Empowering Patients Using Cloud Based Personal Health Record System

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Abstract:

One of the main goals of the electronic health record (EHR) system is to empower patients to access to their own medical decisions. However, medical data is largely coming from clinical institutions so there is no way for them to conttrol or maintain their own medical record. Patients or guardians may need to keep track of their medical data such as observed symptoms or measurements that may not be available in the EHR. Additionally, clinical decision without patient medical history can be error-prone and even be detrimental. Personal medical condition history is considered as the one of the weakest links in the current healthcare systems. For those reasons, it is necessary to have an effective and efficient personal health record system (PHRS) that allows patients or guardians to constantly monitor and control the personal health record. We propose a cloud based personal health record system that allows constant monitoring capability by supporting dynamic creation of clinical document architecture (CDA) document from a mobile device. The generated CDA document may be used to assess current health against major diseases through a clinical decision support system. We provide constant monitoring capability by using easy uploading module and decision support system. Our proposed system uses medical coding standards such as ICD-9-CM, SNOMED CT, etc. to achieve interoperability between different electronic health record systems.

***Keywords**: electronic health record (EHR), personal health record (PHR), cloud based file management, clinical document architecture (CDA), meaningful use (MU), clinical decision support*

1. Introduction

As defined by the Office of the National Coordinator for Health Information Technology (ONC), the meaningful use [1] of electronic health record can benefit not only clinical institutions but also the general public in many ways – the transition from clinician centered to patient centered. Thanks to the interoperable electronic health record (EHR) system – compliant to the meaningful use criteria, taking control of our own medical record is no longer a wishful thinking. However, real-only access to our own EHR has limited benefits since there is no way to report our own health condition during doctor visits. Unrecorded personal medical data such as noticeable symptoms, current medications, medical event (e.g. bodily damage), etc. may be ignored easily and not be shared with clinicians, which results in serious disease later on. Once a patient is diagnosed with a disease, he or she needs to go through painful procedure to cure the disease.

In the United States, about 100,000 patients died every year and more than 1.5 million are affected due to the medical errors. This large number can be significantly reduced by engaging information technology in sharing medical data (e.g. personal medical history and supporting documents, medical treatment). For this reason, there have been growing interests in the design and development of appropriate PHR systems [2, 3, 4].

Thus, we propose a personal health record (PHR) system that allows an individual to monitor and share the data with the clinicians. In terms of the meaningful use, both EHR and PHR must be interoperable with each other via the compliance to all applicable medical standards such as ICD-9-CM, SNOMED CT, LOINC, and HL7.

Our paper is organized as follows: section 2 discusses about the background of electronic health record. In Section 3 clinical document architecture is introduced and explained. Section 4 introduces personal health record system model and section 5 concludes our discussion.

2. Background

The value of patients' medical record lies in some properties as suggested by Iakovidis [7]:

1) Accessibility and availability: Patient medical record should be continuously accessible and available.
2) Usability and flexibility: They should support multiple user views and user-friendly interactions such as inputs and outputs of data.
3) Integration: It should handle different administrative and clinical systems.
5) Performance: It should respond quickly enough
6) Confidentiality and auditability: It also needs to provide an audit trail that keeps track of interactions

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and authentication of information using user's identification such as digital signature.
7) Reliability: ensures data integrity and permanence of original information in agreed format and for given time

Electronic health record system has two main parts – electronic health record (EHR) and personal health record (PHR). They can be defined as:

· Electronic Health Record
An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff across more than one health care organization.

· Personal Health Record
An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.

PHR has been used in many areas such as knowledge sharing, continuity of care, preventive care, and clinical decision support. Li-Hui Lee et al. [2] proposed the design method of PHR system using IHE Cross-Enterprise Document Sharing (XDS) architecture. Their approach was to enhance utilization and interoperability of PHR CDA documents through the registration of the documents in the repository using patient identifier and Dublin Core (dc) for efficient retrieval. The proposed system – Personal health Record and Knowledge Sharing System (PHR & HKS) - was intended to enhance patient's self-care ability.
Pieterjan De Potter et al. [5] attempted build healthcare ontologies to solve the interoperability problem among different data providers.
In a PHR, ICD-9-CM [13] is used to specify the disease a patient suffers from. However, even though ICD-9-CM is useful in specifying diseases, it has limited capability in describing problem list. For better description of problem list, SNOMED CT [10] may be used as it is designed to describe problems with great details.

We propose a personal health record system that utilizes all applicable standards such as ICD-9-CM, SNOMED CT, and HL7 CDA with the intention to provide interoperability with various other electronic health record systems. With the proposed system, patients can manage, share and control their own personal health records in an interoperable way.

3. Personal Health Record in HL7 CDA

HL7 Clinical Document Architecture (CDA) is a document standard that specifies the structure and semantics of "clinical documents" for the purpose of interoperability and exchange of data between healthcare providers and patients. In our proposed system, patient health records are stored in CDA format. The most popular use of CDA is in information exchange, as used among US Health Information Exchanges (HIE). The HL7 CDA describes a clinical document as having the following six characteristics: 1) Persistence, 2) Stewardship, 3) Potential for authentication, 4) Context, 5) Wholeness, and 6) Human readability. EHR/PHR is one of their 5 target usages.

In a CDA document, there are a number of applicable coding standards such as SNOMED CT and ICD-9/10-CM for describing patient's health. SNOMED-CT is a terminology that allows detailed problem reporting but the 9th/ 10th clinical modification of the International classification of diseases (ICD-9/10- CM) code is originally designed for billing. Both standards can aggregate the details into codes so easy reporting is possible. These standards are used to document problem lists, family history, drug reactions, smoking status and hospital procedures in the EHR/PHR. Hospitals and providers were required to make the transition to ICD-10-CM on October 1, 2014 but it hasn't happened yet at the time of this writing. When it happened, it will become the only acceptable coding language for billing and reimbursement within the scope of meaningful use (MU) Stage 2 attestation.

The CDA documents in the PHRS can be categorized into two types:

- Static CDA that has mostly permanent information such as personal information, blood type, immunization record, etc.
- Dynamic CDA that contains temporary information such as blood pressure, pulse, medication, noticeable symptoms, etc.

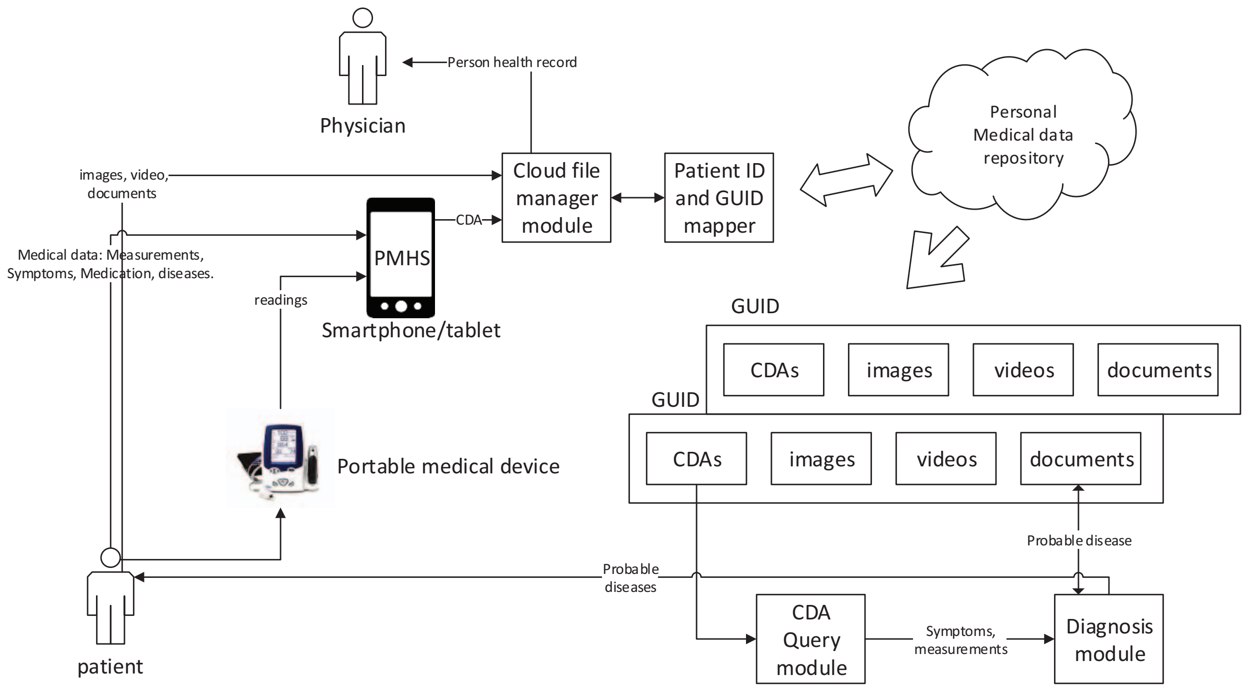

Figure 1: Personal Health Monitoring System

The structure of PHR follows the EHR structure as specified by ISO 13606, i.e., composition, folder, entry, section, element, and cluster.

4. Personal Health Record System (PHRS)

The PHRS, as shown in the figure 1, is a model that allows each individual to store, monitor, and control their health records. It consists of four main modules: data collection and clinical document architecture (CDA) file generation module, cloud based file management module, CDA file query module, and diagnosis module.

4.1 Clinical data collection module

The Android based mobile application – personal mobile health system (PMHS) – as shown in the figure 2 is used to collect medical data for each individual and generate corresponding CDA files. The generated CDA files may be uploaded into the cloud based file management system for storage and monitoring. With the PMHS, each patient will have control over their personal medical information – the information clinical institutions may not have, which will help reduce the complexity of health care delivery to each individual significantly. Home care and residential care will enjoy similar benefits. In short, the general public will be able to manage their own medical data creation, retrieving, utilizing, processing and maintenance, and make it sharable (with physicians) through the PMHS.

4.2 Cloud based file manager module

The module, as shown in the figure 3, is based on any cloud based data storage system such as Dropbox®. It manages each patient's uploaded files such as CDA files, medical images, medical video files, and any

Figure 2. Personal Mobile Health System (PMHS)

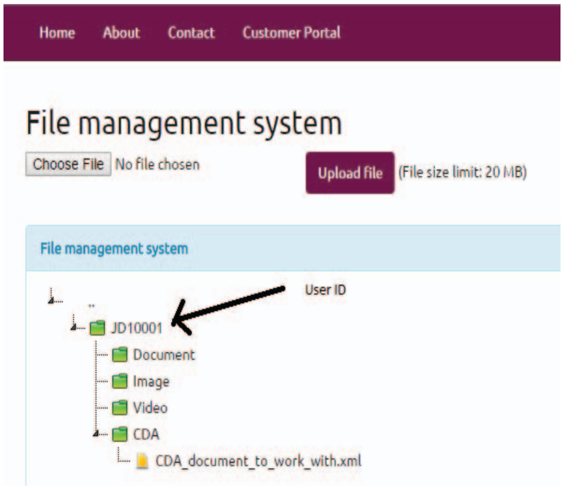

Figure 3. Cloud File Manager Module

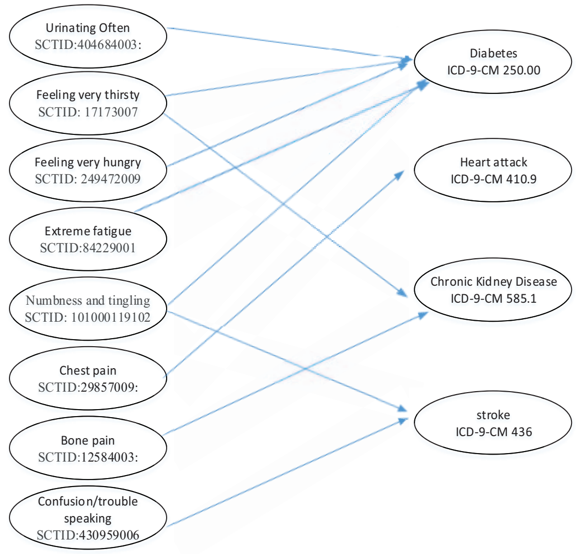

Figure 5. Symptom and disease mapping

other related medical documents (e.g. medical charts, immunization records, etc.). The files will be uploaded by each individual and may be shared with physicians when necessary for the treatment. Each individual will have his/her own storage in the cloud that has four distinct directories – CDA, image, video, and document as shown in the figure 1. To avoid the duplication of identifiers, we use globally unique identifier (GUID) which is an implementation of universally unique identifier (UUID) standard [6] at the top level of individual storage. The mapper between GUID and patient (user) ID provides easy access to the storage. Since it is based on the cloud, the contents of files are accessible to any authorized user such as their physicians.

```
<Observation classCode="COND">
 <code code="39154008" codeSystem="2.16.840.1.113883.6.96"
codeSystemName="SNOMED CT" displayName="clinical diagnosis"/>
<targetSiteCode code="404684003" codeSystem="2.16.840.1.113883.6.96"
codeSystemName="SNOMED CT" displayName="Frequent Urinating">
<name code="17173007" codeSystem="2.16.840.1.113883.6.96"
codeSystemName="SNOMED CT" displayName="Thirsty"/>
<value code="84229001" codeSystem="2.16.840.1.113883.6.96"
codeSystemName="SNOMED CT" displayName="Fatigue"/>
</targetSiteCode>
<reference typeCode="XCRPT">
<ExternalObservation>
    <id root="123.456.789.23.18"/>
</ExternalObservation>
    </reference>
</Observation>
```

```
Code Name:404684003
Effective Time:200004071530
Code Name:17173007
Effective Time:200004071530
Code Name:84229001
Effective Time:200004071530
```

```
from xml.dom.minidom import parse
import xml.dom.minidom

DOMTree = xml.dom.minidom.parse("C:\\SNOMED-CT.xml")
clinical_document = DOMTree.documentElement
def getElements(parent, tags):
    result = []
    for tag in tags:
        children = parent.getElementsByTagName(tag)
        for child in children:
            result.append(child)
    return result
observations =
clinical_document.getElementsByTagName("Observation"
)
for observation in observations:
    tags = ['code', 'value', 'effectiveTime']
    children = getElements(observation, tags)
    for child in children:
        if(child.hasAttribute("codeSystemName")):
            if(child.getAttribute("codeSystemName")
== "SNOMED CT"):
                print("Code Name: %s" %
child.getAttribute("code"))
        else:
            print("Effective Time: %s" %
child.getAttribute("value"))
```

Figure 4. CDA query module with sample data

4.3 CDA query module

CDA query module is to extract the XML attributes- SNOMED-CT code and Effective Time in a consolidated CDA file generated from PMHS. The query module prepares textual output clinically relevant for the diagnosis module.

In order to do so, CDA query module uses a XML parsing program to search nodes with “codeSystemName” equals to SNOMED CT” and nodes with “Effective Time” and then extract the actual SNOMED CT codes and the Effective Time values so that the diagnosis module can use them as inputs. The figure 4 shows an example of CDA file, a XML parsing program and an output from a consolidated CDA file.

4.4 Diagnosis module

The diagnosis module contains Clinical Decision Logic. The personal health data in CDA format is queried and stored in textual format so it can be used as input for the diagnosis module. The diagnosis module matches symptoms in the personal medical data to the diagnosis rules. If there is a matching then the module produces corresponding messages to the user. The SNOMED CT code is used for the symptoms, as shown in the figure 5, and ICD-9-CM code is used for the diseases and procedures. The mapping diagram from symptoms to potential diseases is also shown in the figure. The diagnosis module is used to map from the symptoms to the diseases. Certain symptom are showing strongly relation to a disease.

The proposed diagnosis module uses a rule-based system CLIPS [8] which is an expert system shell. This system matches facts that are symptoms with vital signs and rules. If there is a match, then the matched rules will be activated. Each disease symptom or a vital sign will be facts (input of the system) and the rules in the system will compare these facts with pre-defined diseases and issues a warning sign to the user or issues a summary report to a doctor’s office (as an output) . The figure 6 shows a sample CLIPS code for detecting a diabetes case from a personal health record and figure 6 also shows the CLIPS console running snap shot. Some of the symptoms such as glucose level and A1C level are considered as major and some others such as feeling thirsty or feeling hungry are considered minor (or relevant) symptoms. The purpose of the

```
(person (id 2345)(glucose 180)(urinating
"Normal")(thirst "Normal")(weight_gain
"No")(blurred_vision "No")(itchy_skin
"No")(gum_swolen "No")(numbness_tingling "No"))

(person (id 1234)(glucose 140)(urinating
"Excessive")(thirst "Excessive")(weight_gain
"Yes")(blurred_vision "No")(itchy_skin
"No")(gum_swolen "No")(numbness_tingling "No"))

(person (id 2222)(glucose 90)(urinating
"Excessive")(thirst "Excessive")(weight_gain
"Yes")(blurred_vision "Yes")(itchy_skin
"No")(gum_swolen "No")(numbness_tingling "yes"))

(stage 2)
```

```
(deftemplate person
 (slot id)(slot glucose)
 (slot urinating)(slot thirst)
 (slot weight_gain)
 (slot blurred_vision)(slot itchy_skin)
 (slot gum_swolen)
(slot numbness_tingling) )
;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;;
(defrule Diabetes
   (initial-fact)
   (stage 2)
   (person
(id ?id)(glucose ?level)(urinating ?urine)(thirst ?thirst)(weight_gain ?w
eight_gain)(blurred_vision ?vision)(itchy_skin ?skin)(gum_swolen ?gu
m)(numbness_tingling ?numbness))
(test (> ?level 126))
=>
(printout t "ID= " ?id " High glucose level is detected.")
(printout t " Please see a doctor for diabetes." crlf)
(assert (warning ?id ?level)))

(defrule diabetes-watch
person(id ?id)(glucose ?level)(urinating ?urine)(thirst ?thirst)
(weight_gain ?weight_gain)(blurred_vision ?vision)(itchy_skin ?skin)(g
um_swolen ?gum)(numbness_tingling ?numbness))
   (test (or (and (< ?level 126) (eq ?urine Excessive) )
          (and (< ?level 126) (eq ?thirst "Excessive") )) )
=>
(printout t "ID = " ?id " Your glucose level is " ?level )
(printout t " which is")
(printout t " nomal range " crlf)
(printout t " but other signs indicating diabetes." crlf)
(printout t " Please watch your glucose level." crlf))
```

```
CLIPS> (load "./../diabetes4.txt")
Defining deftemplate: person
Defining defrule: Diabetes +j+j+j+j
Defining defrule: diabetes-watch +j+j
TRUE
CLIPS> (load-facts "./../ddata.dat")
TRUE
CLIPS> (run)
ID= 1234 High glucose level is detected. Please see a doctor for diabetes.
ID= 2345 High glucose level is detected. Please see a doctor for diabetes.
ID = 2222 Your glucose level is 90 which is nomal range
 but other signs indicating diabetes.
 Please watch your glucose level.
CLIPS>
```

Figure 6. CLIPS rule-based module

diagnosis module is to analyze the uploaded CDA documents and be able to notify the users of the potential problems that might exist in the document. The diagnosis module keeps track of abnormal signs or symptoms for all predetermined diseases (major diseases) by saving the probable disease list to document directory in the figure 1. Probable disease list may be referenced for the next assessment.

4.5 Scenario

Personal health monitoring consists of a sequence of activities as shown in the figure 1. The first step is to collect personal medical data including measurements periodically and upload to the repository in the cloud. The medical data can be any personal medical data that is meaningful to each individual such as lab test results, CT-Scan images, medication, chronic disease, observed medical symptoms such as shortness of breath, or scanned immunization record. Most of medical data such as the measurements from portable medical devices (PMD), observed symptoms, medication, etc. may be included in CDA documents.

When a CDA document is uploaded to the cloud, the CDA query module is used to retrieve relevant data from CDA files and convert medical data such as observed symptoms in a text file so it can be used with the diagnosis module. The diagnosis module takes the output from the CDA query module as input for the analysis. It compares the observed symptoms and other measurements against facts such as major symptoms and minor symptoms of diseases. The outcome of the module will be a list of probable diseases, if any.

5. Conclusions

In this paper, we proposed a personal health record system (PHRS) that is to self-monitor and control personal health. Unlike clinical institution centered electronic health record, entire medical data is managed and controlled by individual – patients or their guardians. The PHRs are useful at home care, nursing home, or private care facility where constant monitoring and control are needed. We have used mobile application to collect medical data and stored in HL7 CDA format for interoperability. The cloud based repository may be shared with the clinicians when needed. The proposed PHR satisfies important properties such as accessibility and availability, reliability, confidentiality, and reliability. The PHRS aimed to build long-term personal medical history.

References

[1] The 2014 definition of meaningful use, http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Meaningful_Use.html

[2] Li-Hui Lee, Yi-Ting, Ean-Wen Huang, Der-Ming Liou, “Design of a Personal Health Record and Health Knowledge Sharing System Using IHE-XDS and OWL”, J Med Syst (2013) 37:9921 DOI 10.1007/s10916-012-9921-4

[3] Do, N. V., Bamhill, R., Heermann-Do, K. A., Salzman, K.L., and Gimbel, R. W., The military health system’s personal health record pilot with Microsoft HealthVault and Google Health, J. Am. Med. Inform. Assoc. 18(2):118-124, 2011, doi:10.1136/jamia 2010.004671.

[4] Adida, B., Snayal, A., Zabak. S., Kohane, I.S., and Mandl, K. D., (3041305) Indivo x: developing a fully substitutable personally controlled health record platform. In: AMIA Annu Symp Proc. Pp 6-10, 2010

[5] Pieterjan De Potter, Hans Cools, Kristof Depraetere, Giovanni Mels, Pedro Debevere, Jos De Roo, Csaba Huszka, Dirk Colaert, Erik Mannerns, Rik Van de Walle, “Semantic patient information aggregation and medicinal decision support”, Elsevier, Computer methods and programs in biomedicine 108 (2012) 724 – 735

[6] Robert H. Dolin et al., “HL7 Clinical Document Architecture, Release 2”, J Am Med Inform Assoc. 2006; 13:30-39, DOI 10.1197

[7] Ilias Iakovidis, “Towards personal health record: current situation, obstacles and trends in implementation of electronic healthcare record in Europe”, Int’l Journal of Medical Informatics 52 (1998) 105 – 115

[8] Joseph C. Giarratano, Gary D. Riley, “Expert Systems principles and Programming, Fourth Edition”, Thomson Course Technology, 2005