Standard-based Patient-centered Personal Health Record System

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ABSTRACT

Modern healthcare systems are going through paradigm-shift process – from clinician-centered to patient-centered, as it is essential to implement core values of modern healthcare such as continuity of care, evidence-based treatment and more importantly preventing medical mistakes. In order to implement patient-centered healthcare system, it is necessary to collect all the relevant clinical / non-clinical data for each patient and make such data shareable with caregivers at the time of needs. However, such task requires significant personal effort and close coordination among the caregivers, which is difficult to implement properly. In this paper, we are proposing a personal healthcare system and a Raspberry Pi based clinical data measurement module where patients can take full control over their own health data and also facilitate communications among all participants. The storage can be accessible from patients and physicians so both parties can contribute to the clinical information, which allows monitoring and control of personal health. Our system utilizes personal cloud storage where each patient stores his/her data in a standardized format such as SNOMED CT, ICD-10, HL7 CDA [9], etc. and such storage is completely independent from any applications so patients can own their own clinical information regardless of types of medical insurance plan, hospitals, or doctor’s office.

CCS Concepts

• Applied computing → Health care information systems; Consumer health;

Keywords

Personal health record, electronic health record, medical standards, personal cloud storage

1. INTRODUCTION

The healthcare system in the US is going through paradigm shift from clinician-centered to patient-centered as the one of the six trends pointed out by the Institute of Medicine[10]. The term “patient-centered” implies that the patients take control over their own health information. When it comes to make medical decision, patients must get involved in their own decision making process, i.e., patients should be in charge of their own medical records – “No decision about me without me”. The difficulty of keeping track of personal health information lies in the fact that the health data is in multiple places and the associated formats are not easy to handle. When a multiple doctors with different concerns are involved in diagnosis and treatment, it becomes more complicated to collect all the necessary information about the patient in one place and make it shareable with the caregivers. Having right information at right time to the right people can improve the outcome of the treatment as it enables the continuity of care and prevents potential medical errors. Personal health record (PHR) and electronic health record (EHR) are similar but the main difference is that PHR users maintain their own health records and have control over the access to their own health information. PHR should be the source of clinical information of each individual due to the fact that complete medical history may not be available in one clinical institution while carefully maintained PHR may have. There are many EHR services available but most of them are tethered to certain providers and those services may not be available when the patient leaves the provider’s medical plan. It is patients’ right to have their own health information. However, since there are not many PHR services available across organizations, patients lose their access to their own valuable health information as they move from one provider to another or some PHR service providers may go out of business.

Our goals for the PHR system are:

• Clean separation of clinical data from its application so the same clinical information may be used in many different applications.

• Managing all clinical data and their associated media files in a patient owned storage so it can be monitored and controlled by the patient and/or any authorized caregivers
2. RELATED WORK

An important objective of the Meaningful Use [24] stage 1 is to record, store, and report clinical quality measures. The Meaningful Use of EHR for physician collaboration in a patient-centered perspective was discussed by Cherie Noteboom, et al. [16]. When it comes to effective treatment, nothing is more valuable than the right health information at right time to the right people. June Bronnert, et al. [6], discussed interface terminology to build interoperable electronic health records by using standardized terminology such as Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT), International Disease Classification (ICD), etc. They argued that clinical workflow must be analyzed and inject standard code browsing procedure so clinicians can find relevant code easily. By using the standardized codes, the quality of care can be improved since the codes describe the treatment procedure and patient condition more accurately. Their discussion was limited to clinicians use only. However, electronic health records (EHRs) contains fragments of medical history so the effectiveness would be limited to the amount of information the EHRs. Personal health record, on the other hand, would have better chance of having more health information of a person [3] since the information is not tethered to any particular organization. For that reason, Pringle S, Lippitt A [17] discussed interoperability of EHRs and PHRs. However, there was no consideration of the ownership and sustainability of personal health information.

Paul C. Tang, et al. suggested ways to encourage the adoption of PHR system by removing the barriers [22]. There have been some approaches in semantic interoperability of electronic health records. Catalina Martinez Costa, et al. [7], suggested semantic interoperability using standardized codes. J. Bisbal and D. Berry proposed an analysis framework for EHRs where the authors proposed a framework to build EHRs and make them interoperable [5]. The relationship between physician-patient in the presence of PHR was discussed by Aaron Baird, et al [2]. They showed the early evidence of the active roles from healthcare consumers through the use of PHR.

The mobile PHR applications can come in handy especially in the case of emergency. H. Kharrazi et al. did survey on various mobile personal health records [12]. They found out that most of the applications they surveyed lacked essential features such as security. None of the mobile application has all the features they surveyed. As the mobile technologies continue to advance and the penetration rate of the smartphones continue to grow [20], the mobile PHR applications will play a major role in empowering the patients. The research prototypes that monitor personal health with biosensors are available as shown in Table 1.

3. CLINICAL DATA COLLECTION

Personal clinical data may be collected in a number of ways. Clinical data can be categorized as:

- Measurement data such as blood pressure, SPO₂, etc.
- Observed symptoms such as feeling dizziness, chronic diseases, acute diseases, etc.
- Clinical document from external sources such as hospitals, doctor’s office, lab results, etc.
- Immunization records, medical chart, etc.
Table 1: Health Monitoring Systems with Biosensors

<table>
<thead>
<tr>
<th>Project/Institution</th>
<th>Hardware Description</th>
<th>Medical Applications</th>
<th>Measured Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>HeartToGo[11]</td>
<td>A cell phone &amp; Wireless ECG sensors</td>
<td>Individualized Cardiovascular Disease prevention &amp; detection</td>
<td>ECG</td>
</tr>
<tr>
<td>Personal Health Monitor system[13]</td>
<td>A mobile phone &amp; ECG sensor</td>
<td>Heart attack detection &amp; alerting the emergency services</td>
<td>ECG</td>
</tr>
<tr>
<td>LifeGuard[15]</td>
<td>A wearable device (CPOD) &amp; physiological sensors</td>
<td>Clinical, home-health monitoring, first responder and military applications.</td>
<td>ECG, BP, RESP, T, SPO₂</td>
</tr>
</tbody>
</table>

Figure 2: e-Health board and the measurement result in the serial monitor

- Medical images such as DICOM [23] files and other image and multimedia formats

3.1 Measurement Data Collection

In our approach, we have paired standard Raspberry Pi microcontroller boards with a specialized e-Health sensor board. The initial prototype system is built on top of a Raspberry Pi 3 [18], a microcontroller board with a 900MHz quad-core ARM Cortex-A7 CPU. On top of the Raspberry Pi, we gave added an e-Health Sensor Shield V2.0 (designed by Cooking Hacks [14]) as a platform to integrate and monitor personal health sensors. The Raspberry Pi acquires biosensor data from the sensors of the e-Health Sensor Shield. The e-Health Sensor platform allows users to measure 10 different health metrics: pulse rate, blood oxygen level (SPO₂), respiration airflow, body temperature, blood glucose levels, electrocardiogram (ECG), galvanic skin response (GSR), blood pressure, patient position (accelerometer) and muscle/electromyography (EMG). For example, to measure the blood pressure, the combined platform uses a combination of C++ code and the Cooking Hacks ArduPi and e-Health C++ libraries. A simple demonstration application to print the blood pressure data to a terminal window is shown in Figure 2. Once the Raspberry Pi acquires the data from the medical sensors, the data is processed by a monitoring application for storage and live diagnostic purposes. A prototype configuration is shown in the Figure 3. Finally, the measured data can be passed to a mobile personal health record system (MPHRS) as shown in the Figure 4 for individual storage and record-keeping purposes.

3.2 Mobile Personal Health Record System

The Mobile Personal Health Record System (MPHRS) is an Android application designed to handle the following features:

- Measurement data including lab test results
- Disease data
- Current medication list
- HL7 CDA [9] document creation

Once the relevant data is collected, the MPHRS creates HL7 CDA document for upload. Each created CDA document plays a role as a snapshot of the user. Each snapshot represents current health status of the user. The screenshots of the MPHRS are shown in the Figure 5.

3.3 SNOMED CT Browser

Clinical data must be understandable by caregivers for interoperability. Since there are so many different kinds of diseases with different symptoms, verbal descriptions may not serve its functions – conveying the precise health status to others. For that purpose, Systematized Nomenclature for Medicine Clinical Terms (SNOMED CT) was created. In our project, we are attempting to utilize SNOMED CT code as much as possible. In line with such effort, our SNOMED CT browser – SNOBRO was developed. It is a Java application on Spring TC server.
SNOBRO takes the description of symptoms, disease name, measurement types, etc. as input and returns the corresponding SNOMED CT code as output. SNOMED CT has the most comprehensive medical terminology in the world. SNOMED CT covers multilingual clinical healthcare terminology and is mapped to other international standards. With SNOMED CT, the clinical description can be conveyed to other clinicians precisely. It is also possible to analyze large volume of clinical data automatically. The frequently used medical terms and popular diseases terms are shown in the Table 2 as examples.

<table>
<thead>
<tr>
<th>Concept</th>
<th>SNOMED CT Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Weight</td>
<td>27113001</td>
</tr>
<tr>
<td>Body Height</td>
<td>50373000</td>
</tr>
<tr>
<td>Excessive Thirst</td>
<td>17173007</td>
</tr>
<tr>
<td>Fatigue</td>
<td>84229001</td>
</tr>
<tr>
<td>Chest pain</td>
<td>29857009</td>
</tr>
<tr>
<td>Dizziness</td>
<td>404640003</td>
</tr>
</tbody>
</table>

It is designed to be used by patients and/or caregivers. The SNOMED CT browser was implemented for desktop and for mobile device [19] as shown in the Figure 4.

3.4 Dublin Core Metadata

When various types of clinical data items are stored, the management of those items becomes problematic. In order to manage collected clinical data, we have tried Dublin Core [8] metadata standard. In our proposed system, every clinical data item, at least one metafile is created for the management and query purpose. Every tag in the metafile is used to describe the collected data item. The example usage of Dublin Core is shown in the Table 3.

The contents of metafiles in the system are used to search data items. The quality of the description in the metafile can determine the quality of the search result.

4. PATIENT-CENTERED PERSONAL HEALTH RECORD SYSTEM

As shown in Figure 6, the use cases for the Patient-Centered Personal Health Record System (PPHRS) indicate that the patient has control over his/her own personal health information and only the clinicians authorized by the patient will be given the access to the health information.

When uploading clinical data, metadata creation is required so each uploaded item can be searched. By having his/her own health information, the patient can be able to participate in his/her own medical decision process.

The proposed patient-centered PHRS (PPHRS) has four main principles (DIMC) in mind:

- **Data independency** the separation of personal health information and its applications
- **Interoperability** application of all applicable medical standards for health information
- **Metadata** use of metadata for managing personal health information
- **Communication** ability of communication among and between care givers and patients
Interoperability is one of the main factors in implementing continuity of care, evidence-based treatment, and preventing medical errors. Interoperability enables PHR users to use different applications to manage their health information.
Listing 1: metadata content for the CDA file

```xml
<?xml version="1.0" encoding="UTF-8" standalone="no" ?>
  <Title>EoR generated .xml</Title>
  <Creator>Yeong-tae Song</Creator>
  <Subject>sample CDA file</Subject>
  <Description>Hospital visit summary</Description>
  <Publisher/>
  <Contributor/>
  <Type>.xml</Type>
  <Format>28.1 KB</Format>
  <Identifier/>
  <Source>ABC hospital</Source>
  <Language>en</Language>
  <Relation/>
  <Coverage/>
  <Date>29 Jul 2016 17:54:52 GMT</Date>
</metadata>
```

Figure 9: An example CDA document in the PPHRS

For the interoperability, the PPHRS is using all applicable medical standards:

- HL7 CDA [9] is used for describing various kinds of clinical data including: measurement data, medication list, lab test result, doctor’s opinion, etc. Patient generated clinical data such as measurements data and observed symptoms may be collected by the mobile application (MPHRS) and uploaded to personal cloud storage using the PPHRS. Medical records from other sources such as hospitals and doctors’ offices may also be uploaded to personal cloud storage. An example CDA is shown in Figure 9.

- Dublin Core [8] metadata standard, used for describing all personal health data files including scanned documents, CDAs, DICOMs, and any multimedia files. To upload a document, it is required to create a metadata for the document. The metadata files are used to search relevant clinical data later on. The tags for the Dublin Core is used to describe the characteristics of the document to be uploaded. The content of the Dublin Core metadata for the CDA file in the Figure 3 is shown in the Listing 1. The PPHRS combines all metafiles into one metafile so as to improve effectiveness of the search. The illustration of the combined metafile is shown in the Figure 8. As shown in the

- SNOMED CT is designed to improve the effectiveness of electronic health records. SNOMED CT is useful for clinical documentation, as it describe precise clinical conditions. In PPHRS it is used to describe any physical condition, clinical measurements data, or disease conditions such as major symptoms or minor symptoms along with disease names. The Java-based SNOMED CT browser (SNOBRO), as shown in the Figure 4, was developed to help patients to record their clinical conditions or to understand the clinical terms in the documents from other sources.

4.2 Communications between patient and physicians

In PPHRS, there are two different logins – one for patient and the other for physicians. When patient logs in, depending on the medical plan, available doctors are displayed. When the patient needs to see a doctor in the list, the patient simply select the doctor and give permission to access their clinical document to the doctor. Then the doctor becomes “my doctor”. Once a doctor is selected, the patient and the doctor can communicate with message board. Both parties can be able to contribute to the clinical data. The patient can upload their clinical data such as measurement data, observed symptoms, lab test results, etc. while the doctor can upload visit summary, opinion, referral, prescription, etc. Messages can be exchanged as needed. The communications between physicians are also possible for the implementation of continuity of care, evidence-based treatment and preventing medical errors. In case of emergency,
the CDA that containing current medication list, allergy, or any adverse reaction may be searched for reference.

5. CONCLUSIONS AND FUTURE WORK

In this paper, we have proposed a patient-centered personal health record system (PPHRS) and Raspberry Pi based clinical data measurement system. We attempted to include all applicable medical standards in PPHRS including HL7 CDA, Dublin Core, and SNOMED CT so the personal health information (PHI) can be interoperable regardless of the application that uses the PHI. We also implemented Raspberry Pi based clinical data collection system. The collected clinical data was stored in a CDA file and uploaded to the PPHRS for monitoring and control.

As future work, we plan to make direct interface between medical sensors and smartphone application so clinical data collection process can be automated without user intervention. The decision support system for the collected clinical data will also be considered. Emergency data such as current medication list, allergy, and adverse reaction management can benefit patients when they are in some emergency situation.

6. REFERENCES


