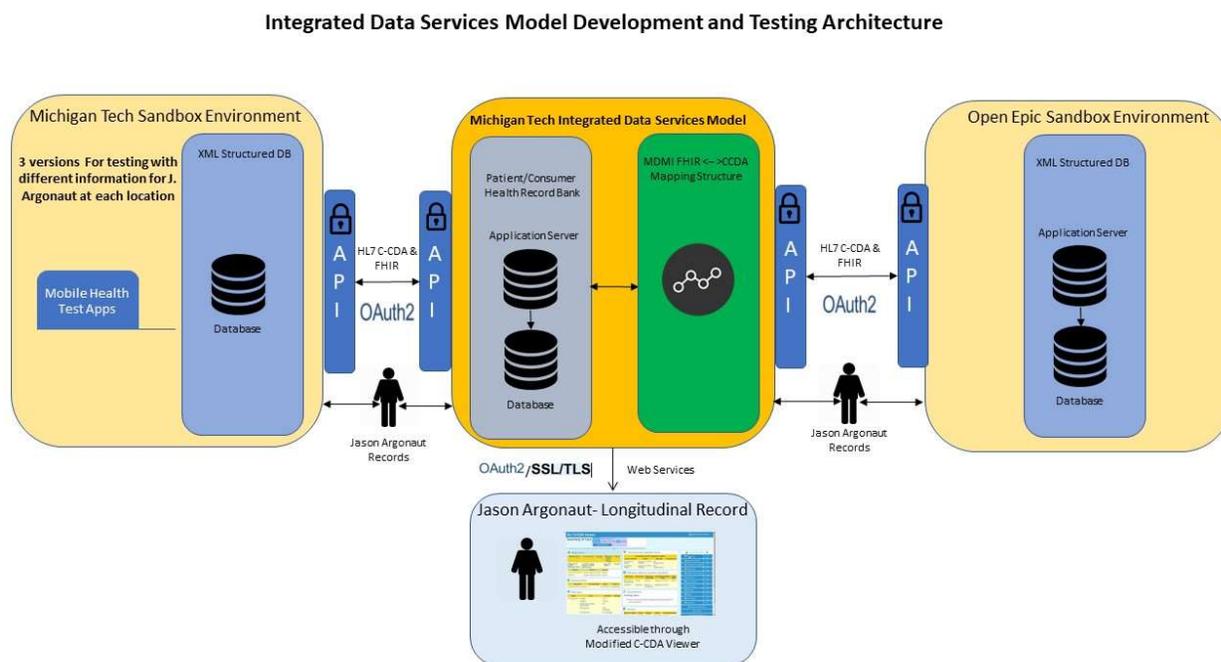


Figure 1.

Once the framework is in place from this concept paper, the testing will occur using mobile health applications which utilize data from wearable devices. The applications will be built using Ionic framework, providing web, Android, and Apple device access to the patient data securely and accurately.

IV. Results and Discussion

This concept paper has provided a framework, that if implemented correctly, could have a major impact on how healthcare data is stored, shared, and most importantly, owned. The integrated service model will allow patients to view and authorize access to their data through trusted sources that are secure. For less technical savvy patients that maybe skeptical of technology, the public library will serve as “trustworthy” location to view and dictate access to their data. This framework will also allow huge advancements in population health management data without additional reporting workload for providers or administrators. This piece cannot be overlooked. Since it is no additional work for clinicians, it will encourage healthcare organizations to sign up with the HRB model. This coupled with the consumer shift to own their health data can revolutionize the healthcare industry. All of the applications and software programs are open source in this project, so there are very low maintenance costs. By removing all the proprietary layers that complicate coordination between organizations, and raise costs, we have built a simpler, cheaper, and consumer driven model for health data management.

V. Conclusion and Future Works

The concepts described in this paper are currently being tested using the above specifications. The future works will be extensive testing, and formal reporting of results. Once successful large-scale testing is completed, the integrated service model can begin implementation for small healthcare facilities that need to meet MU data sharing requirements. From there, the model can grow from consumer demand for more control of their data. The consumers will have the power to drive the health data landscape to a cheaper and more interoperable solution. However, patient’s will need to take more interest in picking healthcare

organizations that participate in this model, since it might not be the first choice for larger proprietary organizations. The future of healthcare data is in the hands of the patients themselves.

Resources

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