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TOWARD PATIENT-CENTERED PERSONAL HEALTH RECORDS SYSTEMS TO PROMOTE EVIDENCE-BASED DECISION-MAKING AND INFORMATION SHARING

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DISSERTATION APPROVAL PAGE

This is to certify that the dissertation prepared by Mohammed Abdulkareem Alyami, entitled "TOWARD PATIENT-CENTERED PERSONAL HEALTH RECORDS SYSTEMS TO PROMOTE EVIDENCE-BASED DECISION-MAKING AND INFORMATION SHARING," has been approved by the dissertation committee as satisfactorily completing the dissertation requirements for the degree Doctor of Science in Information Technology.

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Abstract

Personal health record (PHR) is considered a crucial part in improving patient outcomes by ensuring important aspects in treatment such as continuity of care (COC), evidence- based treatment (EBT) and most importantly prevent medical errors (PME). Recently there has been more focus on preventive care or monitoring and control of patients symptoms than treatment itself. Nowadays, there are many mobile health applications and sensors such as blood pressure sensors, electrocardiogram sensors, blood glucose measuring devices, and others that are used by the patients who monitor and control their health. These apps and sensors produce personal health data that can be used for treatment purposes. If managed and handled properly, it can be considered patient-generated data. There are other types of personal health data that are available from various sources such as hospitals, doctors offices, clinics, radiology centers or any other caregivers.

Aforementioned health documents are deemed as a PHR. However, personal health data is difficult to collect and manage due to the fact that they are distributed over multiple sources (e.g. caregivers, patients themselves, clinical devices, and others) and each may describe patient problems in their own way. Such inconsistencies could lead to medical mistakes when it comes to the treatment of the patient. In case of emergency, this situation makes timely retrieval of necessary personal clinical data difficult. In addition, since the amount and types of personal clinical data continue to grow, finding relevant clinical data when needed is getting more difficult if no actions are taken to resolve such issue. Having complete and accurate patient medical history available at the time of need can improve patient outcomes by ensuring important aspects such as COC, EBT, and PME. Despite the importance of PHR, the adoption rate by the general public in the U.S. still remains low. In this study we attempt to use Personal Health Record System (PHRS) as a central point to aggregate health records of a patient from multiple sources (e.g. caregivers, patients themselves, clinical devices, and others) and to standardize personal health records (e.g. use of International Classification of Diseases (ICD-10) and Systemized Nomenclature of Medicine Clinical Terms (SNOMED CT)) through our proof-of-concept model: Health Decision Support System (HDSS).

We started out by exploring the barriers in adopting PHRs and proposed a few approaches that can promote the adoption of PHRS by the general public so it is possible to implement continuity of care in community settings, evidence-based care, and also prevent potential medical errors. To uncover the barriers in adopting PHR, we have surveyed articles related to PHRS from 2008 to 2017 and categorized them into 6 different categories: motivation, usability, ownerships, interoperability, privacy, and security and portability.

We incorporated the survey results into our proposed PHRS, so it can help overcome some of the barriers and motivate people to adopt PHRS. In Our proposed PHRS, we aimed to manage personal health data by utilizing metadata for organizing and retrieval of clinical data. Cloud storage was chosen for easy access and sharing of health data with relevant caregivers to implement the continuity of care and evidence-based treatment. In our study, we have used Dropbox as storage for testing purposes. However, for practical use, secure cloud storage services that are Health Insurance Portability and Accountability Act (HIPAA) complaint can be used for privacy and security purposes, such as Dropbox (Business), Box, Google Drive,Microsoft OneDrive, and Carbonite. In case of emergency, we make critical medical information such as current medication and allergies available to relevant caregivers with valid license numbers only. In addition, to standardize PHR and improve health knowledge, we provide semantic guidance for using SNOMED CT to describe patient problems and for mapping SNOMED CT codes to ICD-10-CM to uncover potential diseases. As a proof of concept, we have developed two systems (prototypes): first, my clinical record system (MCRS) for organizing, managing, storing, sharing and retrieving personal health records in a timely manner; second, a health decision support system (HDSS) that can help users to use SNOMED CT codes and potential disease(s) as a diagnosis result.

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1 Introduction

1.1 Background

Historically, personal health records (PHRs) are kept on paper files that are stored in hospitals or clinic file cabinets. Paper records make it difficult to share and time consuming when retrieving patient medical data. Paper based medical records cause discontinuity of care and medical mistakes due to unavailability of patient medical records at the time of need. To have continuity of care, medical records must be shared and care must be coordinated among different healthcare providers. Availability of necessary medical records could prevent medical mistakes and enable evidence-based decisions at the point of care. To help improve such issues, electronic health record systems (EHRS) were introduced. EHRS makes it easier for retrieving and storing patient data, but since there are many EHRS vendors and each vendor developed their own system independently, patient medical record exchange between two different EHRS becomes an issue. There can be many reasons for such difficulties, but among other reasons, semantic differences in patient problem description and data definition are considered major issues.

PHRS acts as an important intermediary between physicians and patients [1]. The main goal of PHRS is to enable patients to manage and maintain their personal health records, as well as improving healthcare delivery and reducing cost [2]. PHRS is often provided to consumers by their employers, healthcare providers, health insurers, or independent vendors [3]. PHRS offers many benefits including: (1) improving healthcare quality (e.g. continuity of care, by accessing their records anytime and anywhere); (2) improving the communication between patients and physicians; (3) saving cost and time (e.g. by avoiding repeated tests), (4) improving privacy (e.g. patient can control their own health records and share them only when it is necessary); (5) increasing patient safety (e.g. during the emergency); (6) empowering patients by keeping track of their own medical records, [4]; and most importantly, (7) it will mitigate and prevent medical errors. PHRS have been implemented successfully for many years in many countries such as Australia, Netherlands and Germany, but in the U.S., it is still not widely used. Some of the issues are financial issues, interoperability, security, and privacy [5]. Despite all the benefits

PHRS provide, the adoption rate of PHR by the general public still remains low in the U.S. [1, 5, 6].

Patients usually describe their symptoms in their own terms that may not be consistent with clinical terminologies. According to Benson [7], people use a term in the way that they and their immediate colleagues understand, assuming that everyone else understands precisely what he or she intends it to mean. Over time, groups and institutions develop their own local dialect. In the healthcare domain, this leads to miscommunication among different healthcare providers and between physicians and their patients, especially when they are not communicating face to face. Such situations provide the opportunity for medical errors due to semantic interoperability issue. Semantic interoperability in computer systems means the ability of the systems to exchange data in unambiguous and shared meaning [8]. According to the Institute of Medicine, poor communication and exchange of medical information while transferring patients from one healthcare provider to another are responsible for many medical errors and adverse drug events [9].

According to American Health Information Management Association (AHIMA) [10], PHR can be defined as an electronic, lifelong resource of health information needed by individuals to make health decisions. However, it is not easy to collect all the relevant personal health data because of the fact that they are in different data types, available from different sources, and stored in different media and devices. To overcome such difficulties, it is desirable to have personal health data in one place where users have full control over their own clinical data. In order to be useful, the clinical data should be sharable when needed for the diagnosis and treatment. Without proper clinical information such as medical history, allergies, current medications, adverse reactions, medical mistakes could occur when making medical decisions due to insufficient information. Even if a patient has a complete medical history and all the necessary clinical data, if it is not shared properly among caregivers at the time of need, discontinuity in care may occur. In order to meet the needs of such scenario, PHRS should have the following properties: robust and private storage, easy retrieval and maintenance, secure, sharable, and able to handle emergency situations.

There are two types of PHRS: untethered and tethered. Untethered PHR is an independent PHRS where patients have full control over their own personal health records. They can collect, manage, and share their health records. On the other hand, the tethered PHRS is linked to a specific healthcare providers' EHR system, where the users typically gain easy access to their own records through secure portals and see their own clinical information such as test results, immunization records, family history, and other relevant information. They can also secure messaging with their collaborating clinicians. The participating patients need to share the cost and the information. However, the records may not be complete since the information sources are from one provider only.

1.2 Significance of the Problem

For most people, healthcare is considered important as we experience the increase in chronic diseases such as heart disease, cancer, diabetes and asthma. This requires continuous treatment, reduces quality of life, and increases overall medical expenses [11]. According to the Centers for Disease Control and Prevention (CDC), in the U.S. about 610,000 people die of heart disease every year [12]. In addition, 26 million people suffer from Type I or Type II Diabetes, around 14 million have severe chronic respiratory problems such as Chronic Obstructive Pulmonary Disease (COPD), and 68 million have been diagnosed with hypertension [13]. However, many of these diseases can be prevented if managed through early detection, physical activities, a balanced diet and treatment therapy. PHRS can be used for such purpose.

Currently, the healthcare industry uses different types of systems to manage patient health data, ranging from traditional ways of using paper-and-pencil methods to electronic record keeping. In the health domain, there are huge sets of raw data that are generated from different systems such as EMR, PHR and EHR. This data keeps increasing every day, reaching a terabyte and even exabyte scale. These systems are working in isolation, which makes it difficult to integrate them due to many barriers including, but not limited to, privacy, different IT providers, different software applications, data transmission, functional and semantic interoperability issues, network limitation, and others. Along with that, these raw data sets are based on different data types (e.g. text, image, videos, CSV, seniors, CDA documents, entered data by patients or physicians and others), which makes it difficult to store and retrieve data efficiently [14].

Another issue is the lack of interoperability among healthcare systems (e.g. PHR and EHR), which hinders data exchanging and sharing. This, in turn, limits rich clinical information that are necessary to support decision-making in providing proper treatment. At present, most patient health records are fragmented over different healthcare providers (Hospital A, Hospital B, Hospital N, pharmacies, radiology, dentist, general practitioner, and others) where each keeps part of the patient record based on the services they provided, which contributes to the lack of continuity of care. For instance, when employees change their healthcare providers, employer, or insurance, they generally leave their health records behind, therefore increasing treatment cost and time (e.g. duplicate tests, administration costs, increasing medical errors in case of emergency conditions where quick decisions must be made). Furthermore, incomplete medical records of patients may lead to mistreatment which may put people's lives in danger. According to Healthcare IT news, preventable medical error is considered to be the third killer after heart disease and cancer in the U.S., causing the death rate of 400,000 people each year [6]. PHRS has gained much attention due to its role in improving patient outcome, continuity of care, evidence-based treatment, and preventing medical mistakes. Despite the importance in its role, the adoption rate still remains low in the U.S.

Listed below are the issues with the lack of based shareable health records that can go with a patient as they move across and within the healthcare system:

- Discontinuity of care due to lack of communication that is caused by fragmented PHRs within and across caregivers.
- Lack of evidence-based treatment due to limited access to clinical and diagnostic evidence. This has serious impacts on the patients and their environment including: cost of inappropriate and / or ineffective treatment, extended illness and increased risk of other diseases, long-term or even life-threatening consequences, development of drug resistance, unnecessary and irrational use of medicines, increased use of more expensive laboratory testing and others.

- Medical errors due to lack of medical history or access to emergency health information (e.g. allergies, current medication list, side effects, and others) at the time of need.
- Difficulty communication the relationship between patients and doctors.

1.3 Overview of Clinical Standards

Medical standards play a crucial role in facilitating interoperability for medical information exchange among healthcare systems (e.g. PHR, EMR, and EHR). Currently, available medical standards are listed below:

- RxNorm: Provides normalized names for clinical drugs. It contains a United States-specific terminology in medicine that exist in the U.S. It is part of UMLS terminology and is maintained by the National Library of Medicine. The purpose of RxNorm is to enable interoperability and clear communication between electronic systems. The RxNorm API is available to users to access the current RxNorm data set without required license.
- Logical Observation Identifiers Names and Codes (LOINC): Used for measurements including laboratory tests, clinical measures like vital signs and anthropomorphic measures, standardized survey instruments, and more. It was created and is maintained and distributed freely by the Regenstrief Institute (with support from the U.S. National Library of Medicine (NLM)). The purpose of LOINC is to assist in the electronic exchange and collecting of clinical results (e.g. laboratory tests, clinical observations, outcomes management and research).
- Digital Imagining and Communications in Medicine (DICOM): It was developed by the National Electrical Manufacturers Association (NEMA) to aid the distribution and viewing of medical images, such as CT scans, MRIs, and ultrasounds. Each DICOM file contains both a header (which stores information about the patient's name, the type of scan, image dimensions, and others) and all of the image data (which can contain information in three dimensions).

- International Classification of Diseases (ICD): is a medical classification used by the World Health Organization (WHO) for epidemiology, health management and clinical purposes. The first international classification edition, known as the International List of Causes of Death, was adopted by the International Statistical Institute in 1893. ICD is the foundation for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions. In the U.S., a national extension of the core ICD called Clinical Modification (CM) is used to categorize diseases and procedures for several purposes including: billing, reimbursement, public health reporting, outcome measurement, quality improvement, monitoring of the incidence and prevalence of diseases, resource allocation trends, and keeping track of safety and quality guidelines. Other uses include the counting of deaths, diseases, injuries, symptoms, reasons for encounter, factors that influence health status, and external causes of disease. In 2015, ICD-9-CM, which had been in use for over 30 years, was replaced by its successor, ICD-10-CM. However, some healthcare providers still use ICD-9-CM.

- Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT): Used for clinical terminology. It is the most comprehensive and precise clinical health terminology product in the world, owned and distributed around the world by The International Health Terminology Standards Development Organization (IHTSDO). As of January 1, 2017, the organization is trading under the name "SNOMED International." SNOMED CT contains more than 388,000 active concepts organized in 19 hierarchies, 1.14 million descriptions, and 1.38 million relationships, which covers most medical terminologies. This makes it most appropriate ontology for coding of problem lists and diagnosis. The usage of SNOMED CT requires a license. Annual fees may apply in non-member territories and are calculated based on the territories (as determined by the World Bank) and use. However, there is no charge for use of SNOMED CT in SNOMED International Member countries/territories.

- Clinical Document Architecture (CDA): A HL7 standard, CDA is a clinical encoding standard that specifies the structure of medical documents to facilitate interoperability for medical information exchange, which can be used as a template to generate clinical documents.

- Continuity of Care Document (CCD): is an electronic document exchange standard that enhances interoperability of clinical data. It allows healthcare providers to send electronic medical information to other providers without loss of meaning and enabling improvement of patient care.

- Consolidated-Clinical Document Architecture (C-CDA): is an electronic document exchange standard for sharing patient summary among healthcare providers.

We attempted to utilize the above medical standards in our proof-of-concept. Some of the features including:

- Use of SNOMED CT, ICD-10, and CDA.

- Mapping between SNOMED CT to ICD-10.

- Create electronic health records that are in CDA or CCD format.

1.4 Use of Medical Standards in Health Records

Complete patient medical history based on medical standards can improve patient outcome by ensuring important aspects such as continuity of care, prevention of medical errors and evidence-based treatment. However, since personal medical data are located in multiple places such as caregivers, patients themselves, different devices, and others, it is not easy to collect all medical history. Additionally, each location may use different terms in describing the patient condition and treatments, which may not be consistent with standard clinical terminologies. In addition, some healthcare providers use privatization on their records, which may cause confusion when they refer their patient to other healthcare providers. According to El-Sappagh and Elmogy, physicians always describe patients using vague terms, such as the sugar level is high, the patient is obese, and so on. Moreover, patients often describe their conditions using imprecise terms [15]. This can cause misinterpretation of health records between physicians when referring one patient to another and when patients are moving from one state or country to another. Such situations can disrupt core aspects of care mentioned above and raise the expenses of treatment and increase the time to do so (e.g. duplicate tests, administration cost, increased medical errors, and others).

An example of misinterpretation between healthcare providers can involve use of different terms while describing problem lists and diagnosis. In SNOMED CT, asthma has 25 possible derivations of SNOMED parent code 195967001 (Asthma disorder) including: severe asthma (370221004), exercise-induced asthma (31387002), asthma with irreversible airway obstruction (401000119107), or mild asthma (370218001). Each of these terms and codes would require a different care plan. Similarly, if a patient with mild depression (310495003) is mistakenly coded as having major depressive disorder (370143000), they may see medical insurance premiums increase, may experience a forced plan change with a reduced network of available doctors due to member attribution models applied based on clinical findings, and may have difficulty obtaining or renewing life insurance. In order to avoid such scenarios, it is important that both patient and physician use medical standards such as ICD-10 and SNOMED CT [16].

In our approach, we guide patients to describe their symptoms in SNOMED CT code by choosing appropriate description. This can help their doctors make the right diagnostic decision and provide the best treatment plan for the patient. The use of medical standards such as SNOMED CT and ICD-10, would also help overcome misinterpretation issues between different healthcare providers as it provides a shared medical terminology. ICD-10 is already in use by most healthcare providers because it is used for billing. On the other hand, SNOMED CT, which can be used to describe patient problems precisely, is not used widely. It is also considered to be better than ICD for encoding of diagnosis data [15]. Currently, IHTSDO manages SNOMED CT. IHTSDO has the world's leading e-health countries as members and has issued affiliate licenses to more than 5,000 individuals and organizations, mostly large hospitals in developed countries [17]. It can also manage different languages and dialects and map to another terminology such as ICD-10. Use of both SNOMED CT and ICD-10 can help improve semantic interoperability significantly. Mostly, SNOMED CT has been used by large hospitals, but most small clinics, doctor's offices, and many physicians are unaware of SNOMED CT. According to Steven J. Steindel, the actual use of SNOMED CT in the U.S. is not well documented and is perhaps limited to testing and a few large healthcare institutions [18]. However, most of the time, patients go to small clinics for treatment where very little SNOMED CT is used for the medical records.

Some symptoms end up with patients in the emergency room due to their ignorance of their own symptoms and not sharing such symptoms with their physician in a timely manner. According to American College of Emergency Physicians, the number of emergency cases continually rises (136 million in 2011) and the average waiting time in some states can be 3 hours or more [8]. With such a trend, high quality emergency care may not be achievable in the near future. One solution can be reducing the number of emergency cases by proper monitoring and control of patients' symptoms. For that purpose, we propose an approach that collects clinical data in standard codes such as SNOMED CT and provide potential diseases as diagnoses. We have developed a prototype as a proof of concept called health decision support system (HDSS) that can provide semantic guidance for using SNOMED-CT as input for patient problem description, and ICD-10-CM codes for potential diseases as output. Another purpose of the HDSS is to collect the frequencies of patients' symptoms, which reveals regional characteristics of the location. This can be used to improve public health by taking an action for the accumulated result. For testing purposes, we mainly focused on the most common diseases that occur frequently.

When using the HDSS, patients only need to provide their symptoms as input and then the system guides them to convert the symptoms to SNOMED CT codes and then map to the potential disease(s) as output. The physicians can use the system by asking the patient about their symptoms, so the system can help them to uncover accurate diagnoses. It can also help physicians to use SNOMED CT along with ICD-10, which will increase the physician confidence level in diagnosis. This can be done by showing each disease with its possible major symptoms in SNOMED CT, which are provided by The Unified Medical Language System (UMLS).

1.5 Personal Health Records vs Electronic Health Records

1.5.1 Personal Health Records (PHRs)

PHRs contain the same types of information as EHRs including diagnoses, medications, immunizations, family medical histories, allergies, chronic diseases, illness and hospitalizations, lab test results, check-up results, various measurements, medications, prescriptions, vaccinations, observations of daily living, and othersbut are designed to be set up, managed, accessed, and controlled by individuals. PHRS can be used by patients to maintain and manage their health information in a private, secure, and confidential environment. PHRS can include information that can be drawn from multiple sources including home monitoring devices, clinicians and patients themselves [19].

1.5.2 Electronic Health Records (EHRs)

EHR is an electronic record of health-related information on a patient that conforms to nationally recognized interoperability standards. EHRs contain information from all the clinicians involved in a patient's care and all authorized clinicians can access the information to provide care to that patient. These records can be created, managed, and shared by authorized clinicians and staff across more than one healthcare organization such as laboratories, pharmacies and specialists [19].

1.6 Goals and Objectives

As mentioned previously, PHR is considered a crucial part in improving patient outcomes. However the adoption rate by the general public in the U.S. still remains low. The goal and object of this study is to identify the barriers in PHRS and provide potential solutions so it is easy for the general public to use their own PHRS. The study will consist of the following:

- Identifying Barriers in using PHRS by surveying literature in the field from 2008 to 2017.
- Considering the survey results, we provided an approach to overcome some of such bar-

riers. This was completed through the following:

- Efficient querying using metadata for clinical documents in the cloud
    - Efficient query in big data environment
    - Personal cloud repository management

- Health decision support system based on patient provided data
    - For patients/physicians
    - Conversion of problem list (observed symptoms and measurements) to SNOMED CT and ICD-10. (More details will be provided in the following sections.)

2 RELATED WORK

2.1 Metadata

In the healthcare field, metadata has been used as a method to use confidentiality tags that indicate data sensitivity levels. This enables patients to give consent to the exchange of some parts of their health records (e.g. the medical diagnosis), while withholding consent for the exchange of other areas (e.g. a mental health counseling session) [20]. Other researchers have adopted the ontology approach to quickly search and access relevant and meaningful information among large numbers of CDA documents within healthcare providers' systems (Electronic Health Record System), which in turn enables semantic interoperability [6, 21, 22]. Patel et al. [23] built a system called TrialX on top of PHR where patients not only can search by keywords, as in ClinicalTrials.gov, but also by demographics (e.g. age, gender, city and study site). This system enables patients to match their health condition to clinical trials. Appelboom et al. [24] reviewed the literature on smart wearable body sensors and found that these sensors are accurate and have clinical utility, but still are underutilized in the healthcare industry. These devices can be used to monitor physiological, cardiovascular and many other factors of health variables and transmit data either to a personal device or to an online storage site. The smart wearable body sensors are placed on different parts of the user's body based on the purpose of the sensor device. For instance, the physical therapy sensor is placed on the ankle; the cardiopulmonary sensor can either be placed on the wrist, finger, arm or thigh.

Zhang et al. [25] developed an application to apply metadata efficiently on clinical trial data. The authors chose Microsoft Excel due to the wealth of built-in features (e.g. spell checking, sorting, filtering, finding, replacing, importing and exporting data capabilities), which contribute to the ease of use, power, and flexibility of the overall metadata application. They focused on the analysis process in a drug development environment such as adverse clinical events (ACE), Electrocardiogram (ECG), laboratory (LAB), and VITAL (vital signs), where the raw data is stored in the clinical trial database and then the data can be manipulated.

Another study by Teitz et al. [26] developed a website called HealthCyberMap with the goal of mapping Internet health information resources in novel ways for enhanced retrieval and navigation. They used Protégé-2000 to model and populate a qualified DC RDF metadata base. They also extended the Dublin Core (DC) elements by adding quality and location elements. Also, the W3C RDFPic project extends the DC schema by adding its own elements such as camera, film, lens and film development date for describing and retrieving digitized photos [26]. Ekblaw et al. [27], built a system (RedRec) to enable patients to access their medical health records across health providers (e.g. pediatrician, university physician, dentist, employer health plan provider, specialists, and others). Their system applies novel, blockchain smart contracts to create a decentralized content-management system for healthcare data across providers. RedRec governs medical records access while providing the patient with the ability to share, review, and post new records via flexible interface. The raw medical record content is kept securely in providers' existing data storage. But when the patient wants to retrieve data from their provider's database, their Database Gatekeeper checks authentication and then if it is approved, the Gatekeeper retrieves the relevant data for the requester and allows a sync with the local database.

To ensure security and confidentiality in the cloud computing, Dhivya et al. [21] proposed encrypting the data before it reaches the server in order to avoid internal hacking. Barouti et al. [28], proposed a protocol that allows health organizations to produce statistical information about encrypted PHRs stored in the cloud. Their protocol depends on two homomorphic cryptosystems: Goldwasser-Micali (GM) and Paillier. The queries are executed on K_d-tree from encrypted health records. This protocol ensures privacy of both health organizations and patients [28].

Fox et al. [29] proposed the use of Mashups to create a virtual personal health record where a patient and care provider can collaborate using trusted social networks. This in turn can overcome issues of using centralized data storage of PHR by making the data sharable between the patient and care providers. Genitsaridi et al. [30] proposed some basic requirements for creating an intelligent PHRS including: make the system as a free open source system where it will be available to the worldwide community, make the system a web-based system, make the system compliant to high quality functional standards and make the architecture maintainable, expendable and interoperable. However, most existing research in the health domain focused on a single data type. On the other hand, our study is a comprehensive study that covers many different clinical and nonclinical documents such as images (e.g. x-ray, scanned document, ultrasound, and others), text (e.g. CDA, CCR, CCD, and others), and observed symptoms noted by patients, clinical sensors data. This can help to organize these various data in a way that can help in storing and retrieving such data in an efficient way. Fearon et al. [14] defined metadata as structured information that describes, explains, locates, or otherwise makes it easier to retrieve, use, or manage an information resource. However, metadata standard has not been employed by many repositories and most of the metadata was generally descriptive, rather than administrative or for preservation [31].

2.2 Mapping between ICD-9/10 and SNOMED CT

As mentioned in section 1.1, functional and semantic interoperability of health records is an essential factor for the exchange of medical records. Semantic interoperability is considered more crucial than the functional counterpart, as it may cause misinterpretation. For this reason, medical industry focuses on using standard codes such as SNOMED CT and ICD-10. For clinical decision support, many researchers proposed various mapping algorithms between SNOMED CT and ICD-9 or ICD-10. Brown et al examining using the SNOMED CT crosswalk between two administrative classifications: ICD-9-CM and the U.S. Veterans Benefits Administration (VBA) disability code set.They found that SNOMED CT provided significantly better coverage than ICD-9-CM direct mapping alone [32].

Nyström et al. analyzed the distribution of 2.5 million diagnostic codes from primary healthcare organizations in Stockholm, Sweden. The patient encounters coded with ICD-10 (mono-hierarchical) were mapped to SNOMED CT concepts (poly-hierarchical) through a mapping table. Their study showed that there was hidden information about health problems and diagnoses, and the study also illustrated the advantage of a poly-hierarchy. For instance, in SNOMED CT terms, associated morphology includes inflammation and the attribute value virus, but not in ICD-10, which shows the benefits of using more detailed descriptions about the symptoms. Also, "Chapter I in ICD-10 is restricted to 'Certain infections' and does not contain 'Certain localized infections', which is common within primary care" [33]. Campbell et al. developed knowledge-based tools that support translation of data from SNOMED CT to the ICD- 10 classification. They concluded that, SNOMED source concepts should only be drawn from three hierarchies: clinical finding, event and situation with explicit context. However, the results of their study focused on equivalence relationships and was driven by lexical matching [34]. Even though the mapping between SNOMED CT and ICD is helpful by itself, there is a need to make this mapping usable by healthcare providers and patients to improve preciseness and interoperability of health records. In our approach, SNOMED CT and ICD-10 are implicitly integrated in a way that users were unaware that they were using SNOMED CT and ICD-10 through an interface terminology.

Nyström et al. [35] proposed SNOMED CT to be used with ICD-10 to enhance primary care EHRs. Taboada et al. proposed an automated mapping external terminologies to the UMLS to provide interoperability [36]. El-Sappagh and Elmogy classified the mapping methodologies - clinical text in EHR to SNOMED CT concepts as manual, semi-automatic, and automatic methods [15]. For precise problem description and diagnosis, both SNOMED CT and ICD-10 need to be used in EHR and also in PHR. In this study, we propose a mapping system to be used for both EHR and PHR. Other researchers [37, 38], compared SNOMED CT with other coding systems for their reliability. As the popularity of SNOMED CT increases, various SNOMED CT browsers have been developed including CliniClue xplore, bioportal, CaTTS, CLIVE, EdBrowse, FDB Sphinx, HealthTerm, LexPlorer, Mycroft, and others. These browsers are used as a part of large applications or as a standalone tool [39]. In our approach, we convert patients' symptoms into SNOMED CT codes and then map to ICD-10.

2.3 Symptom Checker Application and Website

There is another type of application called symptom checker that helps people to self-diagnosis and get advice on whether or not to seek further medical care. Some of the currently available symptom checkers are WebMd, Mayo Clinic, Isabel, Everyday Health AARP, iTRIAGE, and others. These resources can be used to aid in self-diagnosis and provide a source of information in regards to causes, risks, and treatments of symptoms. There is a great deal of variation among symptoms checker systems, but each has its own limitations [40]. For instance, Semigran and colleaguse compared the diagnostic accuracy of physicians with 23 commonly used symptom checkers. They found that physicians were twice as accurate compared to symptoms checkers in terms of correctness. Even though physicians generally outperform the applications, they still make mistakes in about 15 percent of cases [41]. Hence, researchers suggest that computer-based algorithms, in conjunction with human decision-making, may help further reduce diagnostic errors [42]. Similar research has been conducted on developing pill identifiers or finders apps and websites e.g. Drugs.com Pill Identifier, Epocrates Pill ID, GoodRx, WebMD Pill Identifier , ID My Pill, and others to help consumers verify medications they received and avoid taking the wrong pills in order to prevent medication errors [43]. Even though these websites and apps are helpful, many are not based on medical standards which can cause interoperability issues.

2.4 Clinical Decision Support System

Clinical decision support system (CDS) aims to assist healthcare providers and the general public in making accurate decisions by providing health- related information that is accessible at the time of need in order to improve the quality and safety of healthcare [44]. Common types of decision support (e.g. drug-drug interaction alerts, order set, and preventive care reminders) are targeted for physicians' use only [45]. Hunt et al. found that computerized decision support is most effective for drug dosing and preventive care, but not convincing enough for diagnosis [46]. Bucur et al. proposed a framework that can enable efficient implementation of CDS that incorporates a large variety of clinical knowledge models to bring clinic comprehensive solutions for personalized oncology [47]. Wright et al. proposed an approach that utilizes Web 2.0 to help developers develop clinical decision support system (CDSS) contents with less effort and cost [45]. While significant effort has been invested in the implementation of CDSS for physicians use, the uptake in clinical decision support system for patient use has been limited. In our study, we developed a decision support system that can help both patients and healthcare providers to identify potential diseases using medical standards such as SNOMED CT and ICD-10, while creating health records in standardized format such as clinical document architecture (CDA) and continuity of care document (CCD). In the literature review, we found that most of the previous work on this topic has focused on the mapping between SNOMED CT and ICD-10 by using specific browsers and CDSS with limited features such as drug altering, reminders, and order sets. Symptom checker systems can help users understand their potential diseases and provide helpful information such as treatment, causes, risks, and others based on their symptoms and clinical measurements. These systems are helpful in improving healthcare, but most of them do not offer interfaces to PHR. In our approach, we attempt to incorporate these features into our system.

As per our knowledge, there is very little work on Personal Health Record System (PHRS) as a central point to aggregate health records of a patient from multiple sources (e.g. caregivers, patients themselves, clinical devices, etc.) and make such records manageable, organizable, shareable and retrievable based on clinical standards in a timely manner. Also, making critical medical information such as current medications and allergies available to relevant caregivers with valid license numbers only in case of emergency has not been extensively researched before.

3 BARRIERS IN ADOPTING PHRS

We have surveyed articles related to personal health record system (PHRS) from 2008 to 2017 and categorized them into 6 different categories: motivation, usability, ownerships, interoperability, privacy, and security and portability. Each category will be described below.

3.1 Motivation

In this section, we identify some of the features and benefits of PHRS that could motivate people to adopt PHRS. PHRS offers many benefits including: (1) improving healthcare quality (e.g. continuity of care, by accessing their records anytime and anywhere); (2) improving the communication between patients and physicians; (3) saving cost and time (e.g. by avoiding repeated tests), (4) improving privacy (e.g. patient can control their own health records and share them only when it is necessary); (5) increasing patient safety (e.g. during emergency); (6) empowering patients by keeping track of their own medical records [48, 49, 50]. More importantly, it will mitigate and prevent medical errors.

PHRs are mostly used by " patients with chronic conditions, frequent users of healthcare, caretakers of elderly patients" [9] and older patients [2]. Both younger and older people can benefit from adopting PHR. However, older people "tend to be late adopters of technology and may be hesitant to adopt a PHR if the benefits are not made clear" [1]. For example, the barrier is higher for those who are in need.

Some of the motivating features that help in adopting PHRS are: tracking chronic conditions, storing health information of their family, sharing health records with physicians and family, drug interactions checker, finding a doctor covered by their insurance network, reference information from trusted sources, uploading medical documents and uploading information from multiple medical devices, accessible by authorized users, and keeping health data secure and private [1, 51]. Other beneficial features of PHRS are presented by Fricton and Davies [52] including: organizing health records, calendars and reminders features, health education, communicating with physicians and health plan providers, accessibility to community services, managing healthcare cost, accessibility online, and easy access to their own medical records.

Another study by Sunyaev et al. [53] identified 25 end-user features for successful PHR implementations including: online accessible, up-to-date medical information, presented in a cognitively accessible way, editable by patients and correctible by physicians, controllable by patients, accessible in case of emergency, traceable, secure messaging, prescription refills, appointment scheduling, reminders, educational information, support groups, device integration, decision support, searchability, and others. Interoperability is also an important factor in the adoption of PHRS [3]. Health risk assessment, as suggested by the Center for Disease Control and Prevention (CDC), can provide health awareness to the general public by providing their "as-is" health condition. Improving health awareness is important and it benefits people to engage preventive care by managing and controlling individuals' health in order to stay healthy. This is something that PHRS can provide.

3.2 Usability

In this section, we identified factors that have caused the slow adoption of PHRS. Pushpangadan et al. [54] specified many themes including:

- Features: lack of necessary functions that allow patients to access their medical records and their family members' medical records, make appointments, reminders, prescriptions, refills, referrals, get test results, find educational resources and communicate with providers for allergies, immunizations, emailing physicians, accessing medical reports, and tracking their health conditions
- Usability: some PHRS users find it easy to use, but they had to deal with difficulty in understanding medical terminology and inaccurate information.
- Communication: adoption of PHRS does not necessarily enhance the communication between patients and healthcare providers. For example, PHRS does not provide a media communication such as messaging between doctors and their patients.

- Digital divide: refers to the resources such as Internet access, computer technologies, and medical devices that patients may not have.

- Medical terminology: Most people have difficulty in understanding medical terminology. Therefore, the medical terminology should be kept as basic as possible or there should be medical training offered to overcome such challenges. Security and privacy also are important patient concerns.

Pak and Song [55] proposed a framework called Health Capability Maturity Model (HCMM) to assess individual's health, based on their health maturity level. This model can be used as a roadmap to help individuals improve their health by assisting them to achieve desired maturity-level so they can adopt a PHRS and take control of their health and medical record keeping. The health maturity levels are described as shown in Table 1. We also applied these levels to the adoption of PHRS as shown in Table 1 below.

Krist et al. [2] found that patients can be effectively engaged in using PHRS in small to medium-sized primary care practice settings, where most patients receive their care. Another study by Price et al. [6] found that seven chronic diseases - asthma, diabetes, fertility, glaucoma, HIV, hyperlipidemia, and hypertension can benefit from having PHR enabled self-management plans. Another paper compared Google Health and Microsoft Health Vault PHR systems on five dimensions - usability, utility, security, privacy, and trust - and found that users experienced difficulty in using these systems due to problems with entering medical information, navigating records, a busy screen, adding details and understanding medical terminology [1]. In this study, Google Health was rated higher on the dimensions of ease of use and utility, while Microsoft HealthVault was rated higher on the dimensions of privacy and trust. A similar study by Archer et al. [56], conducted a literature review on various aspects of PHR such as design, functionality, implementation, applications, outcomes, and benefits. They found some factors that make consumers reluctant to use and implement PHR. These factors include lack of consumer involvement during the development processes (e.g. planning, design, and implementation of PHR system); lack of trust in the provider, security, health literacy, technology literacy, accessibility, awareness; usability and socio-cultural influences; and uncertainty of ownership, transportability, and research on the utility and features needed by consumers.

Similar barriers were identified by other studies [5, 9, 54, 57, 58]. Vydra et al. studied some barriers of provider tethered PHRS and identified the lack of reimbursement for the time physicians spent in portal communication, change of workflow, and resultant change resistance. They suggested that in order to encourage physicians to use PHRS, they should: offer rewards, provide financial reimbursements for the time spent on PHRS, and provide support for staff assistance and training. Other issues in PHRS' adoption are the interoperability with electronic medical records and use by healthcare providers [9].

HCMM Level	Individual's perspective of their health	PHRS adoption
Level 0	Lacking of : • Health self- management • Health Knowledge • Motivation	Not using PHRS
Level 1	• Awareness of the necessary changes • Willing to change to improve their health	Considering PHRS but not adopting it yet
Level 2	Take actions on: • Adopting some healthcare plan • Making decision related to their health management	Slow adoption of PHRS
Level 3	Use of quantitative techniques to: • Self-monitoring • Control performances	Use of some features of PHRS
Level 4	• Proactive rather than reactive • Respond quickly to the health changes and improvement opportunities	Quantitatively monitor and control their health using PHRS

Table 1: Health Capability Maturity Level and the use of PHRS

3.3 Ownership

In this section, we identify the current providers of PHRS and issues related to their systems. There were 117 vendors of PHRS as of July 2010, and 600 vendors of EMR as of July 2011 [4]. Most of them offer their services for free or at little cost [53]. With these many platforms, there is a need to establish a global standard for medical records in order to exchange data among different health systems (e.g. EHR, PHR, MHR); otherwise these systems will not be valuable because they will not meet the patient, physician, care providers, and others expectation and needs. This in turn will reduce the use of these systems especially PHRS.

The tethered PHRS type has been developed by many commercial PHR platforms such as Microsoft Health Vault, Google Health, CBSHealthWatch's, Dossia, and MyGroupHealth [57, 59]. However, even large companies such as Microsoft Health Vault and Google Health services are not available outside the U.S. This can limit the use of their PHR systems to the people who are travelling outside the U.S. In addition to that, most PHRS do not offer built-in emergency access to the record except third-party services available for HealthVault. Also both Microsoft Health Vault and Google Health do not offer features like the ability to search within patient records and provide user interface other than in English [53].

On January 1, 2012, one of the biggest PHRS providers, Google, stopped its Google Health™System and asked their registered patients to retrieve and transfer their files to their computers, other PHRS vendors, or to their physicians by January 1, 2013 [5]. Brandt and Rice identified 22 possible reasons for the Google Health™disconnection including themes of policy, trust, marketing, financial reasons, planning and implementation, user capability, and appeal [5]. Since Google Health is no longer in service, this raises an important question is it possible that Microsoft Vault or other PHRS providers will discontinue their services as well? Patients do not have enough trust on the availability and accessibility of their own PHRS that are offered by a company. Companies may discontinue their services of PHRS (e.g. Google Health) at any time due to many reasons, such as financial issues or lack of profit. Therefore, it will be better and secure to have stand-alone PHRS. In this case, there is a need to build a stand-alone PHRS that can be controlled by individuals based on rules for both individuals and physicians in order to make a comprehensive PHRS that can be trusted and valuable for all parties. This can be done by securely storing their clinical data in the cloud-based repository and follow the international standards such as HL7 standard in order to be interoperable with EHR. We also suggest that separating the clinical data from applications will give the users more freedom by not limiting them to one provider or application. This therefore enables users to access and modify their clinical data anytime and anywhere from any portable devices. In this case, users' clinical data, such as medical history, can be secured even when PHRS providers discontinue their services for whatever reasons (e.g. Google Health). It will also leave the users with more options and choices, which in turn will motivate people to adopt and use PHRS. Consumers' clinical data will be stored in the cloud-based repository using medical format and code standards:

- Medical codes: SNOMED CT, ICD-10, LOINC, DICOM, and others.
- Document format: HL7 CDA.
- Metadata: Use of Dublin Core.

The proposed concept is illustrated in Figure 1. In the figure, the contents of each HL7 CDA document is described in Dublin Core (DC) for easy retrieval.

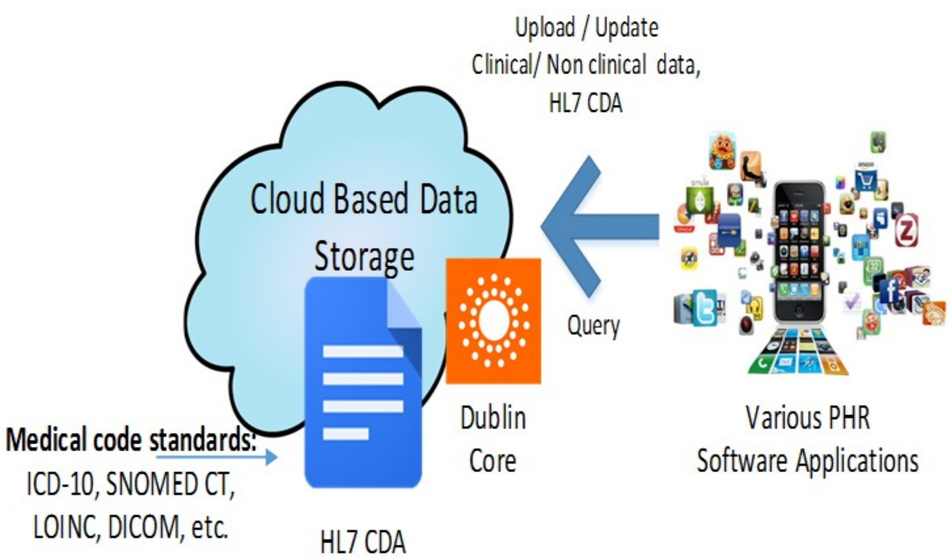


Figure 1: Use of Standards and Separation of Data from PHRS

3.4 Interoperability

In this section, we discuss one of the big issues that hinder information exchange among different healthcare systems. PHRS and EHR are independent systems with the purpose of providing the right clinical information to the caregivers at the necessary time to ensure quality care, while also allowing patients to monitor their own health. In PHRS, patients have full control over their PHRs. However, patients are concerned about their clinical data privacy and are not willing to share their health data with others, which makes it difficult for doctors to provide them with the right treatment, especially in emergency situations. According to the Institute of Medicine "poor communication and exchange of medical information at transition points for patients from one provider to another are responsible for many medical errors and adverse drug events" [9]. According to Healthcare IT News, preventable medical error is considered to be the third killer after heart disease and cancer in the U.S. which cause the death rate of 400,000 people each year [1]. From the patients' perspective, there is no systematic way to share their clinical data in the PHR with their physicians due to reliability concerns. On the other hand, in EHR systems, the data can be shared with many related agencies (e.g. insurance companies, pharmacies, and others), each of which keeps a part of the patients' records based on their specialties. However, EHR systems are developed by independent vendors and designed to meet their customers' needs. This in turn causes interoperability issues that hinder data exchange between PHRS and EHRS and even between EHRS that were developed by different vendors. The interoperability issues include: data definition (e.g. vocabularies mismatching, size, name, and others), change of workflow (e.g. new processes, lack of currency, lack of interoperable software, and others), security and privacy (e.g. authorizing access, data quality, and others) [60].

The major concern from the clinicians' point of view is the integration and standardization in order to share data with multiple care providers [57]. Pringle et al. [60] proposed a technical implementation guide for connectivity between PHRs and EHRs that can help overcome the interoperability issues by creating a set of agreements that are approved and supported by all participants. This approach looks to the resolution of technical concern from the national collaborative efforts, including:

- The Healthcare Information Technology Standards Panel (HITSP) to enable integration between systems in order to share information.
- Integrating the Healthcare Enterprise (IHE) which "is a global initiative that creates the framework for passing vital health information seamlessly - from application to application, system to system, and setting to setting - across multiple healthcare enterprises" [60].
- American Health Information Community (AHIC) was formed by the Secretary to facilitate achievement of Americans to have access to secure electronic health records by 2014.

A study by Kaelber and Pan compared the potential value of PHR systems (e.g. provider-tethered, payer-tethered, third- party, and interoperable PHRs) in the U.S. They found that interoperable PHRs show the most value, followed by third-party PHRs and payer-tethered, while provider-tethered shows negative net value [61]. Jones stated, "As both EHRs and PHRs become standardized, patients will be able to move from one place to another and have their medical records accessible and transferable wherever they go" [3]. The structural standards of PHRS include: Continuity of Care Document (CCD), ASTM Continuity of Care Record (CCR), Clinical Document Architecture (CDA), Digital Imaging and Communications in Medicine (DICOM), Good Electronic Health Record (GEHR), Health Level Seven (HL-7), International Classification of Diseases (ICD-9/ICD-10), Systemized Nomenclature of Medicine (SNOMED), and Vocabularies contained in the Unified Medical Language System (UMLS) [3]. However, incorporating these standards into hospitals' existing systems is challenging because many of them need re-engineering or need to start from scratch [62].

For large PHRS providers like Microsoft there are not major technical barriers to entry, but without adopting data standards for interoperability, it will be challenging to import and combine data in a meaningful way [63]. Health record systems (PHR, EHR, etc.) should take advantage of and/or learn from other information technology successes in other fields (e.g. Apple). Tang asserted that, "An essential first lesson is that ideally, system components should be not only interoperable but also substitutable" [63]. PHRS can be used as the central piece of health information exchange to overcome interoperability issues among different healthcare providers [9]. The patient's PHR can be achieved with a simple, inexpensive, and expedient process if interoperable health data in place [9]. However, these studies basically suggest for all participants to follow standards that are already available to overcome interoperability issues, but they did not mention how to make the PHRS and EHR interoperable in practices.

To overcome interoperability issues that hinder exchanging of health data between different healthcare organizations, DePalo et al. [62], applied enterprise architecture (EA) principles during the implementation of Integrating Healthcare Enterprise (IHE). Most of the existing EA models (e.g. TOGAF, FEA, Zachman, Gartner) focus on aligning business functions, objectives, and goals with IT within organizations, but poorly focused on supporting interoperability externally with other organizations. Therefore, DePalo and Song [62] proposed an approach to leverage the existing EA models by adding an interoperability layer that can deal with external entities since information is needed to be shared among external health organizations (e.g. Hospital A, Hospital B, pharmacies, radiology, laboratories, etc.).

3.5 Privacy and Security

Security and privacy are one of the main concerns for patients in regard to their health records [3, 6, 53]. According to HIPAA, patients have the right to access and get a copy of their health records, although it does not specify the exact manner in which the access is to be given [53]. In addition, all healthcare systems (e.g. PHR, EHR, etc.) must adhere to HIPAA regulations including security, privacy, transmission, and releasing patient's medical information. However, compliance to the regulations related to privacy and security may enact more barriers for the organizations to deploy such systems (PHRS, EHRS, and others) [57]. But how to make PHRS compliant to HIPAA in a technical aspect is still an ongoing research issue. Furthermore, security and privacy are considered one of the issues that hinder the sharing of health data among EHRS and between PHRS because the clinical data cannot be shared unless authorized by patients [59]. Liu et al. [57] found that patients trust downloadable applications more than websites to upload their health records. In addition, patients feel safer using paid services rather than free services for their PHRS. Another study also found that people preferred using PHRS from well-known companies (e.g. Microsoft) for similar reasons [1].

Both older and younger adults have concerns about privacy, backup of information, and identity theft. Although these are very important issues, if assurance is given to the consumer that their information is protected and backed up, that may be enough to thwart their concern. When technologies such as online banking, shopping, or email were first introduced, consumers faced the same concerns about privacy. These technologies are now widely used by consumers of all ages, which indicates that although there was a potential high-risk involved, the perceived benefit, combined with assurance in the system, was enough to get passed these barriers. PHR providers should look to these previous technologies as examples of what measures can be taken to provide assurance to users. In our study, we have used Dropbox as storage for testing purposes. However, for practical use, secure cloud storage services that are HIPAA complaint can be used for privacy and security purposes, such as Dropbox (Business), Box, Google Drive,Microsoft OneDrive, and Carbonite [64].

3.6 Portability

Portability is an important aspect of building PHRS as described in the following statement: "Portability is an U.S. employee's right to keep or maintain certain benefits when switching employers or when leaving the workforce. The HIPAA provides rights and protections for participants in group health plans" [3]. Individuals on Medicare typically have about five or more providers, while patients with chronic diseases often have 14 or more [65]. When employees change their healthcare providers, employer, or insurance, they generally leave their health records behind, which in turn increases treatment cost and time (e.g. duplicate tests, administration costs, increasing medical errors in case of emergency condition where quick decisions must be made, and others). For this reason, it is important for consumers to have portable records that can go with them as they move across and within the healthcare system in order to improve continuity of care. But for the most part, current PHRs do not offer this capability [65]. Therefore, devices including cellphones, computers, tablets, sensors, and others that users are using to monitor their health must be portable to PHRS [54]. According to Huyu, [66], the medical data should not be intercepted and eavesdropped during the data transmission through wireless networks. The use of multiple layers of complex defense mechanisms may help promote the security of medical data. Exchanging information between healthcare systems is facilitated by the adherence to the medical document standards. The HealthVault takes the lead in using electronic document exchange standards such as Continuity of Care Record (CCR) (created by the ASTM) and Continuity of Care Document (CDR) (created by HL7) [53].

Another paper presented an integration of the Healthcare Enterprise (IHE) profile to overcome interoperability issues of transporting medical and sharing information between healthcare providers by utilizing distributed computing technologies such as SOAP envelopes for ebXML over mobile networks. They used networks known as Health Information Exchanges (HIE) and the National Health Information Network (NHIN) to make the interactions between transport facilities possible [67]. For querying, receiving, updating and sending medical records in the transport environment, DePalo et al. leveraged the advantages of ebXML using registries and repositories in mobile networks [62]. Electronic business XML (ebXML) is a standard that uses XML based-messages to exchange business data globally in a secure way, but it is also successfully applied to transport medical data [53]. The summary of section 2.1 is shown in the Figure 2 and the Table 2.

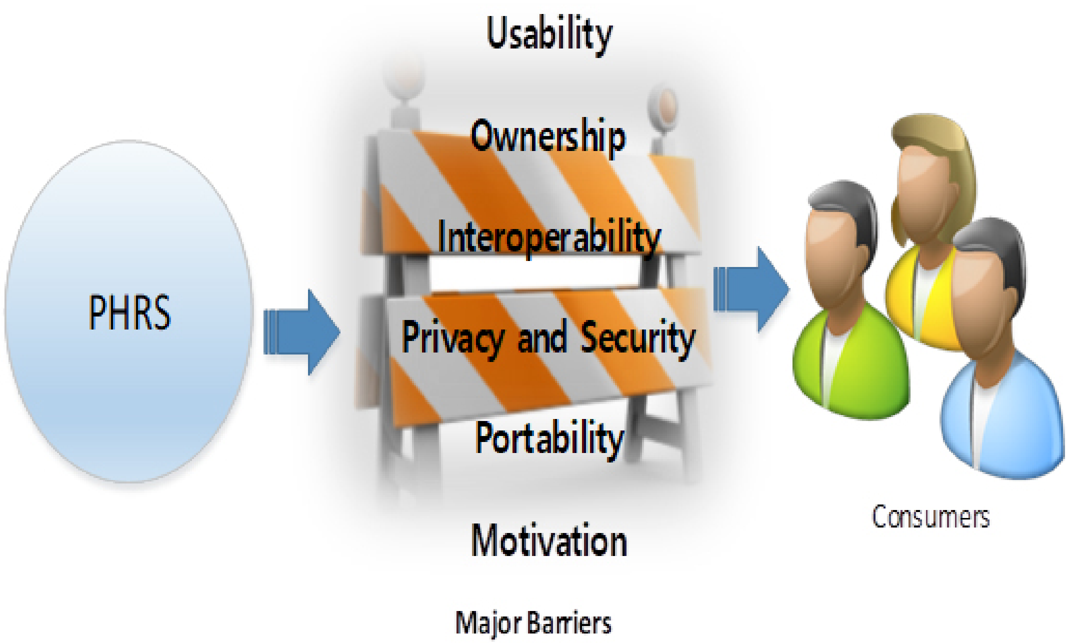


Figure 2: Barriers in PHRS Adoption

Category	**Barriers**	**Proposed solution**
Usability	• Technology literacy • Lack of user involvement - New workflow • Change resistance	• Training support • Guide users through available resources • Involve users from the beginning
Ownership	Lack of trust in the provider	Separate data from application
Interoperability	Lack of interoperability	Impose standards
Privacy and Security	• Hacking • Unauthorized access • Lack of trust	• HIPAA regulations • Encryption and decryption • Control access & time stamp
Portability	• Lack of accessibility • Lack of transportability	Separate data from applications
Motivation	• Awareness of PHR value • Health literacy	• Health risk assessment • Offering rewards for use • Reimbursement for the physician time for portal

Table 2: Summary of Barriers of PHRS Adoption

4 CONCEPT OF PERSONAL HEALTH RECORDS

4.1 Clinical Data

In this section, we describe the types, format, and sources of clinical data.

4.1.1 Measurement Data from Portable Medical Devices, Sensors, or Mobile Application

One way to collect measurement data is through clinical sensors. A clinical sensor is a device that responds to a physical stimulus and transmits a resulting impulse for interpretation or recording. Some sensors are designed to work outside the human body, while others can be implanted within the human body. In this research, we are referring to clinical sensors for home-care settings, such as blood oxygen monitors, thermometers for body temperature, heart rate, sensor glucose (SG), blood pressure, and others. In addition to these textual data type, there can be non-textual data generated from sensors such as electrocardiogram measurement device. The clinical sensors play a major role in healthcare, including early detection of diseases, diagnosis, disease monitoring and treatment monitoring [68].

Another method to collect measurement data is Mobile Health Applications. For instance, most smartphones (e.g. Android, iOS, and others) offer health and fitness apps that help users monitor their daily activities and health (e.g. track diet and nutrition calories, track vital signs, track fitness progress, share health data with their doctor electronically, and others). The data collected from these applications can be sent as a message or an email attachment to whom the users want share it with [69]. For interoperability, the collected data needs to be in standard format, such as HL7 CDA or in standard code such as SNOMED-CT. The health decision support system (HDSS) was designed to produce HL7 CDA or CCD file for collected clinical data.

4.1.2 Observed Symptoms

Patients sometimes experience particular symptoms (e.g. chest pain, nausea, vomiting, shortness of breath, and others). If the patient notices such symptoms, they should be recorded and shared with their physician for proper treatment. If these symptoms are not shared with their physician, properly misdiagnosis or asscoicated diseases could occur. When recording, the observed symptoms should be described in standardized code such as SNOMED-CT. This will allow semantic interoperability, since the same symptoms can be described in multiple ways. Without codified descriptions, there can be discrepancies about the perceptions regarding symptoms between patients, nurses, or physicians [70].

4.1.3 Images

Most of the medical imaging machines produce standard image format called Digital Imaging and Communications in Medicine (DICOM). DICOM is defined as the international standard for medical images and related information (ISO 12052) [71]. There are two types of clinical data images: images that are based on DICOM standard (e.g. x-rays, Computed Tomography (CT), Magnetic Resonance (MR), and ultrasound devices) and scanned documents. The DICOM format combines images and metadata that describes the medical imaging procedure. Accessing data in DICOM files becomes as easy as working with TIFF or JPEG images [72]. On the other hand, the scanned documents (e.g. PDF/ JPEG) are difficult to retrieve because the content is not searchable. For example, some physicians write notes on clinical forms while diagnosing their patients and then type them on the computer or just scan them and upload them to the patient records. Either way is time consuming, difficult to retrieve in a timely manner, and consumes relatively large storage space. In addition, the patient may have more than one doctor or may have been treated by many healthcare providers, which in turn fragments his/her records. So when the patients obtain their records, they mostly got them either in hand copy or in an email attachment. This makes it difficult to retrieve scanned documents because its content cannot be retrieved by computers. To alleviate such issues, we have utilized metadata to describe such medical documents so computerized retrieval and systematic organization is possible.

4.1.4 Clinical Document

EHR data may be collected from healthcare providers based on three types of clinical document format standards: Continuity of Care Record (CCR), Clinical Document Architecture (CDA), and Continuity of Care Document (CCD). The scope of the CDA is the standardization of clinical documents for the purpose of exchange between healthcare providers and patients. A CDA can contain any type of clinical content including a Discharge Summary, Imaging Report, Admission & Physical, Pathology Report and more. It defines a clinical document with the following characteristics: persistence, which refers to documents that exist over time and can be used in many contexts; stewardship, which refers to documents that must be managed and shared by the steward; potential for authentication, which refers to documents that are intended to be used as medico-legal documentation; wholeness, which refers to a document that includes its relevant context; and human readability, which refers to a document that is essential for human authentication. CCD allows healthcare providers to exchange clinical information summary about a patient. CCD Templates include many elements such as header, purpose, problems ,procedures, family history , social history , payers , advance directives , alerts , medications , immunizations, medical equipment, vital signs, functional statistics, results, encounters, and plan of care [73]. However, CCR was excluded from the 2014 edition of EHR Certification, which is standard certification criteria for EHRs that was established by The Centers for Medicare & Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC), as a valid way to send summary of care documents. Hence, the content from a CCR was merged into a CDA format and called Continuity of Care Document (CCD). Currently, with Meaningful Use Stage 2 and the 2014 edition of EHR Certification, Consolidated CDA includes CCD as one of its document types [74]. These clinical document standards foster interoperability of clinical data by allowing healthcare providers to send electronic medical information to other providers without loss of meaning and enabling improvement of patient care.

When using untethered PHRS, patients are responsible for collecting clinical data from their healthcare providers or their own patient-generated measurement data and keeping it in their own storage, such as personal cloud space. For example, CDA and CCD can be obtained from healthcare providers, X-rays can be obtained from the radiology department, and lab test results from test lab or doctors office. Patients can share their health records with their clinicians by either electronically transmitting or granting access to their storage through the PHRS. If electronic sharing is not allowed, the patient may download the file and make hardcopies or store them in a USB, CD, or other mediums for sharing [7]. These clinical documents can also be sent to the healthcare provider or printed out for the patient to carry to the next point of care. The content of each HL7 CDA, CCD document is described in Dublin Core (DC) for easy retrieval in our proposed system (MCRS).

4.2 Non-Clinical Data

There are other type of documents that are not considered a clinical document, but are related to patient health records, such as health insurance information (e.g. coverage, cards, details and other information). These documents can also be stored on the PHRS as text or image (e.g. scanned document). However, when the patients upload non-clinical documents, they must create the metadata for each of these documents in order to make them retrievable.

4.3 Use of Metadata in PHR

There are two different methods of storing metadata. In the first method, metadata can be embedded in the data (e.g. in the header of a digital file). The advantages of this option are ensuring that the metadata will not be lost, eliminating the need for linking data and metadata, and updating the object and metadata together. In the second method, metadata can be stored separately in a database and linked to the objects. The advantage of this option is that it can simplify the management of metadata and can expedite the retrieval of the data [14]. In our approach, we employed the latter method to accelerate the retrieval of clinical data and to enhance expressive power. However, in this method, there can be inconsistencies between metadata and clinical data when transitioning to a new platform, integration between different systems or sharing data across multiple systems [20].

There are many metadata formats that have been accepted internationally including:

Dublin Core (DC), Federal Geographic Data Committee (FGDC), Encoded Archival Description (EAD), and Government Information Locator Service (GILS), to name a few [75]. One of the major issues in using metadata among healthcare systems is the lack of interoperability [76]. We adopted DC metadata as it is the most popular international standard for interoperability.

Metadata benefits personal health record management in many ways. These benefits include the following:

- Consistency in definitions: properly defined tags provide structured information about the clinical data users stored.
- Clarification of the relationships: metadata can be used to clarify the relationships among the clinical data by defining categories and associated relationships in the category. We have defined the usage of each tag in the DC for clinical data organization, as well as easy retrieval. When the data is uploaded or modified, so is the corresponding metadata

4.3.1 Metadata Management

Metadata management ensures that the data is associated with the datasets and utilized efficiently throughout and across organizations [77]. Data governance is needed for successful metadata implementation so it can provide trustworthy, timely and relevant information to decision makers, as well as personal users. For successful implementation, data governance must be aligned with the intended purposes of the users or organizations [78].

4.3.2 Dublin Core Metadata

The DC Metadata Initiative (DCMI), is an open organization supporting innovation in metadata design and best practices across the metadata ecology [79]. The DC Metadata consists of 15 optional elements including: title, creator, subject, description, publisher, contributor, date, type, format, identifier, source, language, relation, coverage and rights [80].

In this study, we defined the usage of DC metadata elements for clinical data to describe and retrieve clinical data efficiently as shown in the Table 3. Some of the metadata elements

- title subject, description, type, data and resource - are mandatory. These elements must be present for every clinical data item. The optional fields can be skipped, but if it has been filled, the metadata quality will be increased as shown in Figures 7, 8 and 11.

Entity	Description
DC. Title	The title of the uploaded document
DC. Creator	The author of the document
DC. Subject	Chief complaint/ reason of visit (pick lists)
DC. Description	Abstract
DC. Relation	• One of the body parts (Thorax, Abdomen, Heart extremities, Integumentary, Head, Urinary or Reproductive) • This element is linked to the subject element
DC. Date	Date of visit, lab test, x-ray, etc.
DC. Type	Type will be used for test for labs (blood work, urinalysis, fecal sample, nasopharyngeal sample, oropharyngeal sample and others) or images (x-ray, cat scan/ CT, Ultrasound, Magnetic resonance/MR, Scanned Document, Electrocardiogram, EKG/ or ECG and others)
DC. Format	PDFs, Text, JPEGs , TIFFs and others.
DC. Identifier	Document ID
DC. Language	English and other languages
DC. Coverage	Geographical and time-related information
DC. Rights	Copyright and access rights (secured or unsecured)
DC. Source	Data source

Table 3: Metadata Schema for PHR

4.4 Personal Cloud Storage

Cloud storage is a cloud computing model where users can store their data and access it anytime, from anywhere, and from any device via the Internet. It is maintained, managed and operated by cloud storage service providers [81]. Cloud storage services have many advantages such as cost savings, ease of use, ability to share data, accessibility, and sustainability. Personal Cloud Storage (PCS) is getting more popular because of the aforementioned convenience. Any cloud storage service provider may be used (SugarSync, Carbonite, IDrive, Dropbox, Google Drive, and others) [82] for storing personal health data as long as they provide required functionality and security. In our proof of concept, MCRS (see section 6), we are currently using Dropbox™as storage. However, for practical use, secure cloud storage services that are HIPAA complaint can be used for privacy and security purposes, such as Dropbox (Business), Box, Google Drive,Microsoft OneDrive, and Carbonite. The contents are organized by directories and described by DC metadata for interoperability. In the case that data has embedded metadata, we create another layer of metadata so entire files can be located through our DC metadata content.

4.5 Personal Health Record Systems Architecture

The architecture of PHR is based on the National Institute of Standards and Technology architectural (NIST) model, which "provides a description of how it addresses the storage, management and access of its health data" [83]. Steele et al. [83] identified five existing PHR architectures. In our classification, we used four categories including: USB or other portable storage-based PHR, smartcard-based PHR, mobile device-based PHR, and a web or cloud - based PHR. The description, providers, advantages and disadvantages of these PHR architectures are summarized in Table 4.

PHRS Architecture Type	Description	Advantages	Disadvantages
USB or other portable storage-based PHR (e.g. SD card) - These devices are commercially available	This type is considered as a stand-alone PHR (e.g. USB, Secure Digital (SD)	Portable Accessible - No need for network connection -Data kept secure and private (by using encryption /decryption methods [67].	-Need concomitant devices for connection with other devices -Required interoperable interface for exchanging data - Small storage - Can be lost or damaged
Smartcard-based PHR [84]. -Providers include: American Medical Association Health Security Card pilot; Lake Pointe Medical Center LifeMed Smart Card; Memorial Hospital LifeMed Smart Card, etc.	This type is considered as a Stand-alone PHR -"A portable integrated circuit (IC) chip-based plastic card (smartcard) can either store an individual's health data physically or under a logical file system" [83].	- No need for network connection to access data - It helps in emergency situations by storing important data (e,g. blood type, known allergies and immunization record) - Easy to use - Small size/ Carry-able - Secure -Portable medical record	-Need for network connection. -Lack of data sharing -Need reader devices Need middleware to exchange data securely - Can be lost easily -No desired control access (e.g. authorized person can access all data) - Virus concern from helath providers point of view
Mobile device-based PHR - Numerous mobile apps Commercially available	This type mostly considered as a stand-alone PHR but can be web-based - Smartphone or tablet can be used as local data repository - May have connection to cloud data repository	- Wireless connection - Real- time access - Provide dynamic data management or update - Doctors can get instant updates on patients' concerns	-Less secure while using wireless connection and slow connection - Limited data sharing with external parties [59]. -Users responsible for backing-up their data - Interface with EHRs limited
A web-based /cloud-based PHR - Providers include: Independent vendors (e.g, Dossia, MyGroupHealth, My HealtheVet, Health Vault and MyChart)	- Combining standalone, interconnected and tethered PHR.	-Need of only web browser -Maintenance and upgrading are completed by providers -Accessibility -Help in the integration sharing, and recovery of data.	- Lack of break-glass access in case of emergency situation -Providers may discontinue their service of PHRS for whatever reasons (e.g. Google Health) -Interoperability and integration problems

Table 4: Summary of PHRS Architectures

5 PROPOSED ARCHITECTURE FOR PHR

5.1 The Current Situation in the Healthcare Industry (AS-IS)

Some of the issues that the current healthcare industry is having are discontinuity of care and unacceptably high rates of medical mistakes due to unavailability of patient medical records at the time of need. Some of the factors that cause these issues are listed below and illustrated in Figure 3 (the numbers listed below correspond to the numbers on Figure 3).

- Personal health data is difficult to collect and manage because they are located over multiple places such as doctor's offices, radiology centers, hospitals, or some clinics (1).
- Heterogeneous data types such as text, images, charts, or paper-based documents (2).
- Discontinuity of care due to lack of communication among caregivers. This is caused by distributed and fragmented medical information (3).
- Lack of evidence-based treatment due to limited access to medical records (4).
- Medical errors due to incomplete medical history or access to emergency health information (e.g. allergies, current medication list, side effects, and others) at the time of need (5).
- Limited doctor availability. For instance, patients may need to be seen on the weekend or on a holiday when their doctor's office is closed (6).

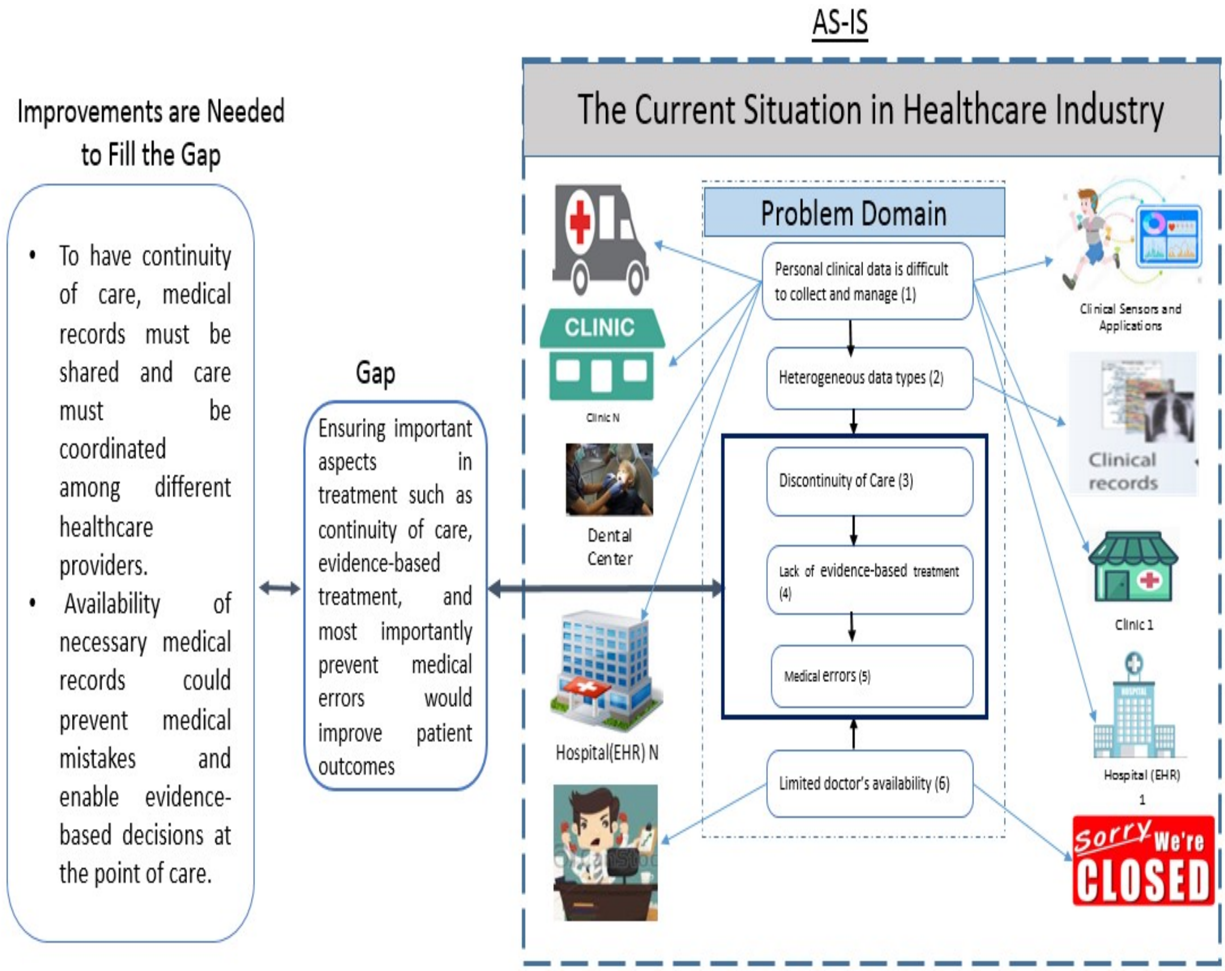


Figure 3: Problem Domain in the Current Healthcare Industry

5.2 Scenario 1 Illustrates the Importance of PHRS

5.2.1 Case 1: Patient without PHRS

John was suffering from tiredness and lack of energy for the past four weeks. He has several chronic conditions (type 2 diabetes, chronic kidney disease, chronic lower back pain, generalized anxiety disorder, depression, bipolar disorder, dyslipidemia, hypothyroidism, coronary artery disease and congestive heart failure) and is on multiple medications prescribed by his PCP, cardiologist, psychiatrist and pain management doctor. John had recently requested to become one of Dr. Smith's patients. Dr. Smith could not obtain John's health records form his previous healthcare provider for almost six months. After multiple attempts, Dr. Smith was able to obtain some of his previous medical records. Dr. Smith also was interested in reviewing his previous medical diagnoses and prior/current medications. Unfortunately there was no integration of the records and medications taken. After several interviews with John and his wife, Dr. Smith was able to determine that the patient was using the same type of long-acting insulin twice a day because one had the generic name and the other had the commercial or brand name. The patient was supposed to use this insulin once a day only. This patient's error kept his glucose at very low levels in blood, which led to constant tiredness and lack of energy. In addition, John was hospitalized due to a heart attack and had been given WARFARIN after leaving the hospital. After John visited his general practitioner, the doctor was unaware that the patient was on WARFAIN, so he prescribed a new medicine called CLOPIDOGREL. However, these two medicines cannot be taken together because they have adverse drug interactions, which increases the chance of bleeding out if the patient if injured in any way. Once the dose was corrected, the patient felt better. The immediate access to medical and prescription information would have allowed Dr. Smith to identify the error faster and provide him with the ability to take prompt corrective measures.

5.2.2 Case 2: Patient with PHRS

D.J. is a 73-year-old white male with a history of diabetes who lives in Los Angeles, CA. He was getting his diabetes medicine from a local CVS pharmacy, as referred by his doctor. Three years ago, he was hospitalized for three days at a hospital in Los Angeles, CA due to a broken leg. At this time, he found out that he has a kidney problem and needed to be referred to a specialist as soon as possible, otherwise it could cause kidney failure. He went to a specialist as recommended and went through many treatment procedures including a physical exam, lab tests, and radiology. When the results were provided, they showed that his kidneys had failed and that he needs dialysis every other day. D.J. used HDSS to collect all of his health records in HL7 CDA or CCD since hospitalization. He also used the cloud-based uploader to upload these records into his cloud storage, so they can be accessible from anywhere at any time. For the non-standard data format such as a scanned document, he used DC meta file to describe what the document was about, so it can be retrievable later on.

A few years later, D.J. moved to Maryland to live with his son. Two months later, he was unconscious due to a heart attack, so his son took him to the emergency room. While he was in the hospital, the physician wanted to give him a drug, but his son provided access to his father's health records that were stored in the cloud. When the doctor checked his health records, he found out that the drug would cause an allergic reaction and could put his life in danger. Therefore, the physician gave him another drug that would not have such a reaction. Also, D.J. did not have to repeat the physical examination, lab tests, radiology, and other procedures because all of his health records were in the cloud.

5.3 Solution Concept

To have continuity of care, medical records must be shared and care must be coordinated among different healthcare providers. Availability of necessary medical records could help prevent medical mistakes and enable evidence-based decisions at the point of care. It would be convenient to have clinical data stored in the same place for easy sharing and retrieval. Well-managed personal cloud space could outlive the lifetime of PHRS since clinical data is stored independently. In our approach, we separate the clinical data from applications to make the data independent from the application. Also, the users can have alternative applications to access their clinical data. Such independence helps clinical data outlive its applications. Our proposed concept is illustrated in Figure 4. In the figure, the clinical data is separated from the application for data independence.

5.4 Our Approach

As discussed in Section 2, there are a number barriers for the adoption of PHRS. As an attempt to overcome some of the barriers, we propose an untethered PHRS that utilizes personal cloud storage, offers simplicity in organizing various kinds of clinical data by utilizing DC metadata, and provides easy access to emergency clinical data to paramedics or clinicians in case of emergency. DC metadata has been successfully applied in many areas, but since it is not specifically designed for clinical data, there are some limitations in its expressive power in the healthcare domain. In this research, we simplified the categorization of clinical data by human body part for easy retrieval of clinical data using DC, so users can manage their own clinical data without in-depth knowledge about clinical information. As a proof of our concept, we developed a system called My Clinical Record System (MCRS) to help users store, organize, retrieve, and share their clinical data with caregivers when needed including emergency situations. In an emergency situation, clinicians (e.g. physicians, paramedics, nurses, and other) can access patient's data using their license numbers, patient name and their date of birth only. Emergency information consists of current medication list, known allergies and side effects. By having complete medical history, the MCRS users may be able to reduce medical errors and improve patients' outcome. It also ensures continuity of care by sharing personal health data among healthcare providers when needed. Our proposed hybrid PHRS is shown in Figure 4. The numbers in this figure correspond to the problems posed in Figure 3.

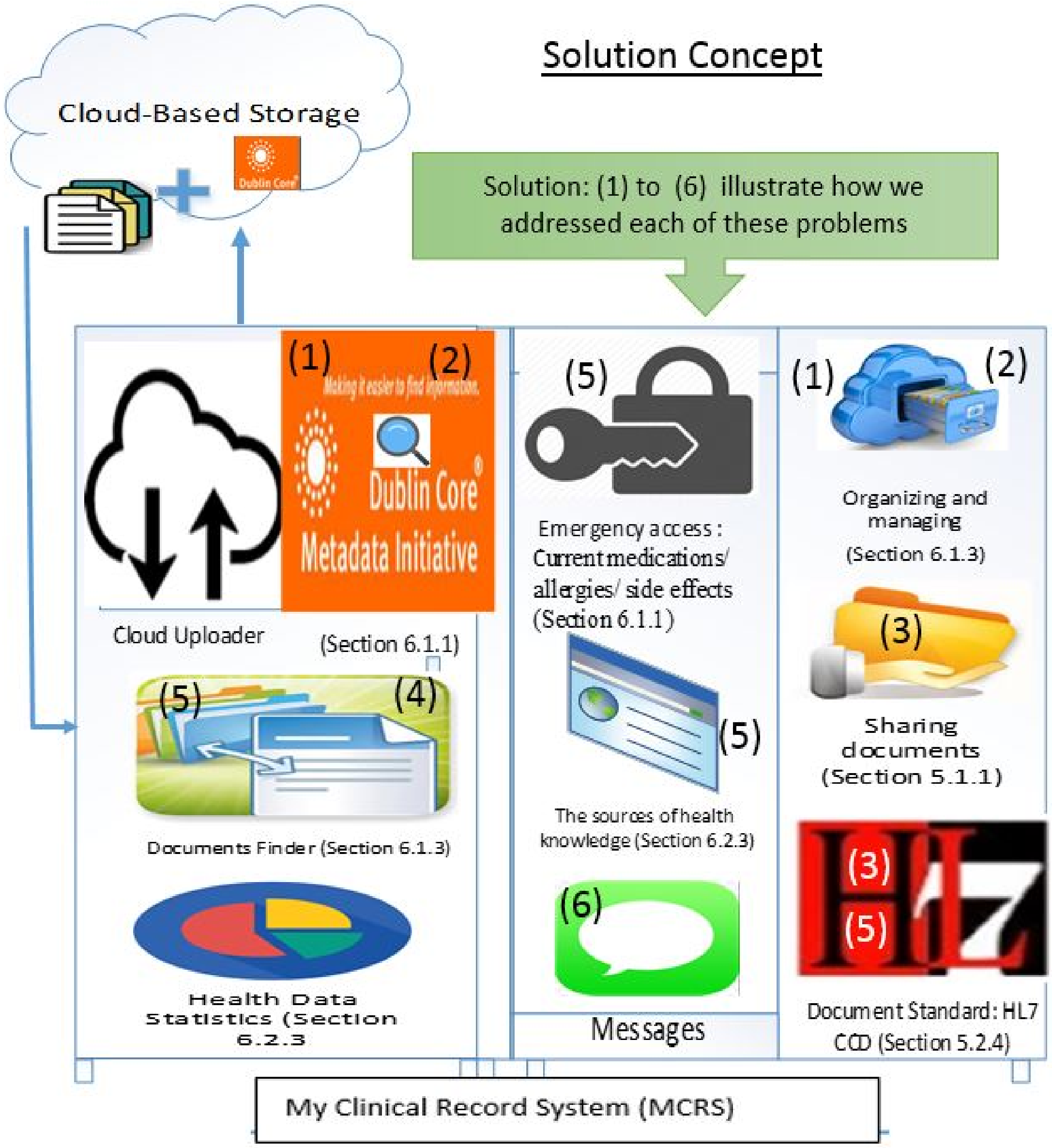


Figure 4: Proposed Hybrid PHR Architecture

6 PROOF OF CONCEPT

As a proof of concept, we have developed two web-based systems (prototypes). The first one is called my clinical health record system (MCRS) and the second is called health decision support system (HDSS). In the following sections, we will describe these systems in more details.

6.1 Introduction to MCRS

Patient generated data or personal health data in general is considered an important aspect in improving patient outcomes. However, personal health data is difficult to collect and manage due to their distributed nature. For example, this data is located over multiple places such as doctor's office, radiology centers, hospitals, or some clinics. It is also heterogeneous data types such as text, image, chart, or paper based documents. In case of emergency, this situation makes necessary personal health data retrieval almost impossible. In addition, since the amount and types of personal health data continue to grow, finding relevant clinical data when needed is getting more difficult if no actions are taken. In response to such scenarios, we propose an approach that manages personal health data by utilizing metadata for organization and easy retrieval of clinical data. We also propose cloud storage for easy access and sharing with caregivers to implement the continuity of care and evidence-based treatment. In case of emergency, we make critical medical information such as current medications and allergies available to relevant caregivers with valid license numbers only.

It would be helpful if all personal health data are stored in one place for easy sharing and retrieval. Well-managed personal cloud space could outlive the lifetime of PHRS since the discontinuity of the service does not affect the data stored in the cloud space. In our approach, we separate the clinical data from applications to make the data independent from the application. Also, the users can have alternative applications for their clinical data. Such independence motivates users to use PHRS with flexibility.

Our proposed concept is illustrated in Figure 5, which consists of:

- Consumer's clinical data collection module: we have developed HDSS to collect clinical data and observed symptoms in standard codes.
- Cloud uploader: we have built a web-based application that can upload various types of files including HL7 CDA, DC metadata, DICOM, and any other documents to cloud-based repository
- Cloud-based data repository: any cloud-based data storage can be used to store personal health data. We are currently using Dropbox™as storage. However, for practical use, secure cloud storage services that are Health Insurance Portability and Accountability Act (HIPAA) complaint can be used for privacy and security purpose, such as Dropbox (Business), Box, Google Drive,Microsoft OneDrive, and Carbonite. The contents of the storage are organized by directories and described by Dublin Core Metadata for interoperability (except for HL7 CDA files).

The data can be collected and uploaded to cloud storage based on three data types:

- Observed symptoms: Entered by patients themselves or legal guardians (e.g. observation of chest pain, shortness of breath, fatigue, and other). If these symptoms are not recorded in clinical standards such as SNOMED CT, it could be misinterpreted by healthcare providers, which may lead to misdiagnosis. For that purpose, we provide semantic guidance for using SNOMED CT to describe patient problems.
- Measurement data from portable medical devices or sensors can be inputted using HDSS to create HL7 CDA or CCD files.
- EHR data, which is collected from healthcare providers. For the non-HL7 CDA data formats, the DC metadata will be used to describe what the document is about in order to retrieve data faster, organize the data, and keep track of the data resources.

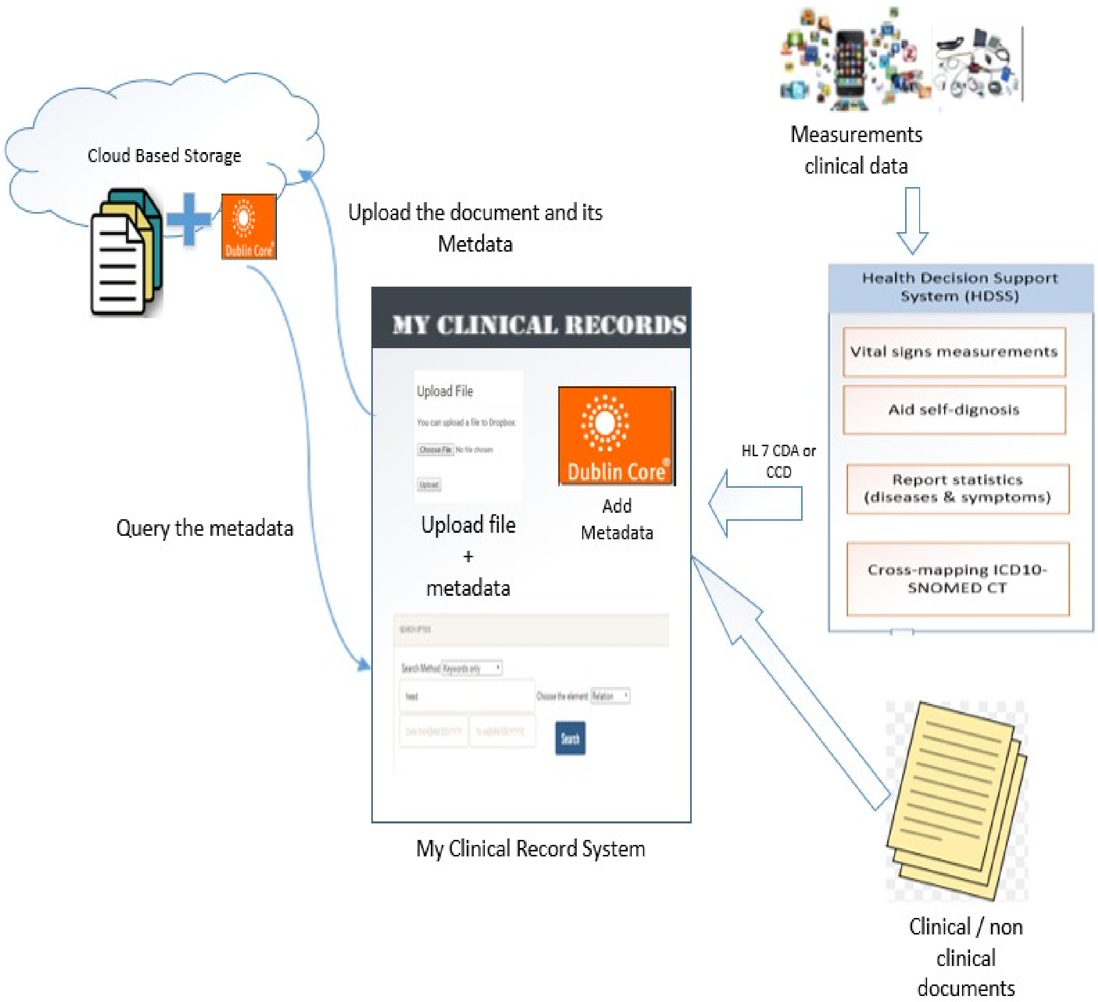


Figure 5: Overview of the Relationships among Metadata, Clinical Data, Cloud Storage, PHRS Application, and Clinical Data Sources

6.1.1 My Clinical Record System (MCRS)

As mentioned in the introduction, there are a number of obstacles in collecting and maintaining personal health data. In an attempt to remove such obstacles, we developed a web-based system called My Clinical Record System (MCRS) that can help users to upload, organize, and retrieve relevant health data. Some of the features of MCRS are:

- Users can search within their health records not only by keyword, but also by any of the metadata elements. They also can search by two elements such as subject and date in order to filter data by showing more relevant data. Additionally, they can find a group of records based on a date range they specify.

- MCRS allows users to share their health records with their physicians using the share document feature as shown in Figure 6.

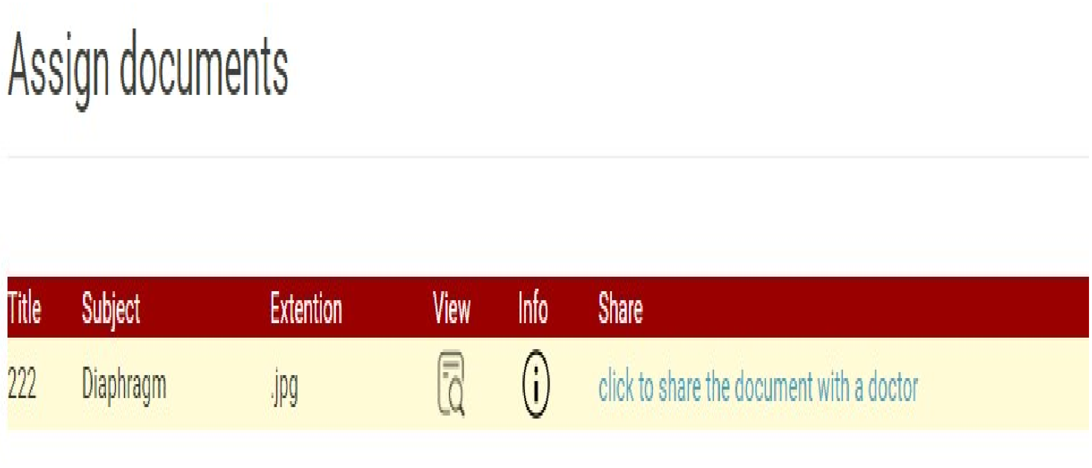


Figure 6: Sharing Health Records with Physician

- MCRS helps users to create metadata for any documents and upload them to their cloud storage. It also helps to retrieve those documents easily and can direct the users to its location if more information is needed.

- To overcome the ownership barrier, we separate the clinical data from applications which will give the users more freedom by not limiting themselves to one provider or application. Also, their data is saved on their own storage, thus we do not have to store it in our system.

- To overcome the interoperability barrier, we used DC standards to describe any clinical data using our tag definition. The DC metadata content for doctor visit summary document is shown in Figure 7 and Figure 8.

```xml
<?xml version="1.0" encoding="utf-8"?>
<Metadata xmlns:xsi="http://www.w3.org/2001/XMLSchema-instance"
xmlns:dc="http://purl.org/dc/elements/1.1/"
xmlns:mcr="http://MyClinicalRecords.net/MyClinicalRecords.aspx"
xmlns:dcterms="http://purl.org/dc/terms/">
  <Report Id="Mohammed1262017233939">
    <dc:Title>doctor visit summary</dc:Title>
    <dc:Creator>Dr. Yoataco</dc:Creator>
    <dc:Subject>nose</dc:Subject>
    <dc:Description>cough, runny nose</dc:Description>
    <dc:Publisher></dc:Publisher>
    <dc:Contributor></dc:Contributor>
    <mcr:Findings>Acute bronchitis with bronchospasm</mcr:Findings>
    <mcr:Treatment>Mucinex Sinus-Max Day &amp; Night Relief </mcr:Treatment>
    <dc:Type>Report</dc:Type>
    <dc:Format>PDF</dc:Format>
    <dc:Identifier></dc:Identifier>
    <dc:Source>GetWell</dc:Source>
    <dc:Language>Eng</dc:Language>
    <dc:Relation>Head</dc:Relation>
    <dc:Coverage></dc:Coverage>
    <dc:DateOfVisit>12/12/2016</dc:DateOfVisit>
  </Report>
</Metadata>
```


Figure 7: DC Metadata Content for Doctor Visit Summary

Metadata Report No. (Mohammed1262017233939)

Patient Information

Full Name : : Mohammed	**Date of birth :** : 06/28/1976
Address : : 710 Bridgeman ter	**Zip code :** : 2124
Phone No. : : 3232836126	**Email :** : aljakman2006@hotmail.com

Report Details

Title : : doctor visit summary
Creator : : Dr. Yoataco
Description : : cough, runny nose
Subject : nose
Contributor :
Publisher :
Format : : PDF
Type : Report
Source : : GetWell
Identifier :
Relation : : Head
Language : Eng
Coverage :
Date of Visit : : 12/12/2016

Figure 8: Visualization of the Metadata

- The easy access to users' health data and the ability to contribute to their record enhances users' motivation to use PHR.
- MCRS enables emergency clinical data access by emergency crew only with valid license number. We use the National Provider Identifier (NPI), patient name, and date of birth for the emergency medical information access as shown in Figure 9. Emergency information contains allergies, current medication list, and side effects. This information is updated regularly by patients as shown in Figure 10. It also contains any references to the time of the last update.
  - Healthcare providers apply for NPI using the National Plan and Provider Enumeration System (NPPES) [85].
  - NPI can be validated through NPPES NPI Registry.

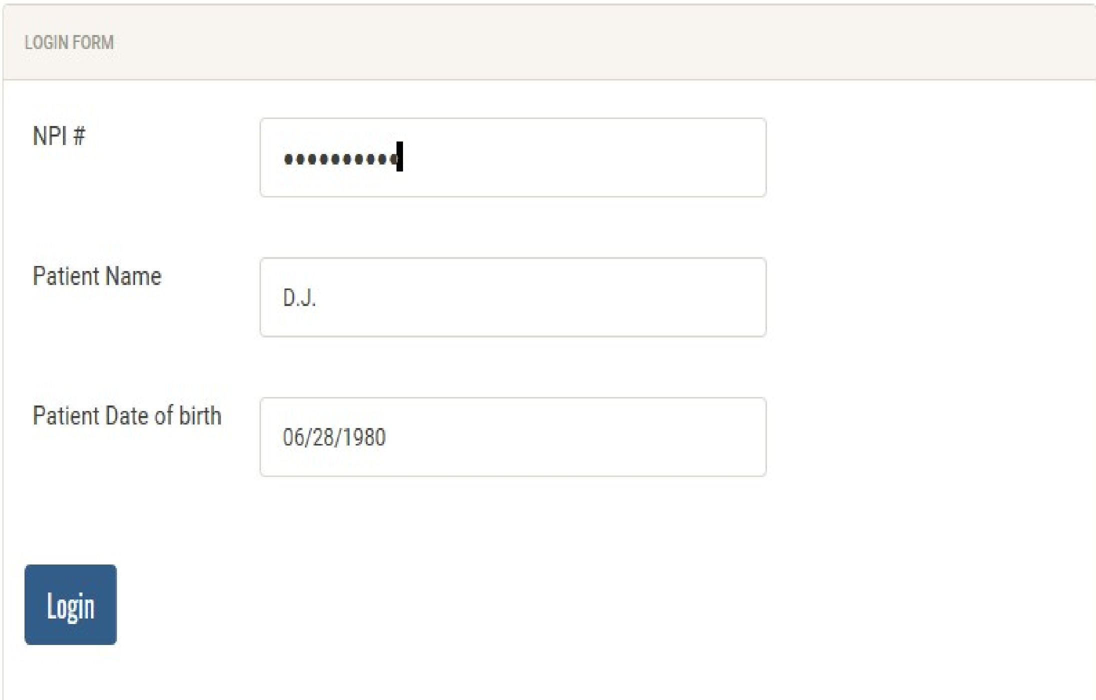


Figure 9: Emergency Access with Valid License Number

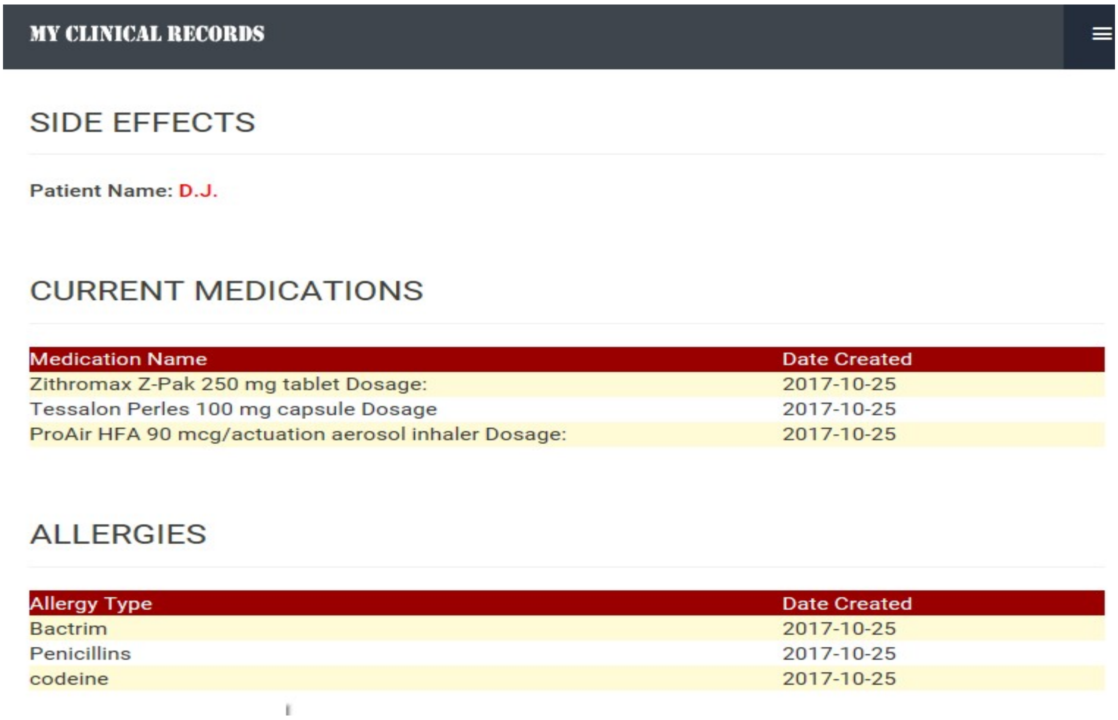


Figure 10: Emergency Information

6.1.2 Using MCRS

We use patients' Dropbox access token to allow the connection between Dropbox and MCRS, so patients can have their own storage and have the ability to provide access to their storage through MCRS when needed. This allows users to keep their own data without binding to any specific application. MCRS contains no clinical data as they are stored in the patients' cloud storage. Patients need accounts for Dropbox and MCRS separately.

6.1.3 Managing Health Data

MCRS categorizes clinical data based on human body parts. There are eight categories: abdomen, heart, head, thorax, extremities, integumentary, urinary, and reproductive as shown in Table 5. Any clinical data will be stored and linked based on these categories using the relation and subject tag elements of the DC metadata. We kept the categories to minimum so it can be simple enough to be used by patients. Users can specify the category (the human body part of interest) when searching for relevant clinical data, so it can show only the clinical documents (e.g. doctor visit summary, x-ray, and others) that are related to that part.

When using the relationships between the resource (DC subject) and target resource (DC relation), it is possible to combine the result to a greater scope, e.g. instead of eyes and ears, it can be categorized by head. This can be done by predefining each part of the human body and associating it with its related category in the system. Also, we have constrained the DC subject to a small core set that can be selected from a drop-down menu (all possible parts of the human body) to best describe the subjects (as shown in Figure 11). So, when the users select the subject element, the DC relation field will be populated automatically with the associated part of its related category. For example, when a user searches by keyword (e.g. head) and chooses the element (e.g. relation), the search results will be filtered and show only all clinical documents that are relevant to the head (e.g. eyes, ears, brain, mouth, teeth, nose, and chin) as shown in Figure 12. This is a less time-consuming method to filter the data instead of showing all documents as shown in Figure 13. Also, the user can filter the search by date if they need to specify a period of time to find clinical documents.

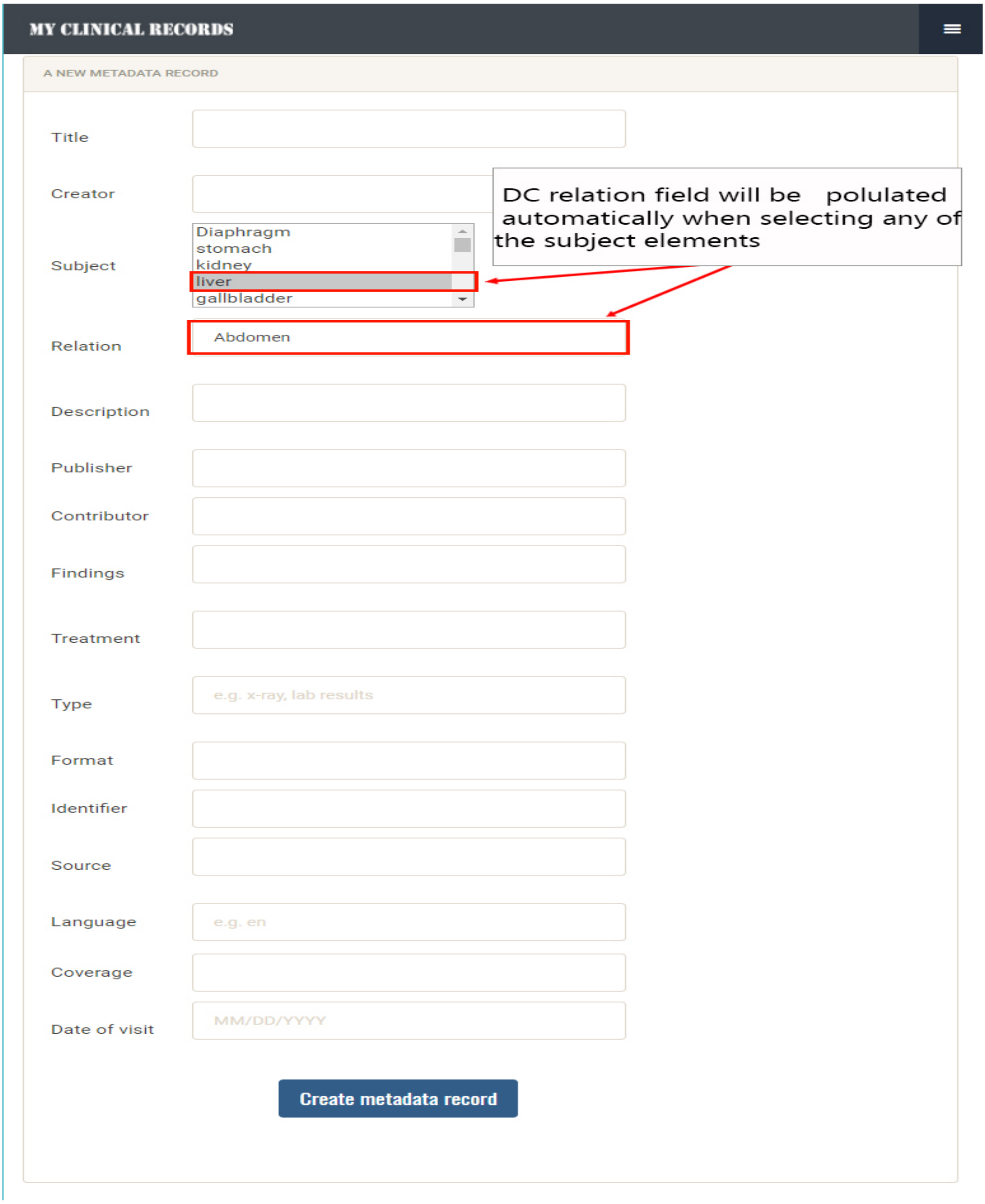


Figure 11: Create DC Metadata

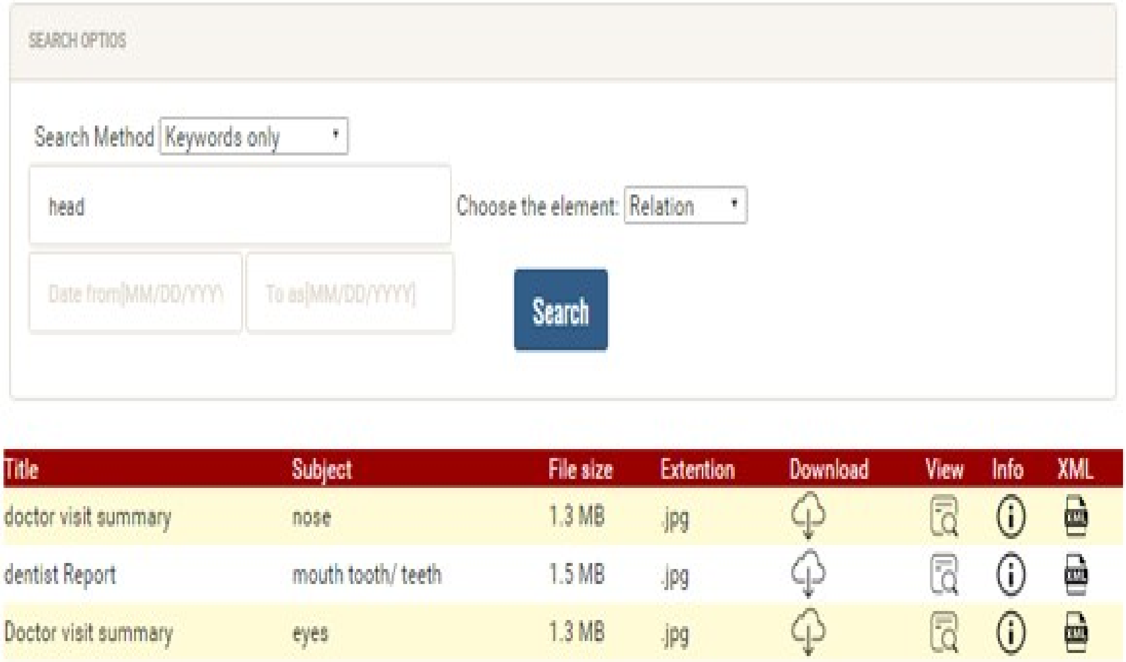
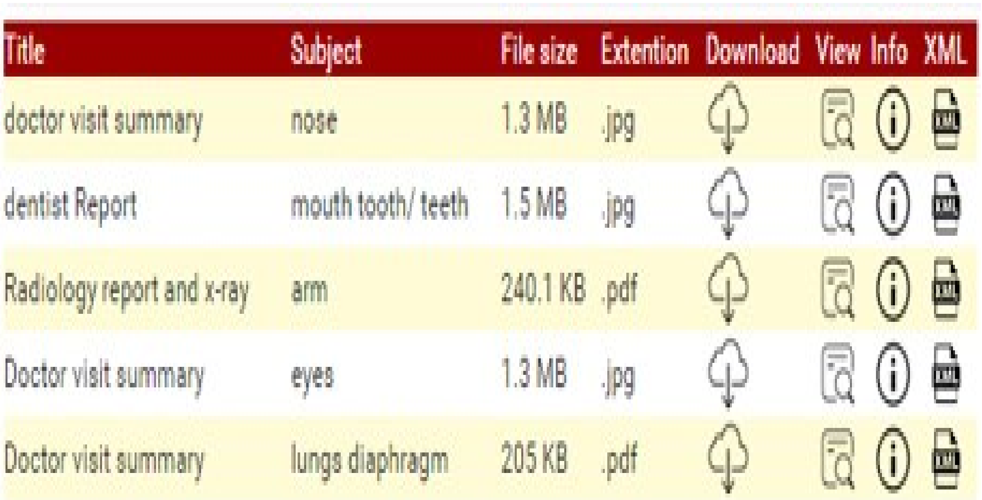


Figure 12: Example of Retrieving DC Metadata for only Related Documents



Title	Subject	File size	Extention	Download	View	Info	XML
doctor visit summary	nose	1.3 MB	.jpg				
dentist Report	mouth tooth/ teeth	1.5 MB	.jpg				
Radiology report and x-ray	arm	240.1 KB	.pdf				
Doctor visit summary	eyes	1.3 MB	.jpg				
Doctor visit summary	lungs diaphragm	205 KB	.pdf				

Figure 13: Example of DC Metadata for all Documents

Body categories	Body parts
The abdomen	Contains diaphragm, stomach, liver, gallbladder, pancreas, small intestine, large intestine, cava, spleen, and others.
Heart	Contains superior vena cava, pulmonary artery, pulmonary veins, pulmonic valve, tricuspid valve, inferior vena cava, right atrium, right ventricle, left ventricle, aortic valve, mitral valve, left atrium, aorta and others.
Head	Contains eyes, ears, brain, mouth, teeth, nose, chin, spinal cord, tonsil, uvula, gullet, meninges, pharynx and others.
Thorax	Contains lungs, diaphragm/pleura, nasopharynx/oral, cavity, trachea/Larynx, ribs, capillaries, bronchial tube, windpipe/trachea, chest, esophagus and others.
Extremities	Contains arms, elbows, hands, wrists, shoulders, hips/thighs, fingers, thumbs, legs, knees, toe, vertebral column, neck, ankles, breast, back pain, feet and others.
Integumentary	Skin and associated structures such as hair, nails, sweat glands, and oil glands
Urinary	Kidneys, ureters, urinary bladder, and urethra
Reproductive	Gonads (testes or ovaries) and associated organs; in females: uterine tubes, uterus, and vagina; in males: epididymis, ductus deferens, prostate gland, and penis

Table 5: Human Body Categories

6.2 Introduction to HDSS

The accuracy and availability of PHR may improve patient outcomes by ensuring important aspects in treatment such as continuity of care, evidence-based treatment and more importantly prevent medical errors. However, getting PHR data can be difficult due to the fact that they are distributed over multiple sources (e.g. caregivers, patients themselves, clinical devices) and each may describe patient problems in their own way. Such inconsistencies could lead to medical mistakes. Using medical standards such as ICD-9/ICD-10 and SNOMED CT can help overcome such difficulties. In our approach, we provide semantic guidance for using SNOMED CT to describe patient problems and for mapping SNOMED CT codes to ICD-10-CM to find out potential diseases. As a proof of concept, we developed HDSS that can help users to use clinical standard such as SNOMED CT. It will also map to potential disease(s) based on symptoms provided by patients as a diagnosis result.

HDSS was designed for both physician and patient use to compared to existing clinical decision support that are designed for physician use only with limited features such as drug altering, reminders, order sets and preventive care reminders. In the sub-sections, we describe the roles of users (patient/physician) and how they use the system (HDSS) as shown in Figure 14. We have also used business process modelling notation (BPMN) to represent the clinical pathways as shown in Figure 15.

6.2.1 The Role of Patients:

Listed below is the information that the users may provide as input:

- Provide age and gender
- The area of complaint by body parts
- The symptoms from drop down list
- Rate their pain on a scale from 1 to 10
- The basics of symptoms including: how they feel, locations in the body, severity, how often they occur, how long did they last and whether they are associated with a certain activity, specific injury, time of day, food or drink, or any other triggers or patterns they have picked up on.

HDSS can help patient in many ways such as:

- Aid in self-diagnosis by providing their observed symptoms and then the systems will provide them with potential diseases and direct them to resources in regarding to treatment, risks, and causes of that disease as shown in Figure 32.
- Can help user to create interoperable and sharable personal health records using Continuity of Care Document (CCD) which allows healthcare providers to exchange clinical information summary about a patient as shown in Figure 23.
- Assists users to improve their health knowledge by providing precise medical terminologies related to their symptoms

6.2.2 The Role of Physicians:

Since every symptom may come from multiple causes, physicians need to narrow down the possibilities. For this purpose, SNOMED CT code was captured using multiple data entry methods, such as drop down lists and free text search.

- Input: entering ICD-10 terms or codes. For example, the physician can enter ICD-10 codes or terms and then the systems will pull associated SNOMED CT codes and names (symptoms) to disease ICD-10 and vice versa. This in turn can increase the physician confidence level because the system will pull all applied symptoms to that disease, which helps to avoid misdiagnosis.
  - In order to get accurate diagnosis, physician may ask patients questions related to their symptoms and use the system to come up with the correct diagnosis.
- Physicians can also validate the output of the system, which allows clinicians to qualify and refine concepts.
  - Since SNOMED CT updates every 6 months, clinicians can report new concepts that does not exist in the current SNOMED CT dataset to the International Health Terminology Standards Development Organisation (IHTSDO)

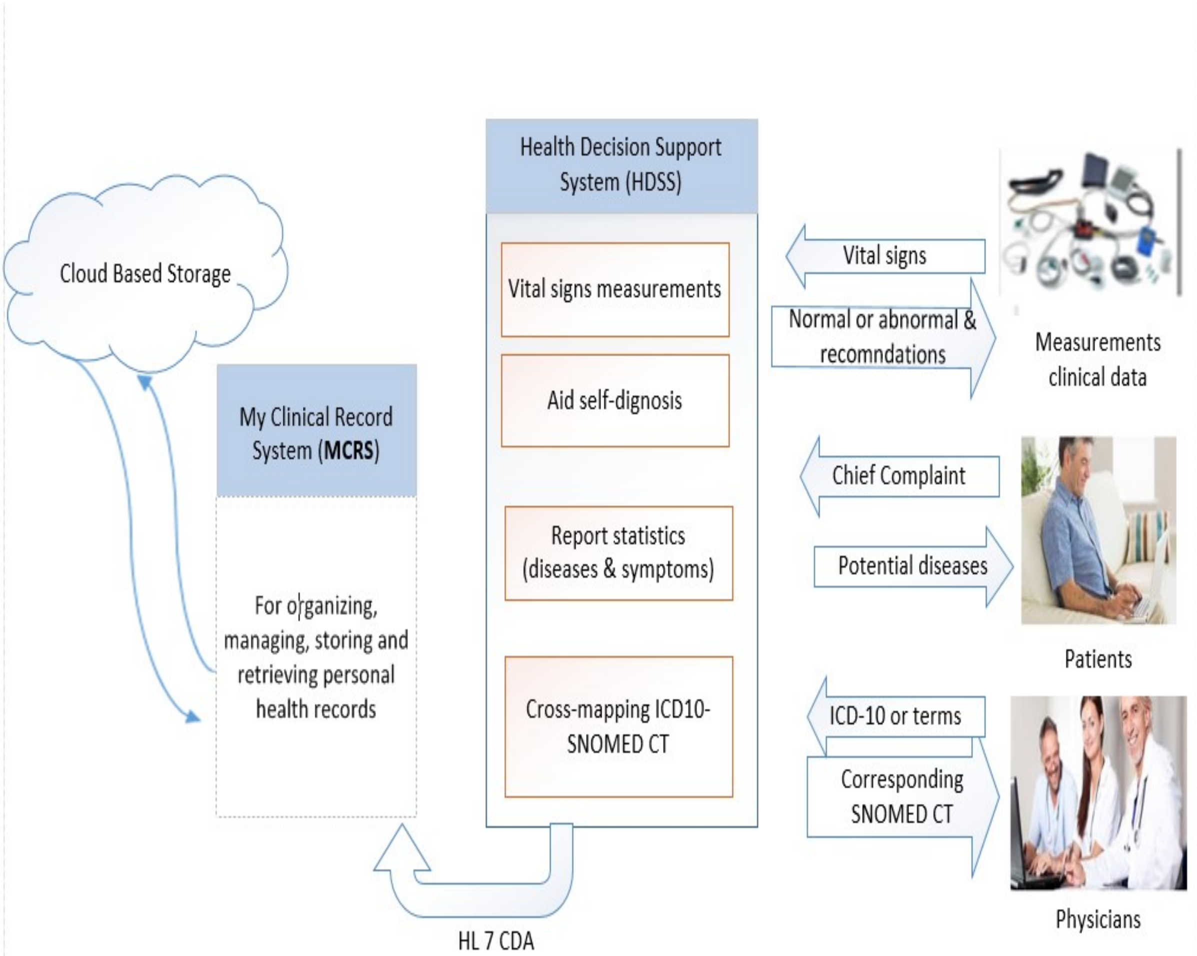


Figure 14: Overview of the Health Decision Support System (HDSS)

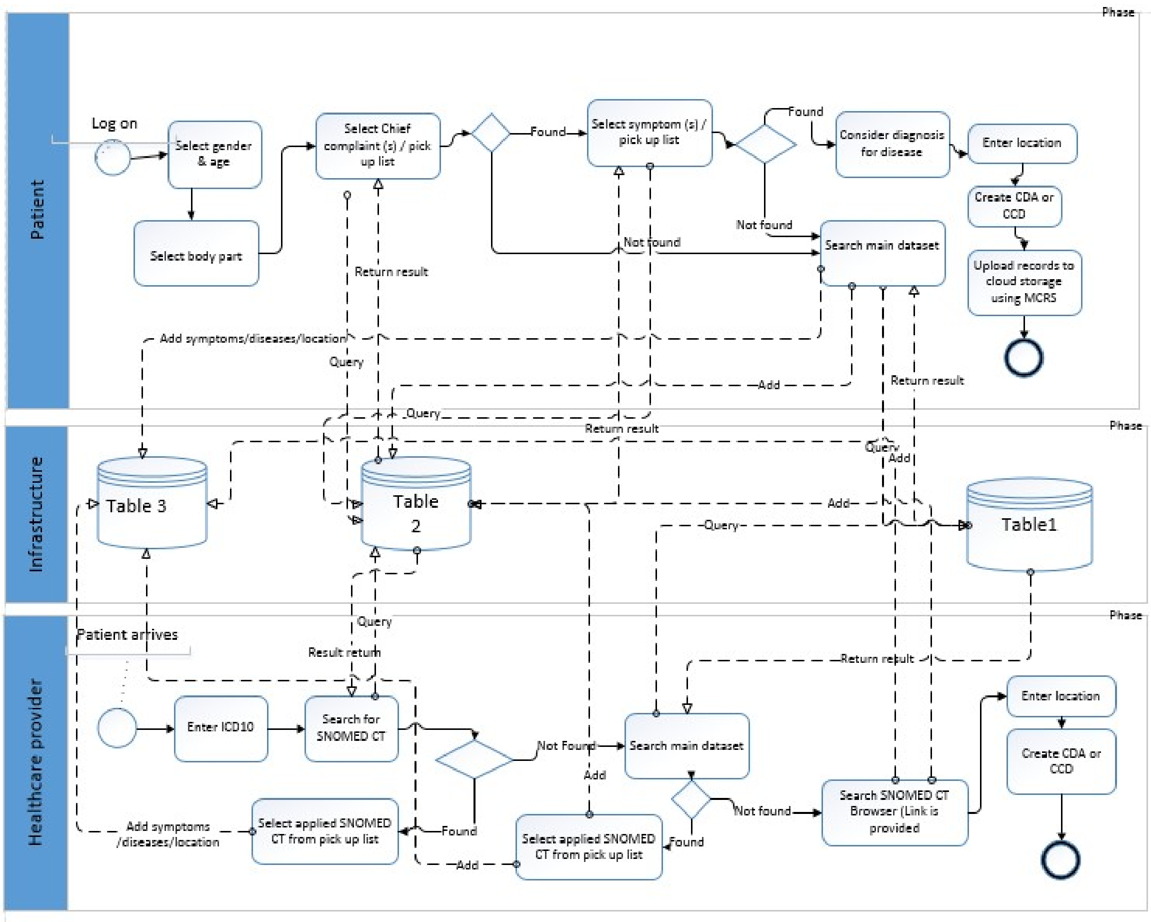


Figure 15: The Workflow of HDSS in BPMN

6.2.3 Clinical Decision Support Process

In this section, we describe how our approach helps identify potential diseases based on patient provided symptoms and vital signs.

6.2.3.1 Vital Sign Measurement

In this section, we describe the importance of vital sign measurements and how they are encoded in our system. Vital signs, as shown in Table 6, are a critical component of patient care. They are used to measure the body's basic functions and to detect early signs of underlying health problems. If these signs are not monitored regularly, it may be possible to overlook serious diseases such as hypertension. High blood pressure can be extremely dangerous and may lead to strokes, heart attacks, kidney disease, or even dementia. Since this may go undetected, it is important to measure blood pressure accurately [86]. Measuring vital signs also can prevent misdiagnosis since many diseases have similar symptoms. For example, hypothyroidism results from the thyroid gland not producing enough hormones. Chief complaints such as fatigue, sluggishness, and sleeping too much may lead a physician to diagnose depression. Even though depression is a common symptom of hypothyroidism, physicians sometimes overlook the likelihood that a person who is suffering from depression may have low thyroid levels. This is because there are other symptoms of hypothyroidism such as slower heart rate, low blood pressure, and weight gain, which cannot be detected without checking vital signs and comparing them to the patient's history. So the vital sign measurements can help physicians to make an accurate diagnosis. Monitoring such vital signs may help doctors resolve issues quickly for better patient outcome. Vital signs may vary depending on age, weight, gender, and overall health. So keeping track of the vital sign measurement data can help monitor, predict, and advise patients to check out their conditions in case of abnormality. In our approach, we record vital signs for better diagnosis results and make it sharable with their physicians.

VITAL SIGNS	LOINC CODE	NORMAL RANGE	IF OUT OF RANGE
HEART RATE	8867-4	60-90 beats per minute	SEEK IMMEDIATE MEDICAL ATTENTION IF YOU HAVE: • DIFFICULTY BREATHING • CHEST PAIN • PALPITATIONS • DIZZINESS • NUMBNESS • DIFFICULTY SPEAKING • SUDDEN HEADACHE
RESPIRATORY RATE	9279-1	12-20 breaths per minute	
BLOOD PRESSURE	55284-4	<130/85mmHg 18-39 years of age <150/90mmHg >60 years of age	
TEMPERATURE	8310-5	97.8-99 Fahrenheit	
OXYGEN SATURATION	59408-5	95-100%	
BMI	39156-5	18.5-24.9Kg/m^2	CONSULT WITH YOUR DOCTOR FOR DIET & EXERCISE RECOMMENDATIONS IF YOU ARE: • OVERWEIGHT 25-29.9Kg/m^2 • OBESE >30Kg/m^2

Table 6: Vital Sign Normal Ranges and Recommendations

6.2.3.2 Pre-processing

6.2.3.2.1 Data Collection and Filtering

In this experiment, our dataset of mapping between SNOMED CT and ICD-10 is from UMLS version 2017. It consisted of a text document (38,995 KB) and a TSV file (60,668 KB). When we converted it to an Excel stylesheet for visualization, some of the records showed invalid characters during the process and it required another manual process to fix as shown in the below examples.

275542004 History of M├─ni├¿re's disease (situation) ←Before

275542004 History of Ménière's disease (situation) ←After

mapTarget	icdName
M84.30X?	Stress fracture, unspecified site, episode of care unspecified

← Before

mapTarget	icdName
M84.30XA	Stress fracture, unspecified site, episode of care unspecified

← After

6.2.3.2.2 Cross- Maps

Cross maps are mappings between SNOMED CT and ICD-10. ICD-10 diagnoses are represented by 3-to 5- character codes with explicit decimals.Each code begins with an alphabetic character that generally corresponds to an ICD-10 chapter. ICD-10 has separate chapters for groups of symptoms and diseases. For example, Code G is for Nervous System chapter, code I is for Circulatory System chapter, code J is for Respiratory System chapter, and code K is for Digestive System chapter. For mapping, our system uses the main three tables as shown in Figure 16:

- Table 1 is the main dataset that contains all ICD-10 codes and their corresponding SNOMED CT for mapping.

- Table 2 initially is empty, and it will be populated every time users are using Table 1 for health records. For example, when the physician selects a disease and symptoms from Table 1, they will be added to Table 2.

- Table 3 contains patient information (e.g. name, ID, address, gender, and age), chief complaint, and vital signs.

- System analyst is based on Table 2 and Table 3, which collects the frequencies of symptoms/ diseases and their location to report statistics to capture the regional health characteristics. Statistics such as the number of patients with diabetes can be used to help establish public health policies or to conduct research for clinical or educational purposes. HDSS can show statistics data (e.g. frequency, gender, and location) for each disease or each symptom as shown in Figure 17 and Figure 18, while also showing the highest number first.

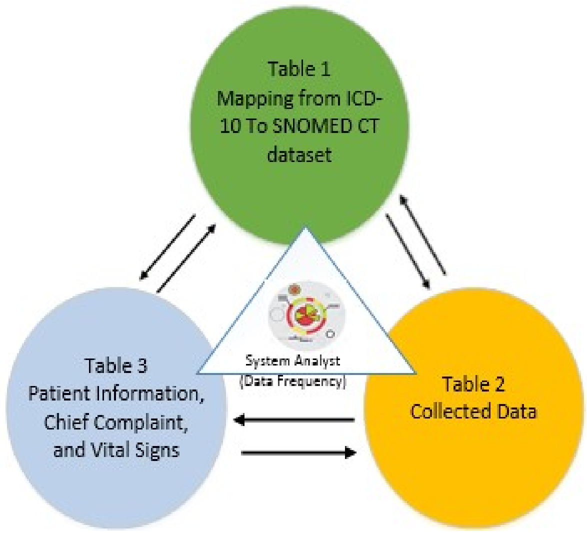
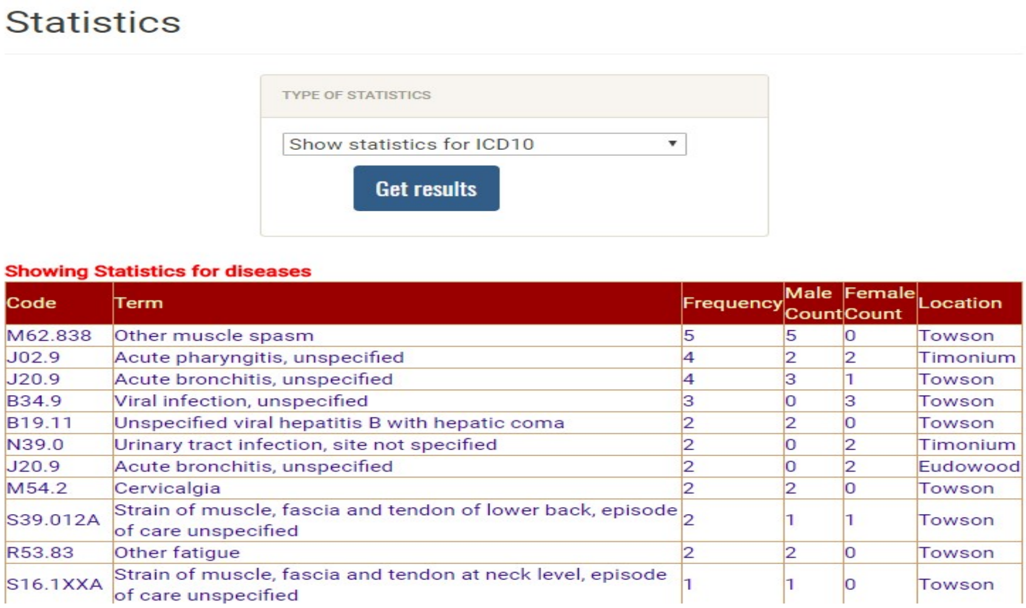
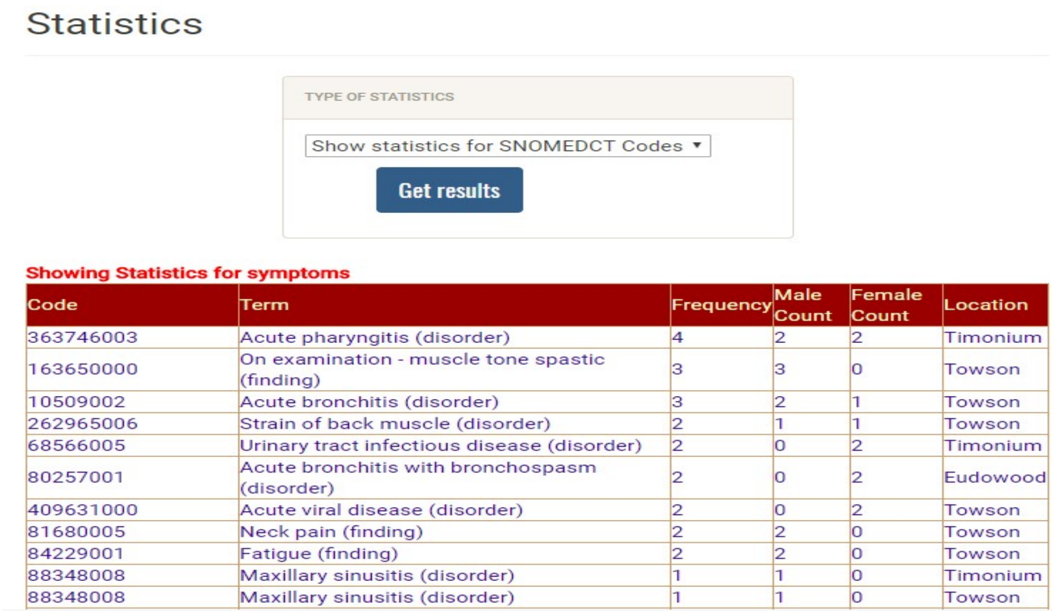


Figure 16: Overview of the Main Tables used in HDSS Database for Mapping



Code	Term	Frequency	Male Count	Female Count	Location
M62.838	Other muscle spasm	5	5	0	Towson
J02.9	Acute pharyngitis, unspecified	4	2	2	Timonium
J20.9	Acute bronchitis, unspecified	4	3	1	Towson
B34.9	Viral infection, unspecified	3	0	3	Towson
B19.11	Unspecified viral hepatitis B with hepatic coma	2	2	0	Towson
N39.0	Urinary tract infection, site not specified	2	0	2	Timonium
J20.9	Acute bronchitis, unspecified	2	0	2	Eudowood
M54.2	Cervicalgia	2	2	0	Towson
S39.012A	Strain of muscle, fascia and tendon of lower back, episode of care unspecified	2	1	1	Towson
R53.83	Other fatigue	2	2	0	Towson
S16.1XXA	Strain of muscle, fascia and tendon at neck level, episode of care unspecified	1	1	0	Towson

Figure 17: Statistical Data for Diseases



Code	Term	Frequency	Male Count	Female Count	Location
363746003	Acute pharyngitis (disorder)	4	2	2	Timonium
163650000	On examination - muscle tone spastic (finding)	3	3	0	Towson
10509002	Acute bronchitis (disorder)	3	2	1	Towson
262965006	Strain of back muscle (disorder)	2	1	1	Towson
68566005	Urinary tract infectious disease (disorder)	2	0	2	Timonium
80257001	Acute bronchitis with bronchospasm (disorder)	2	0	2	Eudowood
409631000	Acute viral disease (disorder)	2	0	2	Towson
81680005	Neck pain (finding)	2	2	0	Towson
84229001	Fatigue (finding)	2	2	0	Towson
88348008	Maxillary sinusitis (disorder)	1	1	0	Timonium
88348008	Maxillary sinusitis (disorder)	1	1	0	Towson

Figure 18: Statistical Data for Symptoms

6.2.3.3 Searching

HDSS categorizes data based on human body systems and parts as shown in Table 6. HDSS categorizes patient input data based on the commonly used human body systems and parts as shown in Table 7. We used the most common body systems that were provided by ICD-10 structure [87]. Even though ICD-10 has different chapters for different diseases, these diseases are applied to one or more of these body systems. For instance, A-B ICD-10 Codes and C ICD-10 Code may apply to multiple categories, such as digestive, respiratory, musculoskeletal, or genitourinary system as shown in Figure 19. However, other diseases that do not apply to these body systems will be in different categories such as ”Injury, poisoning and certain other consequences of external causes” category including S00-T88 ICD-10 code and other. By using organ systems and body parts, we can improve search capability by limiting search results to less than 50, instead of more than 10,000 ICD-10 codes. ICD-10 combines circulatory and respiratory systems (called other specified symptoms and signs involving the circulatory and respiratory systems), which contains 1439 records. It is difficult to search through such large numbers of records in practice. In our approach, we grouped the codes by body systems so it can be easier to search through. After grouping, we only had 324 records for circulatory systems. Further classification can be done by body parts to reduce search results.

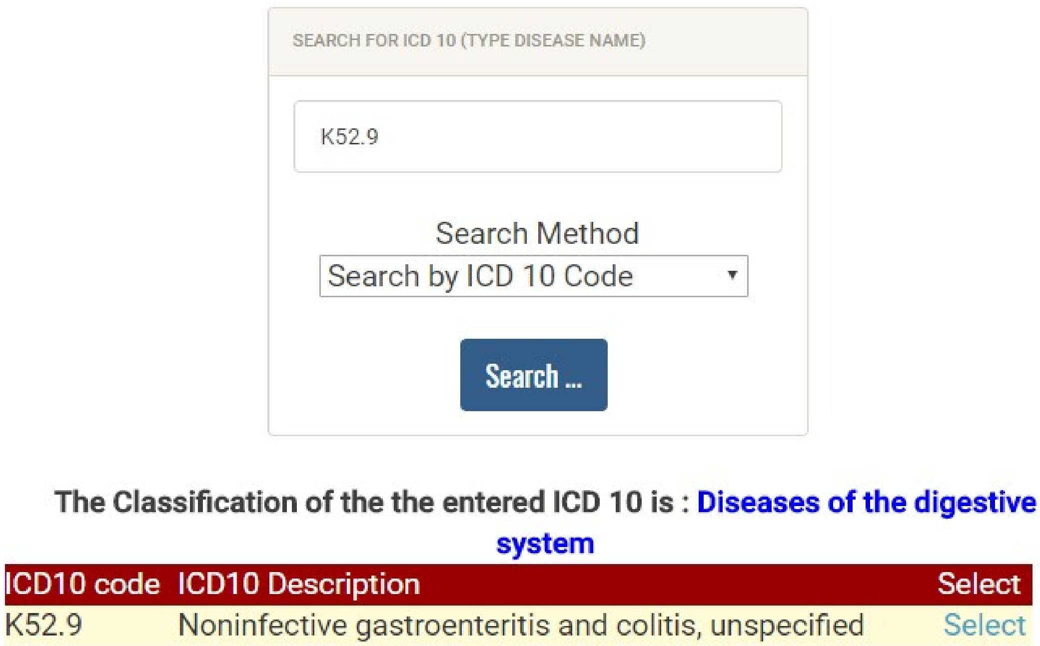


Figure 19: Body Systems

ICD-10 Code	Body Systems	Body parts
K	Digestive	Contains diaphragm, stomach, liver, gallbladder, pancreas, small intestine, large intestine, cava, and spleen, and others.
I	Circulatory	Contains blood vessels and heart (superior vena cava, pulmonary artery, pulmonary veins, pulmonic valve, etc.)
J	Respiratory	Contains Trachea, Bronchi, Lung, and others.
G	Nervous	Contains brain, spinal, nerves, and others.
M	Musculoskeletal	Contains bones of the skeleton, muscles, cartilage, tendons, ligaments, joints, and other connective tissue.
N	Genitourinary	Kidneys, ureters, urinary bladder, urethra, gonads (testes or ovaries) and associated organs; in females: uterine tubes, uterus, and vagina; in males: epididymis, ductus deferens, prostate gland, and penis.

Table 7: Commonly used Human Body Categories

6.2.3.4 Post-processing

In this process, we try to reduce the number of potential diseases that result from the mapping. Let *PD* be the resulting potential diseases and *Ai* be the members in the set.

For each potential disease Ai $\in$ *PD*, $1 \leq i \leq n$

{

Check all SNOMED CT codes mapped for Ai

- *Acquire additional symptoms and vital signs*

  from patient to see if it satisfies the criteria for Ai

- *if not satisfied, remove Ai from PD*

  PD = PD - $\{Ai\}$

}

6.2.4 Scenario 2 Illustrates the Importance of Using Clinical Standards

D. J. was referred from doctor A to doctor B with his personal health records that contained many visits (medical history). When his new doctor B reviewed his records, he faced many issues. Some of the records were hand written and he could not read them, some were incomplete, and some used different terms for diagnoses that his new doctor B was unaware of such as EDEMA, NIDDM, and CELLULITIS as shown in Figure 20 and Figure 21 respectively. So his new doctor had to communicate with his previous doctor to clarify some of the medical history. Doctor B had to create new health records for his patient D.J. and keep his previous uncompleted health records as well. Doctor B also required D.J. to repeat the physical examination, lab tests and radiology in order to get to the accurate diagnosis and complete his records. Even though D.J.'s new doctor B uses EHR system and uses ICD-10 and ICD-9 as shown in Figure 22, he uses different terminologies that may not be understandable by other doctors while reporting the patient symptoms. Compared to the above scenarios, in our approach, we guide patients to describe their symptoms in SNOMED CT code by choosing the appropriate description. That can help their doctors to make accurate diagnostic decisions and come up with the best treatment plan for the patient. We also guide physicians to use SNOMED CT and ICD-10 in order to avoid misinterpretation by using HDSS as shown in Figure 23.

<u>Proposed Solution for Improving Health Records</u>

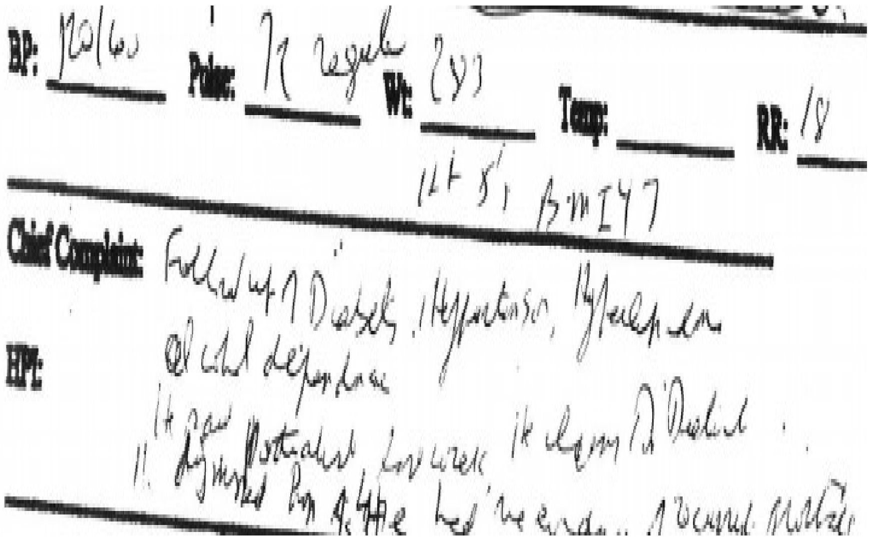
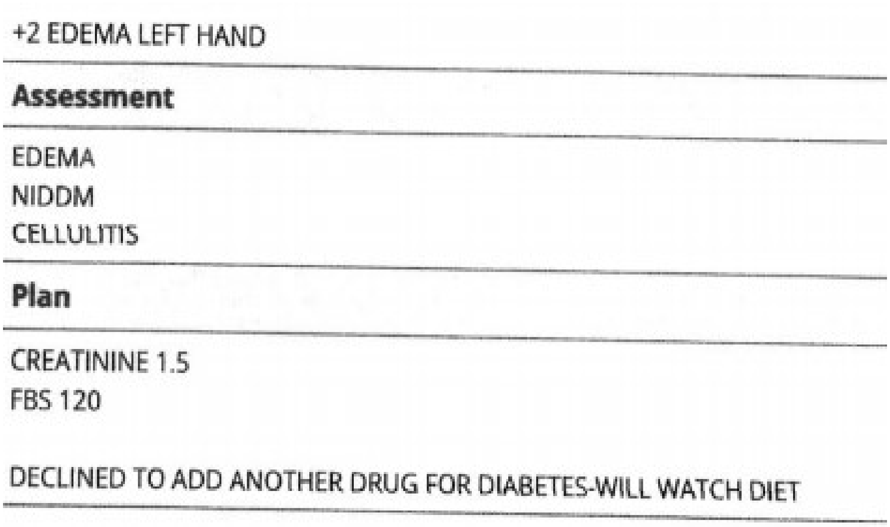


Figure 20: Hand-Written Health Record



+2 EDEMA LEFT HAND

Assessment

EDEMA
NIDDM
CELLULITIS

Plan

CREATININE 1.5
FBS 120

DECLINED TO ADD ANOTHER DRUG FOR DIABETES-WILL WATCH DIET

Figure 21: Example of an Ambiguous Health Record

Impression and Recommendation

Diagnosis

Description	ICD10	ICD9	Onset Date	Status	Status Date	Type	Date Added	Severity
Cellulitis of both lower extremities	L03.115	682.6	12/09/2016	Active	12/09/2016	Diagnosis	12/09/2016	
Cellulitis of foot, right	L03.115	682.7	12/09/2016	Active	12/09/2016	Diagnosis	12/09/2016	
Cellulitis of foot, left	L03.116	682.7	12/09/2016	Active	12/09/2016	Diagnosis	12/09/2016	
Ankle cellulitis	L03.119	682.6	12/09/2016	Active	12/09/2016	Diagnosis	12/09/2016	
Influenza								

Figure 22: Sample EHR without SNOMED CT

REPORT

Full Name: 106
Sex: Female
Address: Towson
DOB: 11/20/1988
Date of Visit10/31/2017 12:00:00 AM

Chief Complaint
Neck pain, arm and hand tingling

Vitals

Heart Rate	97 beats/min
Respiratory Rate	18 breaths/min
Blood Pressure	164mm/103HG
Temperature	99.5 F
Oxygen saturation	80 %
Weight	66.5 In
Height	207.6 Lbs
BMI	33

Diagnosis

ICD-10 Description	ICD-10 Code	Onset Date	Status	SNOMED CT CODE	SNOMED CT Decsription
Other muscle spasm	M62.838	2017-10-31	Active	394679006	Lower limb spasticity (finding)
Other muscle spasm	M62.838	2017-10-31	Active	163650000	On examination - muscle tone spastic (finding)
Other muscle spasm	M62.838	2017-10-31	Active	15744161000119100	Spasm of left piriformis muscle (finding)

Figure 23: HDSS Generated Health Record with ICD-10 and SNOMED CT

6.2.5 Experimental Results

In order to test our system, we provided the system to a local healthcare provider, who is not using SNOMED CT. We were able to collect 120 health records (with up to five ICD-10 for each visit) and insert those records into the system. However, twenty of these records were excluded from the study because they were incomplete. The included records used ICD-10, but not SNOMED CT. These records were inserted into the system without patient identification information in order to protect the patients' security and privacy. The patients' identification information was kept with their physician. The healthcare provider gave us complete medical records, along with patient ID, gender, and modified date of birth (e.g. If the patient's birthday was 06/28/1995, they would change it to 06/18/1995 in order to avoid providing the exact date of birth). This allowed providers to map information to the exact patient. In the case of registering a new patient, we included the following information:

- For the patient name, we used an ID number (such as 102)
- For patient gender, we used the correct gender
- For patient age, we used the correct month and year, but the day was modified slightly. For example, if the patient's date of birth is 06/28/1995, we changed it to 06/18/1995
- For patient address: we randomly selected addresses for patients in areas that were close in proximity to the clinic

According to Sweeney [88] 87 percent of Americans can be uniquely identified by only three types of demographic information: five-digit zip code, gender, and date of birth, which may compromise their privacy. Therefore, we did not include the correct address and modified the day of birth.

The healthcare providers who used the system were able to go through all procedures easily and quickly due to ease of use of the interface. They basically searched for registered patients as shown in Figure 24, or added a new patient. For a new patient, they need to input patient information as shown in Figure 25, chief complaint and vital signs as shown in Figure

26, diagnoses (ICD-10) and select applied symptoms (SNOMED CT) as shown Figure 27, and then generate visit report based on clinical standards that include both ICD-10 and SNOMED CT as shown in Figure 28. For existing patients, the providers just input the diagnoses terms or ICD-10 code and the system will show all corresponding SNOMED CT terms and codes and then they select applied symptoms.

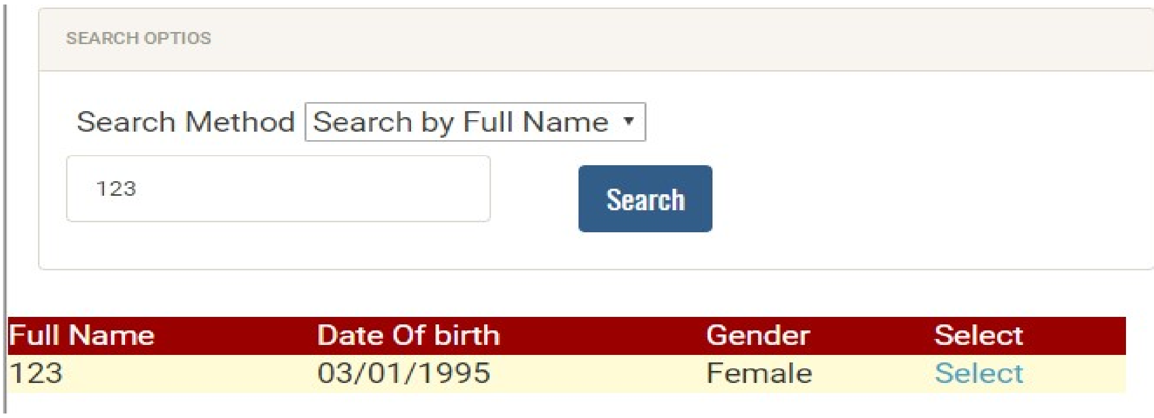


Figure 24: Search for Existing Patient

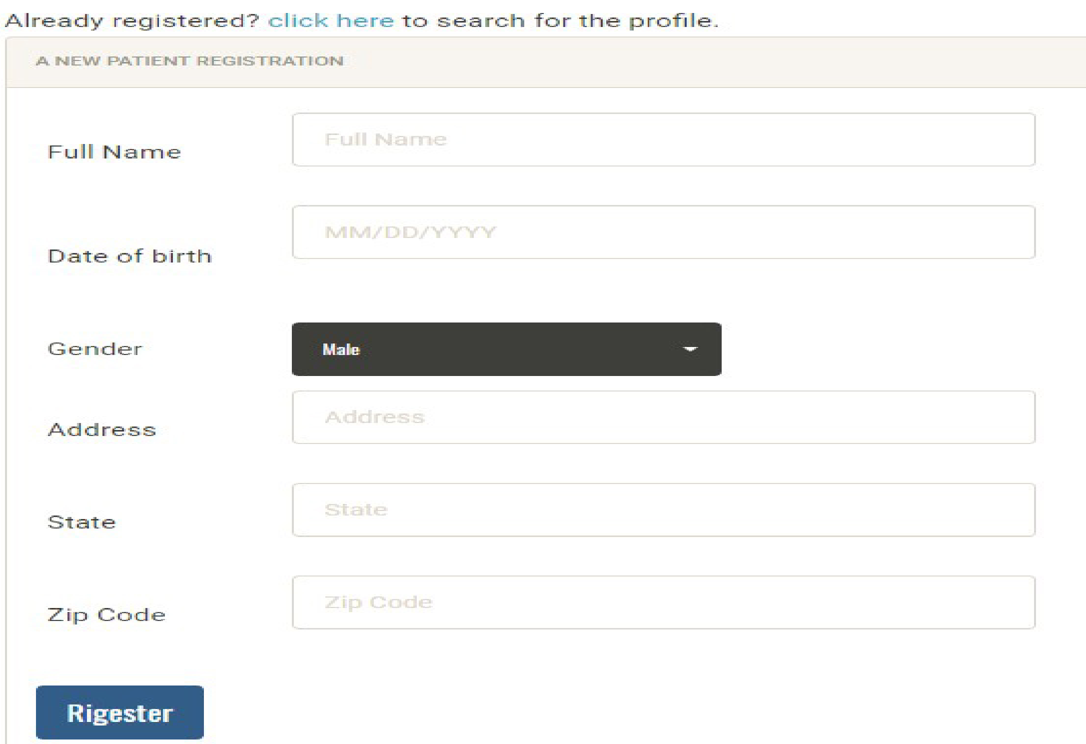


Figure 25: Register New Patient

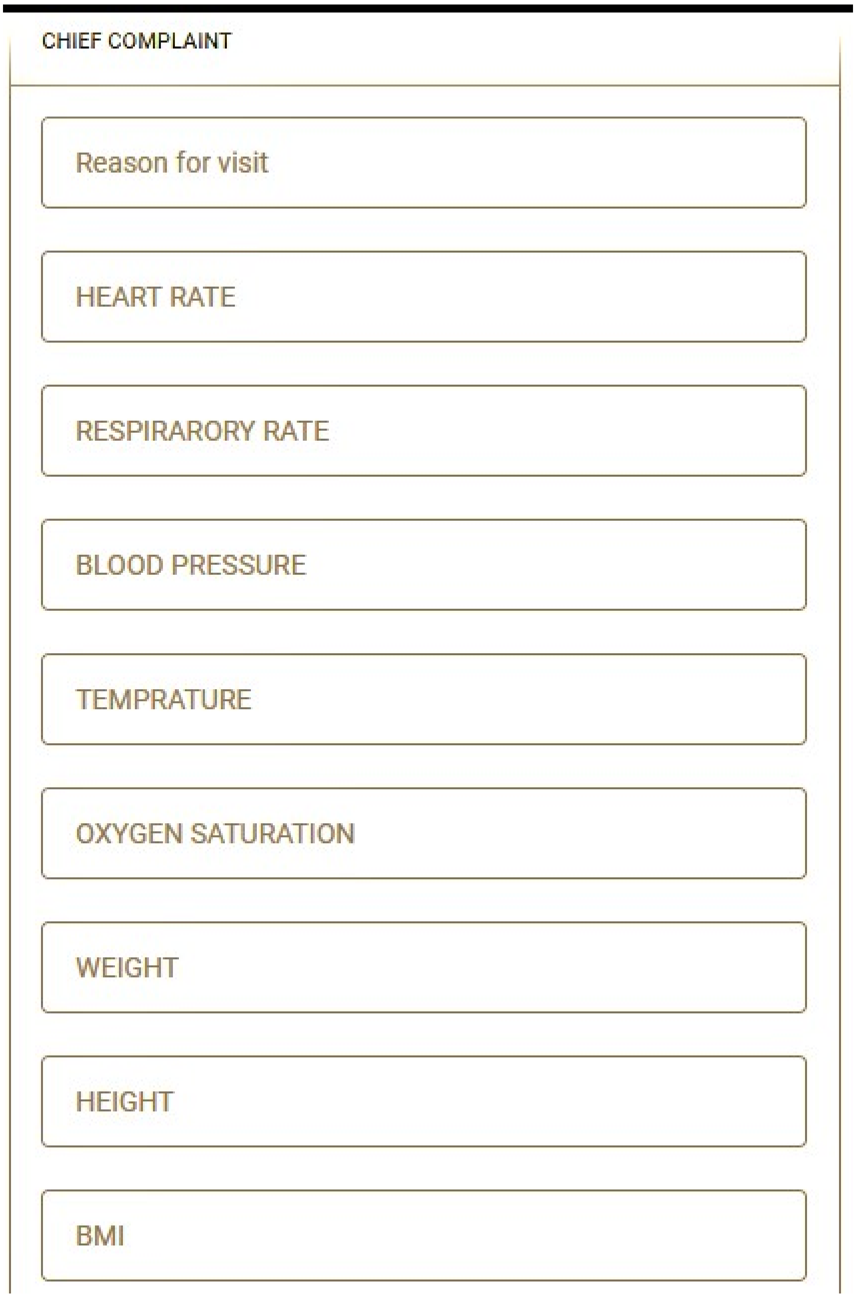


Figure 26: Chief Complaint and Vital Sign Input

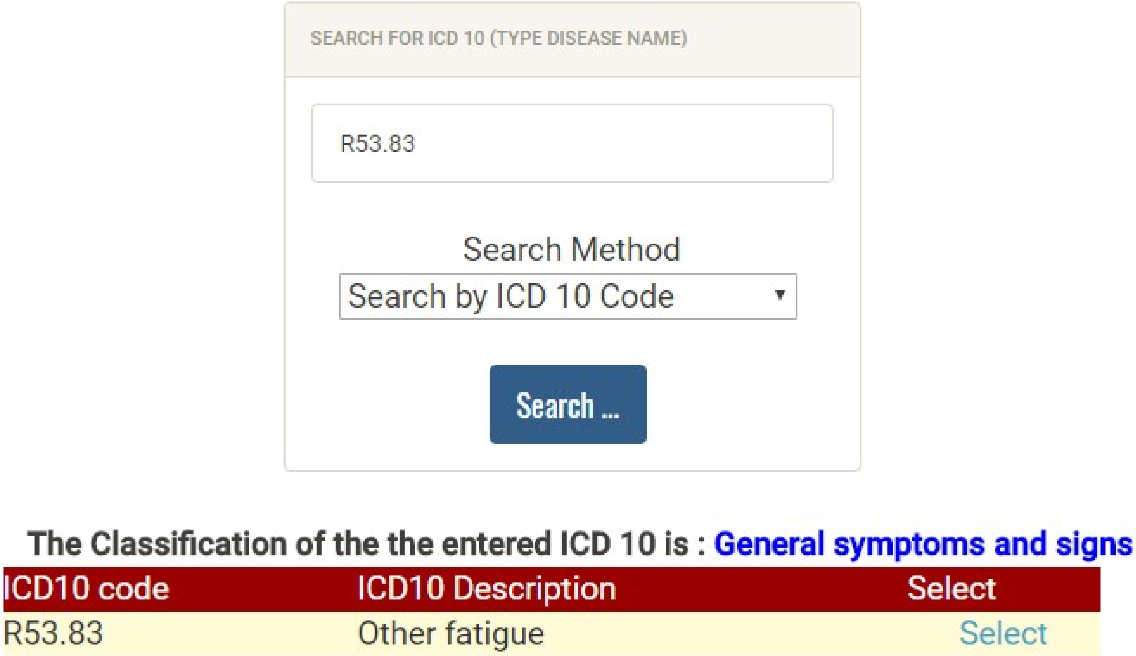


Figure 27: ICD-10 and Corresponding SNOMED CT

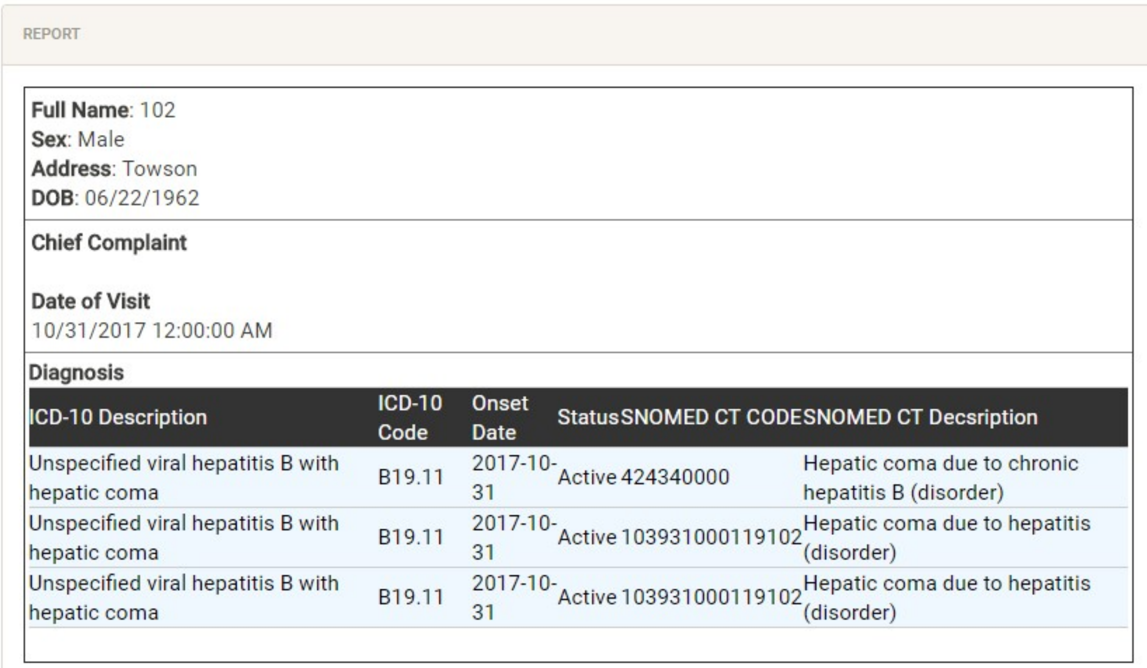


Figure 28: Generate Visit Report

The first time the user inputs ICD-10, the system will show all corresponding SNOMED CT to select from a list of applied symptoms to that disease, as shown in Figure 29. Some diseases (ICD-10) have many symptoms which creates a long list, which takes time to read through and select from. However, for the second entry of the same ICD-10, the system will show previously selected symptoms (SNOMED CT). However, if the list is not showing all possible symptoms that were previously provided, then the physician can have the option to ask the system to show all corresponding SNOMED CT by clicking "populate all records." When new symptoms are selected, the system will be updated with the new selections. This will help reduce the time that healthcare providers have to go through a long list of symptoms. For example, patient ID 136 was diagnosed with the chief complaint: "cold/flu doesn't go away" when they input ICD-10 (J20.9 Acute bronchitis, unspecified), the system showed the previously selected symptom for different patients as shown in Figure 30.

SNOMED CT CODE	Diagnoses	Select
15177007	Apoplectic vertigo (finding)	Select
84769001	Cervical vertigo (disorder)	Select
12151000119105	Chronic vertigo (finding)	Select
103292006	Constant vertigo (finding)	Select
404640003	Dizziness (finding)	Select
271789005	Dizziness and giddiness (finding)	Select
473188002	Dizziness due to drug (disorder)	Select
429530004	Dizziness of unknown cause (finding)	Select
407645004	Dizziness on standing up (finding)	Select
315018008	Dizzy spells (finding)	Select
103297000	Drug-induced vertigo (disorder)	Select
230782004	Dysequilibrium syndrome (disorder)	Select
361270009	Episodic recurrent vertigo (disorder)	Select
103282003	Essential vertigo (finding)	Select
103018003	Exertional dizziness (finding)	Select
404641004	Giddiness (finding)	Select
103303007	Hearing loss remits during vertigo attacks (finding)	Select
449834008	Lateral vertigo (finding)	Select
386705008	Lightheadedness (finding)	Select
89419008	Loss of equilibrium (finding)	Select
446079007	Mal de debarquement syndrome (disorder)	Select
232289002	Multisensory dizziness (disorder)	Select
449835009	Nocturnal vertigo (finding)	Select
50611000119105	Non-labyrinthine vertigo (disorder)	Select
50041000	Objective vertigo (finding)	Select
78977005	Ocular vertigo (finding)	Select
249988004	Oscillation of surroundings (finding)	Select
82510005	Posttraumatic vertigo (disorder)	Select
103017008	Postural dizziness (finding)	Select
103298005	Severe vertigo (finding)	Select
103299002	Severe vertigo, acute onset (finding)	Select

Figure 29: First Input of ICD-10

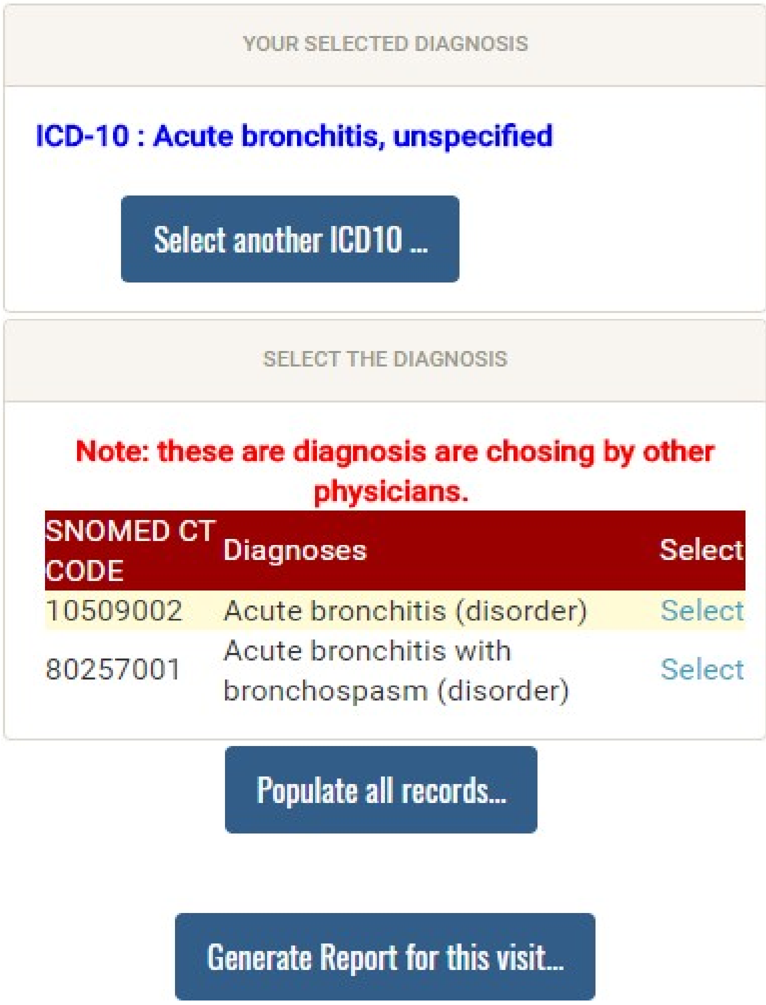


Figure 30: Previously Selected Symptoms

6.2.6 Benefits of using HDSS

HDSS helps both patients and physicians to use medical standards for interoperability of EHRs and PHRs. It can also produce potential diseases as diagnoses based on patient input. Some of the features of HDSS are:

- Mapping between SNOMED CT and ICD-10 as shown in Figure 31.
- Assists healthcare providers to use SNOMED CT
- It also can help physicians to use SNOMED CT along with ICD-10 and increase the physician confidence level by helping them to get to the correct diagnosis

- Aid in self-diagnosis by providing their observed symptoms and then the systems will provide them with potential diseases and direct them to resources in regarding to treatment, risks, and causes of that disease as shown in Figure 32.

- Can help user to create interoperable and sharable personal health records using Continuity of Care Document (CCD) which allows healthcare providers to exchange clinical information summary about a patient as shown in Figure 23.

- Assists users to improve their health knowledge by providing precise medical terminologies related to their symptoms

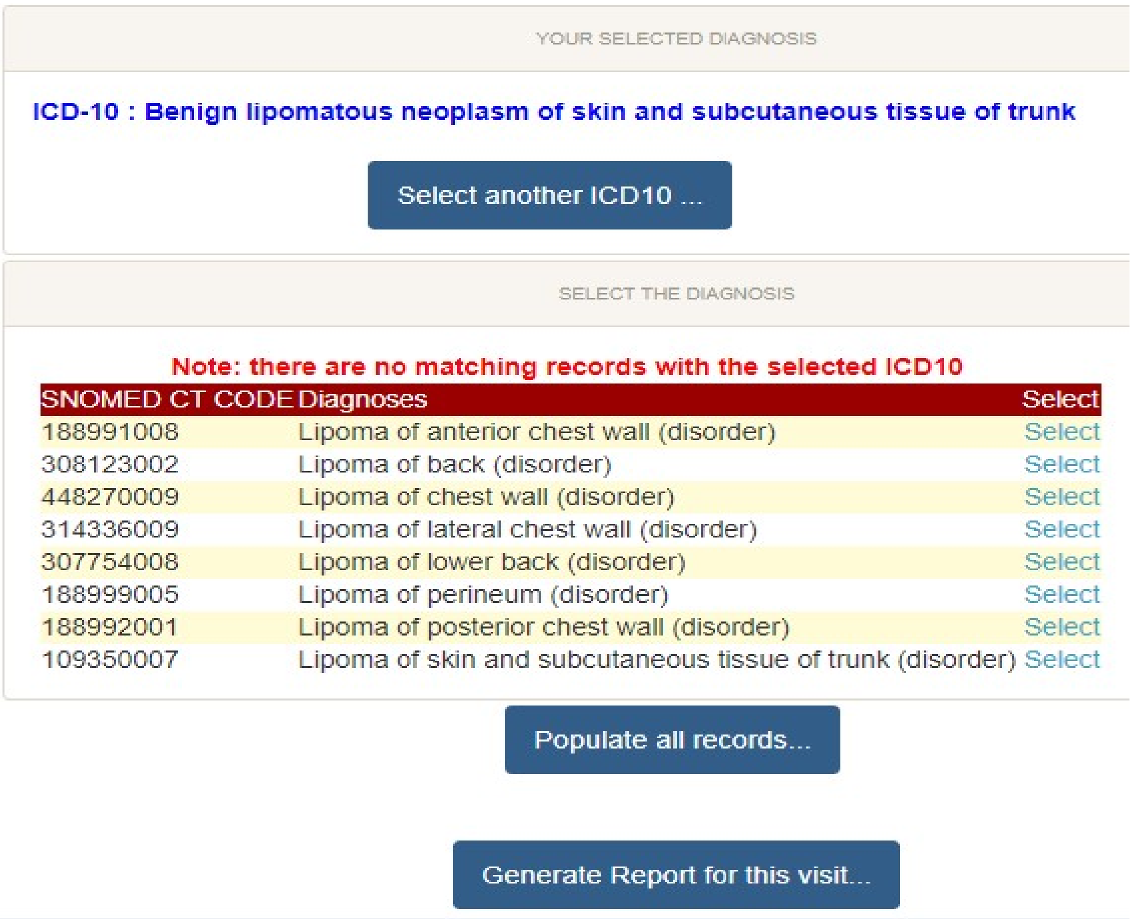


Figure 31: Mapping between ICD-10 and SNOMED CT

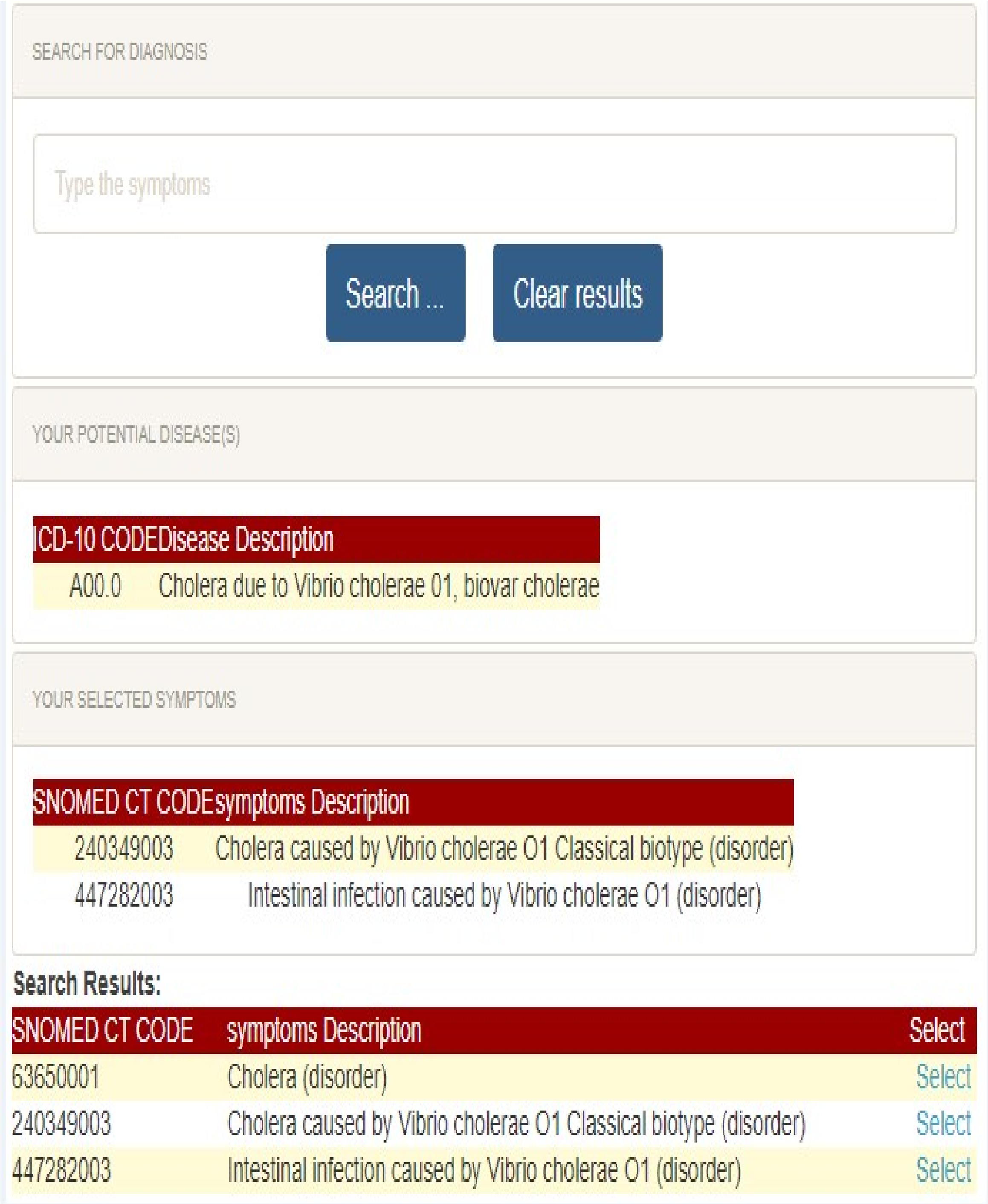


Figure 32: The Potential Disease for the Given Symptoms

7 CONCLUSION

As the medical industry is going through a paradigm shift from clinician-centered to patient-centered, readily available complete personal medical history has become a crucial part to ensure the three major goals in medical industry: evidence-based treatment, continuity of care, and prevention of medical mistakes. In this research, we surveyed articles related to PHRS from 2008 to 2017 to uncover the barriers in adopting PHRS. We have identified the barriers from 6 different aspects: motivation, usability, ownership, interoperability, privacy and security, and portability that hinder the adoption of PHRS. We also surveyed existing PHRS architectures and categorized those into 4 different types with respect to the barriers of PHRS adoption. By considering the survey results, we attempted to address the concerns in using PHRS in the proposed PHRS architecture with the following concepts in mind: separating clinical data from the applications for flexibility, embracing standardized medical codes and processes for interoperability, and making the clinical data searchable using any applications that are compliant to the standards.

In this research, we proposed an untethered PHRS to implement such goals mentioned above. To do so, we have developed two systems (prototypes) as a proof of concept. First, our proposed system, MCRS, showed how to collect and organize heterogeneous personal health data using DC Metadata. The retrieval of the organized data was done by the reorganized DC tags, which allowed the organization of clinical data by body parts for easy retrieval. Finally, we allowed the personal emergency clinical data to be accessible by emergency crew only by their license number at the time of need.

Discontinuity of care has been a major issue in the medical industry. We attempted to provide interoperability of EHRs by using medical standards that allow both patients and healthcare providers to exchange information. The guidance to use SNOMED CT and aid in self-diagnosis may help patients monitor and control their symptoms while preparing personal health record standard based. Secondly, we have implemented a HDSS for both patient and physician as a proof of our concept. We attempted to include all applicable medical standards in HDSS including ICD-10, SNOMED CT, and HL7 CDA. This allows the personal health information (PHI) to be interoperable regardless of the application that uses the PHI. Our main contribution consists of the following helping users to use SNOMED CT, help prevent medical mistakes by providing complete medical history, aid in self-diagnosis, improve public health and health knowledge, standardize, store, share, organize, manage and retrieve personal health records at the time of need, which in turn can ensure continuity of care and evidence-based treatment.

On future work, we plan to expand the usage of clinical data collected from the application to analyze and identify the regional characteristics in health mapping to build better public policy for the nation. We also plan to expand this idea to developing countries, where there is more need due the lack of available medical sources. This approach would apply to any country in order to improve patient outcomes through PHRS.

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A Appendix A: MAIN LIBRARIES

```
using System;
using System.Collections.Generic;
using System.Linq;
using System.Web;
using System.Web.UI;
using System.Web.UI.WebControls;
using Nemiro.OAuth;
using System.IO;
using Nemiro.OAuth.Clients;
using System.Collections.Specialized;
using System.Reflection;
using DevDefined.OAuth.Consumer;
using DevDefined.OAuth.Framework;
using System.Globalization;
using System.Data;
using System.Xml.Linq;
```

B Appendix B: CREATE A SEPERATE METADATA (XML RECORD)

```
string timeanddate = DateTime.Now.ToString("MdyyyyHHmmss",
    CultureInfo.InvariantCulture);
      string RandomName = Session["UserFullName"].ToString() +
        timeanddate;
       string path = Server.MapPath("Temp/" + RandomName + ".xml");
       XNamespace xsi = "http://www.w3.org/2001/XMLSchema-instance";
       XNamespace dc = "http://purl.org/dc/elements/1.1/";
       XNamespace dcterms = "http://purl.org/dc/terms/";
       XNamespace mcr =
           "http://MyClinicalRecords.net/MyClinicalRecords.aspx";

       // Create an XML file
       XDocument xmlDoc = new XDocument(
           new XDeclaration("1.0", "utf-8", ""),
             new XElement("Metadata", new XAttribute(XNamespace.Xmlns
                 + "xsi", xsi), new XAttribute(XNamespace.Xmlns +
                 "dc", dc),new XAttribute(XNamespace.Xmlns + "mcr",
                 mcr), new XAttribute(XNamespace.Xmlns + "dcterms",
                 dcterms),
                 new XElement("Report", new XAttribute("Id",
                     Session["MetaDataFolder"].ToString()),
                 new XElement(dc + "Title", TextBox1.Text),
                 new XElement(dc + "Creator", TextBox3.Text),
                 new XElement(dc + "Subject",
                     DropDownList2.SelectedItem.Text),
                 new XElement(dc + "Description", TextBox12.Text),
                 new XElement(dc + "Publisher", TextBox2.Text),
                 new XElement(dc + "Contributor", TextBox4.Text),
```

```
            new XElement(mcr + "Findings", TextBox5.Text),
            new XElement(mcr + "Treatment", TextBox6.Text),
            new XElement(dc + "Type", TextBox7.Text),
            new XElement(dc + "Format", TextBox8.Text),
            new XElement(dc + "Identifier", TextBox9.Text),
            new XElement(dc + "Source", TextBox10.Text),
            new XElement(dc + "Language", TextBox11.Text),
            new XElement(dc + "Relation", TextBox13.Text),
            new XElement(dc + "Coverage", TextBox14.Text),
            new XElement(dc + "DateOfVisit", TextBox15.Text)
    )));
    xmlDoc.Save(path);
```

C Appendix C: How to Upload File into Dropbox

C.1 First Use the Below API function

```
public HttpPostedFile ConstructHttpPostedFile(byte[] data, string
    filename, string contentType)
    {
      // Get the System.Web assembly reference
      Assembly systemWebAssembly =
        typeof(HttpPostedFileBase).Assembly;
      // Get the types of the two internal types we need
      Type typeHttpRawUploadedContent =
        systemWebAssembly.GetType("System.Web.HttpRawUploadedContent");
      Type typeHttpInputStream =
        systemWebAssembly.GetType("System.Web.HttpInputStream");

      // Prepare the signatures of the constructors we want.
      Type[] uploadedParams = { typeof(int), typeof(int) };
      Type[] streamParams = { typeHttpRawUploadedContent,
        typeof(int), typeof(int) };
      Type[] parameters = { typeof(string), typeof(string),
        typeHttpInputStream };

      // Create an HttpRawUploadedContent instance
      object uploadedContent = typeHttpRawUploadedContent
        .GetConstructor(BindingFlags.NonPublic |
          BindingFlags.Instance, null, uploadedParams, null)
        .Invoke(new object[] { data.Length, data.Length });

      // Call the AddBytes method
      typeHttpRawUploadedContent
```

```
        .GetMethod("AddBytes", BindingFlags.NonPublic |
            BindingFlags.Instance)
        .Invoke(uploadedContent, new object[] { data, 0, data.Length
            });

    // This is necessary if you will be using the returned content
        (ie to Save)
    typeHttpRawUploadedContent
        .GetMethod("DoneAddingBytes", BindingFlags.NonPublic |
            BindingFlags.Instance)
        .Invoke(uploadedContent, null);

    // Create an HttpInputStream instance
    object stream = (Stream)typeHttpInputStream
        .GetConstructor(BindingFlags.NonPublic |
            BindingFlags.Instance, null, streamParams, null)
        .Invoke(new object[] { uploadedContent, 0, data.Length });

    // Create an HttpPostedFile instance
    HttpPostedFile postedFile =
        (HttpPostedFile)typeof(HttpPostedFile)
        .GetConstructor(BindingFlags.NonPublic |
            BindingFlags.Instance, null, parameters, null)
        .Invoke(new object[] { filename, contentType, stream });

    return postedFile;
}
```

C.2 Call the API Function

```
if (Session["AccessToken"] == null)
      {
         Response.Write("Error. Access token not found.<br /><a
            href=\"/\">Try again</a>.");
         return;
      }
      var token = Session["AccessToken"].ToString();
      //FileName and path in dropbox
      string serverPath = "/" + Session["MetaDataFolder"].ToString()
         + "/" + "metadata.xml";
      // folder_name - should exist in dropbox
      var fileInfo = UniValue.Empty;
      fileInfo["path"] = serverPath;
      fileInfo["mode"] = "overwrite";
      fileInfo["autorename"] = true;
      fileInfo["mute"] = false;
      var result = OAuthUtility.Post
      (
        "https://content.dropboxapi.com/2/files/upload",
        new HttpParameterCollection
      {
        {
           ConstructHttpPostedFile(File.ReadAllBytes(path),path,"text/xml")
           }
      },
        headers: new NameValueCollection { { "Dropbox-API-Arg",
           fileInfo.ToString() } },
        contentType: "application/octet-stream",
        authorization: String.Format("Bearer {0}", token)
      );
```

```
if (result.StatusCode != 200)
{ // error
   Response.Write(result["error"].ToString());
}
else
{  // get shared link
   result = OAuthUtility.Post
   (
"https://api.dropboxapi.com/2/sharing/create_shared_link_with_settings",
     parameters: new HttpParameterCollection
  {
   new
   { path = serverPath,
     settings = new
     {
       requested_visibility = "public"
     }
   }
  },
     authorization: String.Format("Bearer {0}", token),
     contentType: "application/json"
   );

   if (result.StatusCode != 200)
   {
      Response.Write(result["error"].ToString());
   }
```

D Appendix D: How to Connect to SQL Database

We developed a class that has one parameter (sql statement).

```
using System;
using System.Data;
using System.Configuration;
using System.Web;
using System.Web.Security;
using System.Web.UI;
using System.Web.UI.WebControls;
using System.Web.UI.WebControls.WebParts;
using System.Web.UI.HtmlControls;
using System.Data.SqlClient;

/// <summary>
/// Summary description for SelectCalss
/// </summary>
public class SqlCalss
{
  public SqlCalss()
  {

  }
   string connectionString;
   SqlCommand command;
   public string ConnectionString
   {
      get { return connectionString; }
   }
```

```
    // pass sql string as parameter
    // return dataset to separate data from interface
    public DataSet ExecuteCmdSelect(string SqlCmd)
    {

        connectionString =
            System.Configuration.ConfigurationManager.ConnectionStrings
        ["ConnectionString"].ToString();
            command = new SqlCommand();
            SqlConnection MyConnection = new
                SqlConnection(ConnectionString);
            //Open the Connection to the Sql Server
            MyConnection.Open();
            string SQLs = SqlCmd;
            command.CommandText = SQLs;
            command.Connection = MyConnection;
            SqlDataAdapter MyDataAdapter = new SqlDataAdapter(command);
            DataSet DS = new DataSet();
            MyDataAdapter.Fill(DS);
            MyDataAdapter.Dispose();
            MyConnection.Close();
            return DS;

        }

}
```

For example, whenever we want to use a select statement, we use the following code (Login page)

```
SqlCalss Obj = new SqlCalss();
      DataSet Ds = new DataSet();
         Ds = Obj.ExecuteCmdSelect("select * from Users where
            UserName='" + TextBox1.Text.Replace("'", "") + "' and
            Password='" + TextBox2.Text.Replace("'", "") + "'");
         if (Ds.Tables[0] != null && Ds.Tables[0].Rows.Count > 0)
         {
            Session["User_Id"] =
               Ds.Tables[0].Rows[0]["Id"].ToString();
            Response.Redirect("Default.aspx");

         } else
         {
            Label1.Text = "Error! please enter a valid username and
               password.";
         }
```

E Appendix E: How to View the Content of a XML file in ASP.NET Web Page

```
// the link of the xml file is already stored in a session
 XDocument doc =
    XDocument.Load(Session["AllMetaDataURL"].ToString());
       var records = (from data in doc.Root.Elements("Report")
                     select data);
       if (records != null)
       {
          DataTable dt = new DataTable();
          dt.Columns.Add("Title", typeof(string));
          dt.Columns.Add("Subject", typeof(string));
          dt.Columns.Add("Extention", typeof(string));
          dt.Columns.Add("FileLink", typeof(string));
          dt.Columns.Add("Id", typeof(string));
          foreach (var item in records)
          {
             DataRow dr = dt.NewRow();
             dr["Id"] = (string)item.Attribute("Id");
             dr["Title"] = (string)item.Element(dc + "Title");
             dr["Subject"] = (string)item.Element(dc + "Subject");
             dr["Extention"] =
                GetExtention((string)item.Element("FileLink"));
             dr["FileLink"] = (string)item.Element("FileLink");
             dt.Rows.Add(dr);
          }
          GridView1.DataSource = dt;
          GridView1.DataBind();
       }
```

CURRICULUM VITAE

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- California Lutheran University, Thousand Oaks, CA

    MBA-Master of Business Administration Emphasis in Marketing & Information Technology, August 2009 (GPA: 3:58/4)

- King Abdulaziz University, Jeddah, Saudi Arabia

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Publication

- Alyami, M. A., Almotairi, M., Yataco, A. R., & Song, Y. T (2017, November). Improving Patient Outcomes Through Untethered Patient-Centered Health Records. Submitted to Advances in Science, Technology and Engineering Systems Journal (ASTESJ).

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- Alyami, M. A., Almotairi, M., Aikins, L., Yataco, A. R., & Song, Y. T. (2017, May). Managing personal health records using meta-data and cloud storage. In Computer and Information Science (ICIS), 2017 IEEE/ACIS 16th International Conference on (pp. 265-271). IEEE. Invited for publication in Advances in Science, Technology and Engineering Systems Journal (ASTESJ).

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