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Longitudinal Patient Records: A Re-Examination of the Possibility

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LONGITUDINAL PATIENT RECORD: A RE-EXAMINATION OF THE POSSIBILTY

by

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ABSTRACT

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It has long been recognized that the Longitudinal Patient Record (LPR) has been defined as "A life-long incremental process where each clinical encounter is merely an updating of the file" (Gabrieli, 1997) Understanding the health condition of patient longitudinally is very important to the care of the patient. However, it is not clear to what extent a longitudinal patient record is in fact possible, since a true longitudinal patient record would need to include all information for a patient, from cradle to grave, and across all healthcare providers and systems. Maintaining such a record is a problem of staggering practical difficulties. There is no doubt of the potential benefit to the patient of the availability of such a record to the patient's caregivers. In this thesis, we re-examine the possibility of a longitudinal patient record, both in its pure logical sense, and in a practical sense. One point of view that we stress is to model the longitudinal patient record not so much as a static thing, but rather as a functional entity. The longitudinal patient record is understood as a set of processes that provide the physician and clinician decision maker with whatever longitudinal view of the patient information is available to serve the current context of decision making. That is, the model we suggest is one of making the most out of whatever patient information is available to the decision maker.

To my father, Hassan Bassi, and my mother, Hayat Alsarraf, I wouldn't be here without you.

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LIST OF ABBREVIATIONS

IT – Information Technology

EHR – Electronic Health Records

HIE – Health Information Exchange

NPI – National Provider Identifier

UPI – Unique Patient Identifier

EMR – Electronic Medical Records

LPR – Longitudinal patient records

CPOE - Computerized Physician Order Entry

PHR – Personal Health Records

HITECH - The Health Information Technology for Economic and Clinical Health Act

HIPPA – Health Insurance Portability and Accountability Act

CDS – Clinical Decision Support

MI – Multiple Imputation

HL7 – Health Level 7

DICOM- Digital Imaging and Communications in Medicine

SNOMED - The Systematized Nomenclature of Medicine

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Chapter 1: Introduction

Brief Overview of the Research Project

It has long been recognized that the Longitudinal Patient Record (LPR) has been defined as "A life-long incremental process where each clinical encounter is merely an updating of the file" (Gabrieli, 1997) Understanding the health condition of patient longitudinally is vital to the care of the patient. However, it is not clear to what extent a longitudinal patient record is, in fact, possible, since a true longitudinal patient record would need to include all information for a patient, from cradle to grave, across all healthcare providers and systems, across all corporate or geographic or national boundaries. Compiling or maintaining such a record is a problem of tremendous practical difficulties. There is no doubt of the potential benefit to the patient of the availability of such a record to the patient's caregivers and providers. In this thesis, we re-examine the possibility of a longitudinal patient record, both in its pure logical sense and in a practical sense. The point of view we stress is to model the longitudinal patient record not so much as a static thing, but rather as a functional entity. That is, the longitudinal patient record is understood as a set of processes that provide the physician or other clinician decision maker (or for that matter the patient himself) with whatever longitudinal view of the patient information is available and practical to serve the current

Definition of Electronic Medical Records

The Electronic Medical Record (EMR), is one of the technologies that have been adopted by health care facilities and has since drawn much attention from the society, managers, professionals, and even policy makers. EMR is always defined as an electronic record of the health related information of an individual that can be created, collected, managed, and finally used for decision-making by qualified and professional physicians in a given health care organization. Some of the features that EMR contains include patient problem, allergies, medications, progress notes, multiple test results, and health maintenance data. There are many features and functional objects in EMR. Two of the most important applications of an EMR are

- Clinical Decision Support (CDS) that help caregiver make safer decisions, for example; it provide information about drugs; and

- Computerized Physician Order Entry (CPOE), which gives providers the ability to enter orders electronically for lab tests, procedures and other requests.

The Electronic Medical Record (EMR) is a digital version of paper charts in physician offices, clinics, and hospitals. EMRs contain notes and clinical data regarding the patient visit and health information collected by caregivers and for them.

Electronic Health Record (EHR) is where all patients the information gathered in one system, information from all aspects such as; registration, medications, laboratory reports, insurance information, financial claims and others. The EHR also can support other care-related activities directly or indirectly through various interfaces, including evidence-based decision support, quality management, outcomes reporting, and Computerized Physician Order Entry (CPOE).

Personal Health Record (PHR) is managed and designed by patients. PHRs contain the same information as in EHRs; medications, immunization family history, and provider contact information. PHRs can include data from various resources, different vendors, and the patient themselves.

Given the foundation of an EMR, we may consider the steps to build a Longitudinal Patient Record. A first step is to examine what kind of records are used by caregivers and patients, as well as education institutes, insurance companies, and any health related industry.

History

In the early 1960s, medical care activities became highly complex, and doctors had fears that it would be difficult for them to access health histories of patients. The need to have more available and comprehensive medical information when needed led to multiple innovations

The idea of EMR widely spread in the early nineties, and it was implemented by many health care organizations across the world. Organizations that were not using EMR were using computer programs to ensure that they properly managed their data concerning test results as well as patient demographics. Health care information technology concludes that a fully integrated EMR was becoming a logical step for health information systems.

The unmaintainable health costs growth, the increasing inequalities in health care and the increasing lack of healthcare access have forced countries such as the United States to begin changing the delivery of healthcare. In the U.S., the major initial step in this line was the HITECH law, part of the U.S. Recovery and Reinvestment 2009 Act (U.S. Department of Health & Human Services (HHS), n.d.). This law approved up to $19 billion in national subsidies to hospitals and physicians for the real/ exemplary use of electronic health records. Secondly, the 2010 Patient

Protection and Affordable Care Act has provisions that reassure providers to start being accountable for the care cost and quality. These law sections allow demonstration projects to quantify the price of patient-focused medical homes as well as payment bundling. Also, the health reform act instructs the Centers for Medicaid and Medicare services to develop a shared saving program for ACOs (Accountable Care Organizations). The program, which started in early 2012, was to be followed by latest Medicare ingenuities that will punish hospitals for preventable readmissions and base part of their compensation on quality measures. (Konver & Knickman, 2011)

Physicians take a significant portion of their time with a patient recording important things during their meeting. One of the most important is making records of all relevant information within the shortest time and in the easiest way. It is, therefore, important to look for electronic systems that are cost effective as regard to the initial capital outlay as well as to the cost that will be required to service the system (Babbott, et al., 2014). The system must also be very reliable and easy to use by physicians.

Longitudinal Patient Records

A Longitudinal Patient Record (LPR) is one of the health care technologies that has been there for quite some time but is still facing significant slow widespread in the market.

(Gabrieli, 1997) defined an LPR as "A life-long incremental process where each clinical encounter is merely an updating of the file."

Patients visit many health care settings, hospitals, walk-in clinics, ambulatory care, emergency departments, and dental facilities. Each of these care facilities may have an electronic health record, but sharing clinical information may yet not be possible electronically. However, sharing this information among providers is crucial. Clinical data on a given patient may not be considered urgent or important at the time, but it may be substantial when regarded as part of a larger pattern. For example, a blood pressure measurement of 128/88 maybe not considered as a risk for hypertension, but it would be noteworthy if, within the past three years, blood pressure measurements indicated an increasing trend, say 115/75, 120/84, 126/80 and now 128/88. This steady increase might mean the development of a chronic condition, or a need for behavior change.

Significant of the Research Project

These considerations suggest that a complete clinical recording of the patient's information – diagnosis, observations, laboratory results, treatments and other useful information—that is collected over time involving multiple providers and health institutions, will have value far greater than an isolated single provider-based record. (Kristina Star, 2015)

Like other technology in the industry, LPR equally requires a high level of innovations as well as breakthroughs that are usually outside health care.

Some standard terms to describe LPR are; 'cradle-to-grave', 'womb-to-tomb', or even 'sperm-to -worm' (Fung, et al., 2007).

Chapter 2: Literature Review

The longitudinal electronic patient record goes past the healthcare of the patients, and identifies the perceptions of "well-being" as a term signifying financial, social, and environmental situations that influence patients and their collective health. The collection of articles we gathered have different studies about an LPR, however, most of these studies are in one setting, yet it still shows the benefit and the need for a longitudinal record that is accessible to caregivers to give the best treatments plans for patients.

Literature Review

Many case studies have shown the effectiveness and necessity of LPR in specific illness and chronic disease, to prove that LPR could close the gap between existing knowledge and actual clinical care.

According to (Hripcsak, Sengupta, Wilcox, & Green, 2007) , the emergency department signifies a considerable shift of care for patients and the comprehension of the longitudinal patient health situation (for instance, allergies, medicines, challenges, diagnoses, previous procedures, and pending tests) is vital to the formulation of a suitable strategy for care. Since most visits to the emergency departments are impromptu and urgent, the health conditions of the patients might not be known beforehand to the caregivers. Even in cases that the information is availed to the caregiver, time constraints may limit their ability to pursue it (Hripcsak et al., 2007). Such information gaps could result in the not just poor quality of care, but also inefficiencies in care, redundant tests, care impediments, and less successful treatments.

The objective of Hripcsak et al. (2007) was to examine the manner in which medical data from earlier visits is presented by the longitudinal electronic patient record and applied in the emergency department. The authors employed comprehensive user inspection logs to gauge access to different forms of data. The longitudinal electronic patient record was found mostly valid in the diagnosis by the health professional and provision of radiology and laboratory data, which proved valuable in most occurrences (common forms of details were utilized in 5 to 20 percent of the instances). Information was accessed in less than half of the incidences (from 20 to 50 percent of situations) even in occurrences that the user was informed of the existence of data. The degree of access demonstrates that the medical information exchange programs ought to be conservative in approximating how regularly shared information will be employed, and the broad range of the accessed data signifies that though a medical summary has the potential of being valuable, a perfect solution will offer a full scope of information.

In their study, (Takuva, et al., 2013) affirm that among persons infected with HIV, the strongest risk aspect for the worsening of the disease and death, regardless of viral load and CD4 count, is anemia. The authors carried out a prospective analysis of 10259 HIV-positive individuals. The laboratory information was presented in a longitudinal electronic patient record where the prevalence of anemia during the commencement of antiretroviral therapy was 25% (Takuva et al., 2013). Following the instigation of antiretroviral therapy, hemoglobin improved, irrespective of the form of treatment and the level of immunosuppression (Takuva et al., 2013); (Kotze & McDonald, 2012). Because a low level of hemoglobin is an ascertained undesirable prognostic indicator, prompt access to records of anemia via the longitudinal electronic patient record could lead to improvements in mortality and morbidity of patients commencing antiretroviral therapy.

Electronic medical records of longitudinal health data are useful resources in clinical studies (Welch, Bartlett, & Petersen, 2014). One hindrance to the use of databases of medical records in epidemiological assessments is that caregivers mostly record only the information they consider medically applicable. Welch et al. (2014) sought to tackle missing information (such as

Multiple Imputation (MI)) in the use of the inaccessibility of measurements as a missing data challenge. The majority of software executions of MI failed to consider the longitudinal and dynamic structure of the information and was difficult to implement in massive databases with the very many people and extensive follow-up entailed. In the article, Welch et al. (2014) recommended the two-fold conditional specification algorithm is the imputation of missing information in longitudinal data. It ascribes missing details at a particular position, which depends on data at that point and directly bordering time positions. The recommended new command twofold executes the two-fold conditional specification algorithm and is extended to hold MI of longitudinal health records in huge databases (Welch et al., 2014).

Welch et al. (2014) establish that most executions of Multiple Imputation of missing information are intended for simple rectangular data formations disregarding temporal arrangement of information. In this regard, while employing Multiple Imputation in the longitudinal electronic patient record with the sporadic models of missing details, several alternative approaches have to be taken into account. One way is dividing information into set sections and executing MI separately at every section. Another technique would be the incorporation of all the sections in a given model. Nonetheless, the article has some shortfalls in the presentation of these approaches as with the rising quantity of sections; the methods have a high probability of breaking down due to linearity and over-fitting. On this note, the novel two-fold fully conditional specification Multiple Imputation algorithm is in the best position of tackling such concerns, by just conditioning on dimensions that are limited in time (Welch et al., 2014). This necessitated Welch et al. (2014) to express and discuss the outcomes of an innovative simulation study to assess the two-fold fully conditional specification algorithm critically and evaluate its appropriateness for the ascription of longitudinal patient records.

Following the creation of an entire data set, about 70% of chosen constant and clear-cut variables were made absent randomly in every one of the ten sections (Welch et al., 2014). Consequently, the authors suitably employed a simple time-to-occurrence representation by comparing the effectiveness of approximated factors from a comprehensive records examination, Multiple Imputation of information, and the two-fold fully conditional specification algorithm. The findings indicate that the two-fold fully conditional specification algorithm maximizes the application of the available information, which relies on the potency of correlations amid the variables (Welch et al., 2014). The application of this strategy also augments plausibility of the absent random presumptions through the utilization of continual measurements with time and variables whose essential values could be lacking.

In South Africa, the longitudinal patient record has been of significance in the provision of antiretroviral therapy for HIV patients. It displays all the treatments that the patient has received in the health care facilities in the country. The evaluation and monitoring of antiretroviral therapy effectiveness are of importance. However, the current information system of a patient is not sufficient enough to give the necessary information that manages the rollout of the antiretroviral therapy program (MCDONALD, 2008). An information store that consists of data marts that integrated several other disparate systems that are related to antiretroviral therapy for HIV/ALDS patients into a single department. This, however, did not make it possible to trace a patient information across the many data marts in the information store easily. This is because there were no unique identifiers for the patients' records in the data marts. They also had differentiated structures.

The clinical online patient information systems that used to exist could not meet the role of providing an antiretroviral therapy program that is highly active. The traditional clinical systems only dealt with operational issues of the accumulating data of the patients. There was the minimal provision of the functionality that dealt with the complexity of clinical outcome management of the antiretroviral therapy program. Additionally, other online systems such as standalone human resource systems and notifiable blood test systems and disease tests, are related to HIV/AIDS and need to be interrogated to again understanding the effect of the antiretroviral drugs. These systems were incompatible to each other. Combining information under the microscope has been a problem in the online systems. The remedy was the use of integrated electronic patient records (EPR) that allowed real-time electronic entry, review of the result, documentation, and the clinical support.

By El-Sappagh, El-Masri, Riad, & Elmogy (2012), the database represents a fundamental element in longitudinal patient record (LPR) system, and the creation of information model for such a database is difficult because of the special nature of the coordination. Attributable to the intricacy, spatial, homogeneity, sparseness, interrelatedness, sequential, and quick evolution of LPR, modeling of the database is an intricate progression. El-Sappagh et al. (2012) made commendable strides in their efforts to create dynamic, inclusive, and secure data model for LPR database. They called for the application of a generic, medical, and temporal information model for the LPR database with the help of object-relational data representation. This is realized through the utilization of a mixed design comprising of typical and generic tables with the objective of accurately representing forms of diverse data in the database (El-Sappagh et al., 2012). Such a design promotes the tasks of data mining and improves decision-making, which are the core elements of a longitudinal electronic patient record system.

In the article by Gabrieli (1997), the very first part captures the attention of the reader on the importance of the study by affirming the dearth of research concerning the frequency of summary reports of shared medical experience, which has been reducing regardless of the bewildering array of new treatments, analytical techniques, and surgeries. This has made health care to lose it compasses that shows the accurate direction and resulted in rising discrepancies in medical care. The mounting gap between knowledge in healthcare and real provision of care is the inevitable outcome of the lacking feedback. This demands better means of managing clinical information, facts, and understanding. The article thus sought to decrease the insufficiency of research in this field by shedding light on the significance of longitudinal electronic patient records in healthcare and a financial imperative for the medical culture.

In his other study, Gabrieli (1992) begins by presenting a lifetime electronic file as an extended chain of documented occurrences. The author affirms that even when such a file is excellently classified and algorithmically listed, the file of an elderly individual could hold many medical episodes and numerous records in the course of care with a large amount of discrete data. In this regard, it 's hard for a busy caregiver to struggle through the entire records, which start from the perinatal information and countless other details up to the present illness of the patient. On this note, the author makes the reader see the dire need for a focused automated data lessening. The first part of the article captures the attention of the reader as it meticulously illustrates the value of LPR as a greatly sensitive matter. Even if both articles lack research questions or a clearly indicated introduction section, they exhaustively demonstrate the statements of conviction upon which the author bases the focus of the studies.

In both articles, the author fails to offer an adequate focus on pre-existing research works that generate the underlying principles and details of the studies. Gabrieli (1997) seems to have depended on an extensive set of studies throughout the literature, which fortifies the arguments and enlightenments provided. Through his inclusive tackling of the issues in both articles, the author ensures that the studies are explicable not merely by nurses and other health professionals, but every stakeholder in the medical field, and any other individual that reads them. The literature in both articles is sufficient and comprehensive as it adequately discusses different concerns of longitudinal patient records, their impacts on the quality of care, and their relevance in decision-making by health professionals.

The article by Gabrieli (1992) is outdated and lacks value on the application of LPR in the health care sector in that some of the discussed problems in the enhancement of the quality of care are currently posing no challenges. For instance, the author talks about a future where a countrywide health care system will face the challenges of record sharing; nevertheless, through the advancements in technology, the storage, and sharing of data has become very smooth and unproblematic. Therefore, the future that the author referred to is already in the past. Similarly, there is currently no logistical challenge concerning gathering patient records collected at different instances or sites as technology ensures that inter-linkages in the medical systems carry as much information regarding a patient as possible, and the accessibility of any information can easily be put in the public domain if need be. In his explanations of the means in which computers allow the rethinking of the documentation of patient care, Gabrieli (1997) offers a valuable study. Moreover, he discusses the essential transformations of objectives and improvements of clinical review necessitated by the longitudinal patient records. This signifies that apart from elucidating the vitality of longitudinal patient records in ensuring the quality of care, because if wrongly understood/used they could lead to detrimental impacts, the article is considerably indispensable in that it provides crucial explanations and recommendations.

A patent of a Longitudinal Electronic Record System and Method (US Patent No. 20080065452 A1, 2008) that could be a reference to LPR , is used to keep, organize and manage electronic record. The method captures the existence of data elements and their interaction over a period. The standards that were introduced to enable the exchange of information have failed to deliver on this. The standards meant for messaging purposes have allowed non-machine readable data to be transmitted while information models are letting in semantic interoperability.

The invention captures all information within data. It may be scalable, congruent to publishable standards and answer daily patient workflow and its management. It provides continuity over time. This continuity can be achieved by making a track of the relationship between the initial instance information and repainting of the pointer. Besides, it also collects visit level information for administrative purposes. This information can be subjective, demographic, assessment, objective or plan information (Aeneid Corporation, 2014).

LEMR has got various requirements. The patient's medical history since birth is recorded, ranging from chronicle diseases to growth milestones. Due to this, LEMR is a web of interactions. It captures all the information concerning the patient visits. (Myers and Culp, 2008).

This system indicates a longitudinal electronic medical record (LEMR). The LEMR automates and streamlines the workflow of a clinician. It can produce a full record of a patient medical encounter and support other activities that are care related either directly or indirectly. The important idea about LEMR is that it indicates a patient's data over a period as well as its relation to other points of data. Its elements could be codified or discrete (Vining, 2007).

Additionally, this invention comprises a system that carries out the method. The system could contain user interface layer or module, business logic, data storage and access layer, storage functions and communication layer that extend to the eternal system. It may also include a visualization layer that is supported by at least one layer. Besides, the system can have controlled modules for vocabulary including codified, controlled clinical vocabularies (Aeneid Corporation, 2014).

Some of the functions provided by LEMR as a device for the collection of data include the collection of visit data, the assumption of management for follow up items and collection as well as maintenance of a patient list of items. Others include maintenance of item versioning and implementation of privacy protocol. The patient is the most important unit of the LEMR. Considering the record, a patient can have more than one medical record. The success in implementing a comprehensive LEMR could involve the implementation of a medical vocabulary that is controlled (Schoenberg, 2002).

Another patents, Interactive multi-axis longitudinal health record systems and methods of use (US Patent No. 20100131293, 2010). Some embodiments of the current invention contain patient health record in graphical timeline and systems that provide health records electronically over patient medical encounters. The system involves a spectrum with a graphical representation of varying information about patients. The representation can be navigated by users enabling them to access more than one medical data that relates to a patient. It also includes indicators of plurality whose division represents the based encounter (Evans, 2009).

Clinics and hospitals have information systems. These could be radiology information systems (RIS), clinical information systems (CIS), hospital information systems (HIS), and cardiovascular information systems (CVIS). Besides, there are also systems of storage including library information systems (LIS) and picture archiving and communication systems (PACS) among others. Information like test results, diagnosis, imaging data among others may be stored. This information can be stored at one point centrally or divided and stored in different locations. Healthcare workers may access the information at various locations in the course of their work. A variety of medical data is available but can't be found easily and presented and there are several risks associated to this (Wilkins, 2003).

This invention provides a system that displays and interacts with the data of a patient within encounters. The user makes use of the multi-dimensional display giving him or her greater understanding of the longitudinal data across the continuum of the records. The user can have a macro view of the data in this system. This view, therefore, provides an improved insight of the underlying pathologies (Schoenberg, 2002).

The system provides a three-dimensional view of the medical data. Individual data is contained in the labeled elements which are indicated by color depending on the type and relativity to the values of normative. Medical information such as allergies, medications, immunizations, procedures among others is displayed. An innovative way of displaying and interacting with data elements is described. The end user can obtain information all over the systems of the enterprise (Myers and Culp, 2008).

Information systems used in the healthcare become effective when users can locate and utilize the relevant information across the patient care timeline. Visualization strategies are provided with a graphical interaction across the enterprise. The user can sail across, manipulate and view varying information at various levels by playing around with the cursor using the mouse. Information gets more visible through magnification. This system allows the users to review and edit some lab results, immunizations for children, appropriate treatment plans among others.

Therefore, the system and method enable the users to view the entire clinical record at a glance (Evans, 2009).

Summary

For the establishment of efficient and first-rate care of the patients, extensive and accurate data regarding the conditions and practices implicitly and explicitly associated with their welfare has to be offered and administered carefully (Lopez & Blobel, 2006). The system and method may be scalable, have congruency with published standards for medical data interoperability, answer day-to-day patient management workflow and be compliant with the Health Insurance Portability and Accountability Act (HIPAA). (US Patent No. 20130080191 A1, 2013)

Chapter 3: Research Question and Method

Research Question

The specific research question of the thesis is

"What are the possibility of a longitudinal patient record, both in its pure logical sense and in a practical sense?"

The purpose of this paper is to analyze the concept of Longitudinal Patient Record to promote the benefits and necessity of LPR

Including in the analysis are the following:

1- A historical review of Electronic Health Record

2- A literate review of LPR and analysis of the present status.

3- Implanting strategies.

The paper selected focuses on establishing a longitudinal patient record. The thesis conducted in perspective of identifying the possibility of implementing a Longitudinal patient record and define strategic (definitions) as well show the challenges that could face having an effective LPR model.

Applying Electronic Medical Records and Longitudinal Patient records as narrative search terms yielded in 130 Articles, 62 articles are relevant to the thesis.

Each article was reviewed and then all articles were grouped into the following categories: temporal pattern discovery, predicted analysis, interoperability, data exchange standards, Usage of multiple EMRs and security issues in EHR systems.

Chapter 4: Requirements, Vision, Model, and Challenges

In this chapter, we will discuss requirements for an LPR, a general vision of an LPR, and our proposed model of an LPR. Also, we will discuss the challenges of implementing the model.

Requirements for an LPR

The documented medical history of a patient is a longitudinal record of all patients' data since birth. By reviewing every documented information of patient before the current visit, it helps with giving clues to current problems and guide caregiver in the diagnosis of new problems and treat older ones.

LPR is a method to gather all of the patient records generated by encounters in a provider setting.

LPR becomes a web of relationships within a widespread axis of time. LPR could be designed to include the ability to collect information pointers directed at other activities within the LPR model. In the figure below 4.1, the LPR are added to the existing IT infrastructure to allow a shared, secure health record for patients that were seen by different health providers which are covered by HIPPA regulations and to obtain an NPI. Those health care providers such as; Chiropractors; Dentists; Nurses; Pharmacists; Physical Therapists; and Physicians. And Examples of organization HIPAA-covered entity health care providers include Ambulance Companies; Clinics; Group Practices; Health Maintenance Organizations (HMOs); Home Health Agencies (HHAs); Hospitals; Laboratories; Nursing Homes; Pharmacies; Residential Treatment Centers; and Suppliers of Durable Medical Equipment (DME). (NPI Application, 1998-2004)

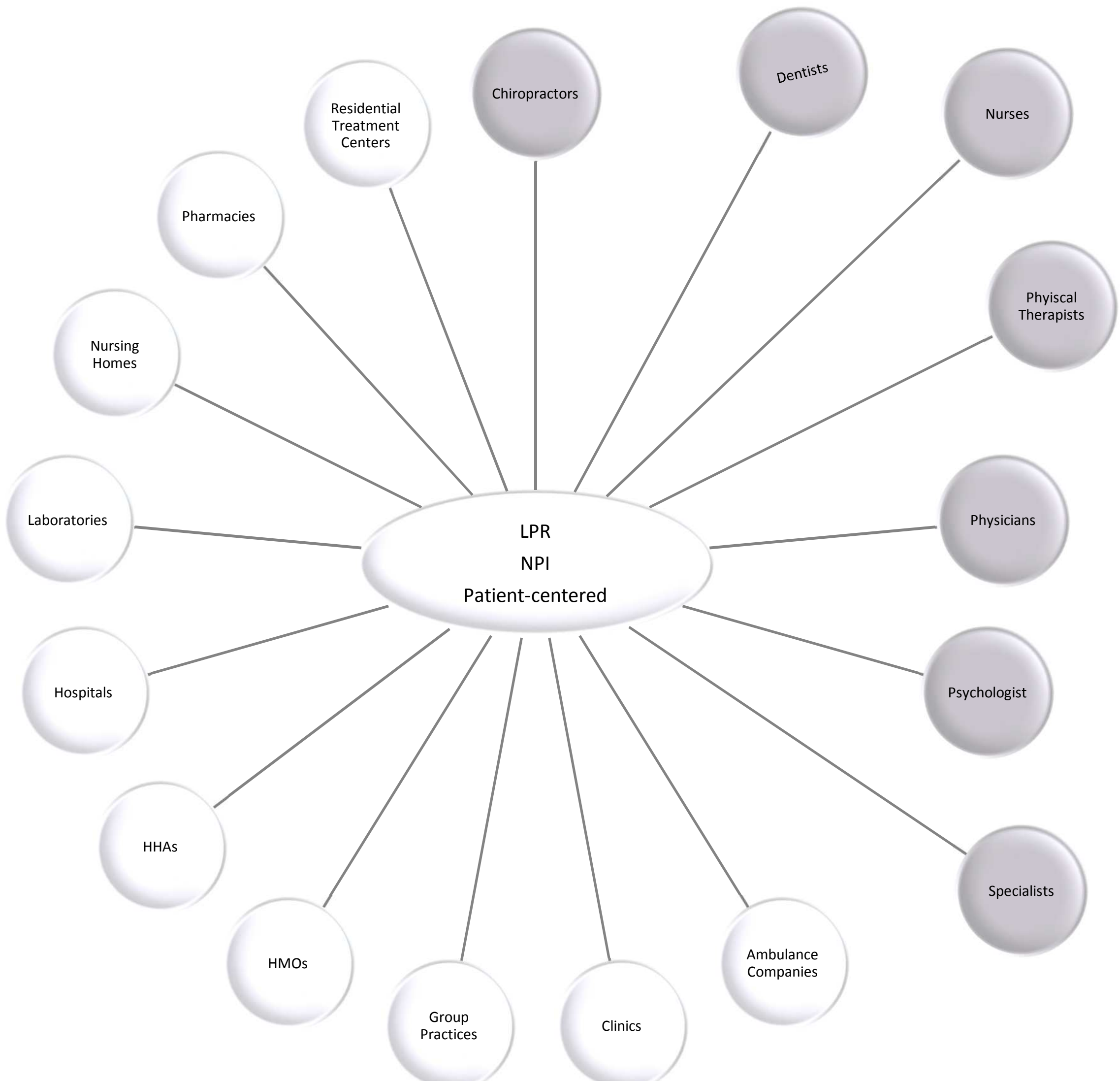

Figure 4.1: A suggested generic model for LPR Environment. The colored circles show individuals as opposed to the white circles that shows organizations.

The LPR is a record linking that may provide the following functions:

- Maintain patient list of medication, allergy, problems, surgeries, etc.
- Implement a privacy protocol as HIPPA
- Support secure data exchange.
- Support task-based workflow.
- Support for document management function

- Support PDF formats.
- Support for E-mail workflow
- Support for HL7 communication Service.
- Support a controlled medical vocabulary such as SNOMED

A) Generic component-object models and architectures.

There are two architectures of EHR (Sriram, 2009) , basic and universal. As shown in figure 4.2, basic EHR architecture is connected to all hospital information systems and it has a centralized database system.

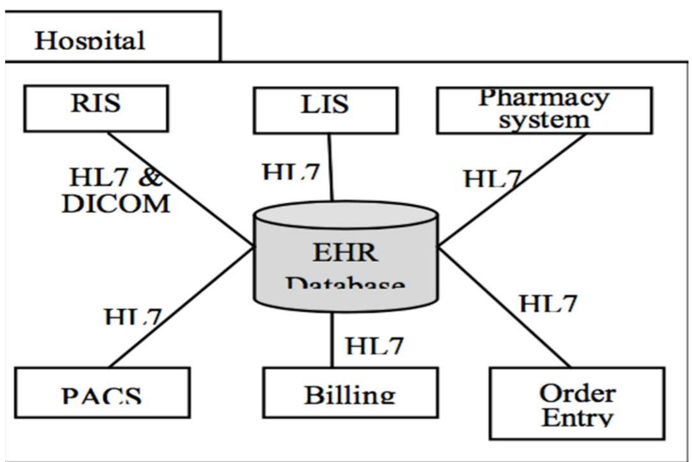

Figure 4.2: Basic EHR architecture

In figure 4.3, the EHR database is centralized and collect data from all operating healthcare systems in the hospital as radiology information system (RIS) and others.

A universal EHR architecture has two categories: first a centralized universal EHR architecture and the second is a distributed universal EHR architecture.

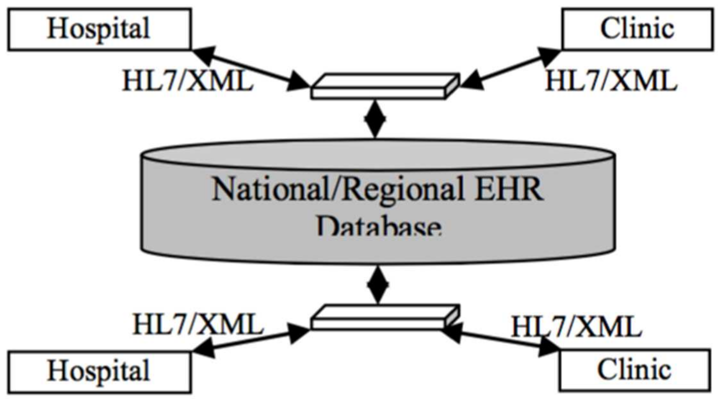

Figure 4.3: Centralized universal EHR architecture

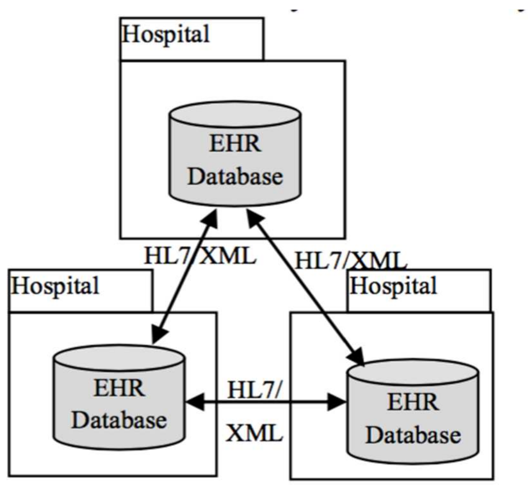

Figure 4.4: Distributed universal HER architecture

The architecture of a Longitudinal Patient Record is designed to support the construction of some types of systems.

Key attributes of Longitudinal Patient Record (LPR) include electronically and systemically collecting patients' data and storing it in a standards-based platform that can integrate disparate systems

Such data is then easily shared in different health care environments and departments. For LPR to work, the information should distribute through network-linked systems or other data-supporting arrangements and data exchanges. LPR could entail the need to link patients with an identifier, to find medical related information.

LPR systems are meant for accurate data storage and capturing of the condition of the patient while discovering any changes with time. On this note, LPR assists in the eradication of the need to track down the previous health records of the patient on paper and ensures that every detail is correct and readable. This way, LPR eliminates the chance of data replication since there is just a single modifiable file, which signifies that the record has a high likelihood of being up to date, and reduces the effect of lost information recorded on paper (Meum, Ellingsen, Monteiro, Wangensteen, & Igesund, 2013).

Attributable to the electronic data being available in one file, longitudinal electronic patient records are more efficient when retrieving clinical data for the assessment of the likely inclinations and occurring variations.

The LPR facilitates clinical decision support, analysis of diagnoses and treatments, and best practice multidisciplinary guidelines to the patient (Green & Bowie, 2005) The result of patient data gathered from different location and various status

An LPR is more than a clinical data collected, it should also merge scheduling, billing, coverage and demographic data. However, the patient-centric LPR must be the result of an integrated approach to different medical records from various facilities and providers. To build the best practice guideline, individual organizations should be able to analyze outcomes and help with the growing mass of medical knowledge in an efficient manner. (Eichhorst, 2002)

It is important to offer a framework for the creation of advanced systems with the ability to incorporate structures based on electronic healthcare record (EHR) and electronic public health record (EPHR) with medical care approaches. The Generic Component-Object Models consider the longitudinal patient record in three aspects.

The first aspect decreases the difficulty of actually interconnecting domains through unraveling them. For instance, the unraveling involving the healthcare scope and the public health field is vital for interactive functionality and cooperation.

The second aspect decreases the structural difficulty of structures via decomposing them. In this regard, the coarseness of the system could be enhanced by business perceptions through relationship systems and basic services/operations up to the realization of information that encompasses fundamental conceptions (Lopez & Blobel, 2006).

The third aspect demonstrates the perspectives of Standard International Standards Organization (ISO 10746).

Understanding the architectures about LPR is not a simple undertaking. From the view of EHR developers, it demands the identification of enhanced level of knowledge regarding methodologies, approaches, models, and instruments from the basis of systems evaluation and information sciences to mention a few. The LPR (generation) progression entails the participation of not just the function developers, but as well end-users, coordination integrators, practitioners, and project directors amid others who have diverse standpoints on the operations of the systems and the solutions to the potential problems. It also calls for extensive experience and knowledge concerning the healthcare system and the specifics of the medical field (Lopez & Blobel, 2006). From the perception of the LPR obligations, advanced electronic health records have to deal with the difficulties of candor, scalability, elasticity, semantic functionality, portability, delivery at

Internet stage and adherence to global standards. Moreover, they must be reliable and propelled by the progression of healthcare (Reichert, Kaufman, Bloxham, Chase, & Elhadad, 2010).

A component-oriented architecture is the most suitable way of addressing the specification regarding LPR systems with the requirements mentioned above (Lopez & Blobel, 2006).

The application of component-oriented architecture offers numerous, dissimilar explanations to the fundamental sources of software development challenges (Lopez & Blobel, 2006). For instances, it establishes that components enhance strong architectures and that modularity paves the way for a clear distinction of issues amid the facets of a system that are prone to variations. The architectures about longitudinal patient record could be demonstrated as a set of artifacts defining the different stages of granularity of the elements of the system (Lopez & Blobel, 2006). Designing longitudinal patient record systems is an intricate practice that calls not just for an all-encompassing knowledge regarding the medical field but as well matters of Information and Communication Technologies, which are crucial in the management of eHealth networks and international standards. A thorough methodological process is vital for the analysis, planning, and execution of longitudinal electronic patient records (Lopez & Blobel, 2006).

As well as Developing software for today's organizations is highly challenging due to numerous stakeholders, changing user requirements and an evolving domain. As a result, traditional development strategies for information systems hardly fulfill the expectations of the user domains in either the short or the long term. (Christensen & Gunnar, 2016)

B) Security and Privacy

Issues of security and safeguarding the privacy of sensitive personal details have to be handled if the confidence of the consumers is to be upheld when longitudinal electronic patient records are broadly available. Medical systems and vendors are presently actively creating nationwide infrastructures to facilitate the communication and recording of health information and incorporation of the necessary security aspects for the protection of such data (Shapiro, Kannry, Kushniruk, Kuperman, & NYCLIX, 2007). The security of data in electronic health records has to be executed through protection and access structure that makes sure that just the suitable individuals linked with the care of the patient can access, retrieve, and edit the data in the LPR. This has to be done within a secure infrastructural communication system that permits the faultless incorporation of extant (legacy) and novel computer networks. Patients (and probably members of their families) have to have the access to and ability to edit entries in the longitudinal patient records to allow for the contribution of their feelings of medical status and requirements. Stakeholders in the healthcare industry can boost the medical care practice by promoting the development and execution of open source, interoperable electronic health record elements. Such elements ought to be anchored in globally accepted stipulations and meet security and privacy demands while backing the creation of interoperable and evolving medical applications.

Near-term goals and financial plans could make it appear striking to try to resolve the difficulty of merging medical systems at a national stage through the definition of local standards or restricting alternatives to a small number of arrangements. Nevertheless, medical care and patient mobility are progressively turning international, and ultimately both outlays and the safety of the patients will be enhanced if it will be possible to realize worldwide accords on the means of sharing and analyzing longitudinal electronic health records. Standards for backing LPR communication are at a highly developed level. The significance of the LPR architectural advance is that varied medical, as well as health care; details can be recorded and communicated in a standardized manner, which can be appraised and rectified (Norén, Hopstadius, Bate, Star, & Edwards, 2010). The blend of the Reference Model and the utilization of Archetypes (pioneered via openEHR and standardization assists in making sure that medical care can be given safely, strengthened by explicit and comprehensive information.

The establishment of the connection involving health professionals and patients include the provision of medical attention to the utmost privacy and the esteem for the independence of patients. Such evidently signifies that the need for informed consent and confidentiality are considerable moral values for an excellent LPR. Patients ought to apply the choice over the information and accessibility of their medical records as is in line with quality care and confidentiality concerns (Krist et al., 2014). The LPR should be generated, processed, and handled in manners that strictly ensure the privacy of the information and the legitimate management, if possible by the patients, in the way such data is accessed and utilized. The sharing of the clinical data to a third party ought to occur just with the approval of the patients unless an emergency or critical conditions call for safe assumption of informed consent. Across the world, such values are progressively enshrined in healthcare information protection regulations. In every ideal case, the entries in the records of the patients should be linked to a provided control list of people that have the permission to access such data, which ought to be created or endorsed by the patients and establish the dynamic situation of the authorized individuals with legal responsibility of care toward patients throughout their existence.

The access permission list will preferably encompass the people that have been allowed to view the records of the patients for other motives apart from the burden of care (for instance, health service administration, epidemiology, informed research) but prohibit all the details that they do not require to access or which patients take to be personal and confidential. On the contrary, the indication by patients or their family members of data as confidential is not supposed to hinder the people that rightfully ought to access such details in an emergency state, or offer true health professionals such a filtered view that they are hoodwinked into the inappropriate management of the patients. The perceptions of the patients on the inherent understanding of entries in their medical details might change with time with the variations in their personal health concerns or transformations in the community approaches to medical challenges (Zakim & Schwab, 2015). Patients may decide to provide heterogeneous rates of access to their families, friends, caregivers, and community members, in addition to other stakeholders in their well-being. Family members could desire to offer a means through which they have the ability to access some sections of the patient's records (but not essentially to equal degrees) for the purpose of monitoring the development of inherited situations within the family.

A deep understanding of heterogeneity issues in distributed EHR systems would possibly design appropriate security solutions enabling secured transition of EMRs between disparate hospitals. Some of the basic security goals for LPR are

¬ Data confidentiality, only the intended receiver can read the data;

¬ Data authenticity, the sensor data linked to the correct patient. Linking data to the wrong patient could lead to wrong diagnosis and eventually mistreating the patient. (Shalini Bhartiya, 2014)

C) LPR standards, translation, and standardization.

The conceptual outline of LPR should correspond to expert understanding of the medical domain. All patient's data and clinical events are stored in one record and organized based on a temporal discovery. To simplifies the notion of LPR , standardization of EMR is needed.

American Society for Testing and Materials (ASTM), is an organization entirely dedicated to supporting the development of standards. Over 12,000 ASTM standards operate globally. ASTM 31 is a committee where their focus on drafting clinical informatics standards. This committee started in the early 1980s and has developed several standards such as; Properties of electronic health records and record systems, Universal healthcare identifier and Sharing modular health knowledge bases. (ASTM.org, 1996)

Standards

Standards are agreements about how to do something where the organized act is required. The Standards in Healthcare are viewed as the primary foundation to guarantee the flexibility and the security needed among the HIS. These include standards related to exchange messages (HL7); terminologies (Systematized Nomenclature of Medicine - Clinical Terminology SNOMED-CT); clinical information and patients records (openEHR and HL7 Clinical Document Architecture CDA); and images (Digital Imaging and Communications in Medicine DICOM) (Khan WA, 2012)

To achieve the objectives of the LPR initiative, it needs additional standards, including ones dealing with authentication and security, health care delivery processes, representations of medical knowledge that are interpretable by a computer, and interfaces to software components. (WILLIAM W. STEAD, 2005)

The increased accessibility, collection, and standardization of electronic health data from a variety of sources in various formats and delivery systems, has resulted in increased the complexity to share information that is available. The Variety of these databases and systems to collect data from includes:

- Electronic Medical Record systems
- Insurance Claims Database
- Nursing Homes
- Dental Facilities
- Mental Health Facilities
- Clinical Trial Registries

As well as Developing software for today's organizations is highly challenging due to numerous stakeholders, changing user requirements and an evolving domain. As a result, traditional development strategies for information systems hardly fulfill the expectations of the user domains in either the short or the long term.

(Christensen & Gunnar, 2016)

Standards considered are:

- CCR: The Continuity of Care Record is a patient health summary standard. It is an approach to make adaptable reports that contain the most important and opportune center of patient health data, and to share it electronically from a system to another. It involves different sections such as patient demographics, insurance information, diagnosis and problem list, medications, allergies, etc. It is a "preview" of a patient's wellbeing information at a point in time, yet does not address important issues related to the longitudinal patient medical record. (William R. Braithwaite, 2004)
- HL7: The HL7 Interoperability Work Group has developed a framework which covers three aspects of interoperability that are interdependent and beneficial in information exchange, they are

semantic, technical, and process interoperability. (Benson, 2012) .Health Level, 7 standards framework, is for the exchange, integration, sharing, and retrieval of electronic health information HL7 standards support clinical practice and the management, delivery, and evaluation of health services, and are recognized as the most commonly used in the world. (HL7 Standards, 2006-2017)

- HL7 RIM: The Health Level 7 Reference Information Model which is a static object-oriented model in UML notation This is to establish semantic interoperability across a vast and growing number of subject domains (e.g., laboratory, clinical health record data, problem- and goal-oriented care, public health, clinical research, etc.), which are loosely but critically related. The RIM was conceived as a data model, where all data elements known from HL7 version 2 and some large electronic health record data models were put on a single information roadmap. (USA Patent No. US20080262868 A1, 2008)
- HL7 CDA: The HL7 Clinical Document Architecture (CDA) is a document markup standard that specifies the structure and semantics of "clinical documents" for the purpose of exchange. Similarly to CCR, this represents a "snapshot" of a patient's health data at a certain point in time and does not address an overall design of longitudinal electronic patient medical record structure. (US Patent No. US8589400 B2, 2013)
- SNOMED CT: Systematized Nomenclature of Medicine, Clinical Terms SNOMED CT aims to improve patient care through the development of systems that record health care encounters accurately. (Shalini Bhartiya, 2014)
- DICOM: Digital Imaging and Communications in Medicine is an association of medical industry and professional medical organizations, working under the umbrella of the National Electrical Manufacturers Association (NEMA). DICOM is a standard that allows medical images exchange and related information. (Begoyan, 2007)

A standard vocabulary is required for each department or health facility to successfully exchange heterogeneous health data with each other, such standard is important to allow sharing and exchanging medical data with an LPR function, some of these standards are:

• ICD: International Classification of Disease standard for billing from World Health Organization (WHO) and the various country-specific versions. It is the standard diagnostic tool for epidemiology, health management, and clinical purposes.

(WHO, 2016)

• NDC: The National Drug Code is a universal number that identifies a drug or related drug item. The complete NDC number consists of 11 digits with hyphens separating the number into three segments in a 5-4-2 format such as ”12345-1234-12.”

((NDC), 2016)

• HDD: Healthcare Data Dictionary supports the integration of coded data in the Clinical Data Repository (CDR) (Bouhaddou, et al., 2008)

• RxNorm: RxNorm provides normalized names for clinical drugs and links its names to many of the drug vocabularies commonly used in pharmacy management and drug interaction software, including those of First Databank, Micromedex, MediSpan, Gold Standard Drug Database, and Multum. By providing links between these vocabularies, RxNorm can mediate messages between systems not using the same software and vocabulary. (Rouse, 2011)

• UMLS: Unified Medical Language System integrates and distributes key terminology, classification and coding standards, and associated resources to promote the creation of more effective and interoperable biomedical information systems and services, including electronic health records. (NIH, 2009)

The Vision of LPR Functions

Longitudinal patient records could be used to benefit and help patients all around the globe. The idea of an LPR for every individual patient that can be managed and viewed from different places. These are some of the benefits that are conducted from various studies and cases. The following potential visions can be thought of on an LPR purpose:

♣ ***Quality:*** Sharing health data from various resources (Medical Records, Pharmacy, Insurance claims, Laboratory reports, Dentistry, etc.) and show all data by the LPR methods have the potential to make healthcare data available whenever and wherever needed. LPR could make the data in these records more accessible, meaningful and actionable for patients. Real-time data could help push the right medical actions at the right time.

♣ ***Effectiveness:*** Improved decision making through decision support tools with access to the patient's whole EHR. LPR method could improve patient's direct visibility and control over their health metrics and ongoing health needs.

♣ ***History:*** for the purpose of LPR to have a patient-centric, lifelong electronic health record that entails a holistic view of patient needs as opposed to function problem-solving and decision-support techniques for limited diagnostic purposes; LPR would show the history of patients, which is the first thing to go through in order to come up with a diagnosis. (OpenEHR, 2005)

♣ ***Safety:*** Capture data and identify events, LPR could be a source of reference in the early phases of signal detection and analysis of clinical data (Star, Watson, Sandberg, Johansson, & Edwards, 2015). Reducing adverse events arising from medication errors, duplicate tests, and inappropriate treatments.

♣ ***Readmission Rate:*** According to the latest report from RWJF (Robert Wood Johnson Foundation), hospital readmission becomes quite common and continues to increase drastically across nations. In fact, 1/5 of the patients end up being readmitted to the hospital within a month of discharge. At some points, some of the causes of patients readmission are; post-surgical care guidelines/instructions were not clear and quite confusing or completely missing, medical lists were not available, no or little communication existed between doctors when the patient was transferred from one facility to another, as well as or follow up appointments were never made. Reviewing the medical record of patients' history should not be limited to the latest medical record. Using LPR allow physicians to check the history of patients from various visits and different locations based on the date they desire to find clinical information. LPR could help tremendously with decreasing readmission rate due to missing patient information.

♣ ***Communication:*** LPR method would have the potential to help patients become more engaged in their healthcare and enable them to have the best care that possibly offer, cost-effective ways. By linking EMRs from various sources and different facility with the NPI for caregivers to have a complete visibility of the patient longitudinal clinical information.

♣ ***Research:*** Retrieve data for research purposes and clinical trials.

♣ ***Population Health:*** Health Management in population is long time project series. It needs sustained effort and systematic across system for winning and maintaining the gains obtained. LPR could be an opportunity to promote better data access and sharing between patients and providers.

Logical Model of an LPR

We must distinguish between an LPR that is built organically as the patient travels through the healthcare system, and one that is post-constructed at some point by gathering information about the patient's previous encounters in the healthcare system. We define here an LPR that is post-constructed.

Another important point to note is that our model does not assume a universally unique patient identifier for the healthcare system.

As shown in figure 4.5, We define the LPR as a set of triples consisting of a healthcare organization,

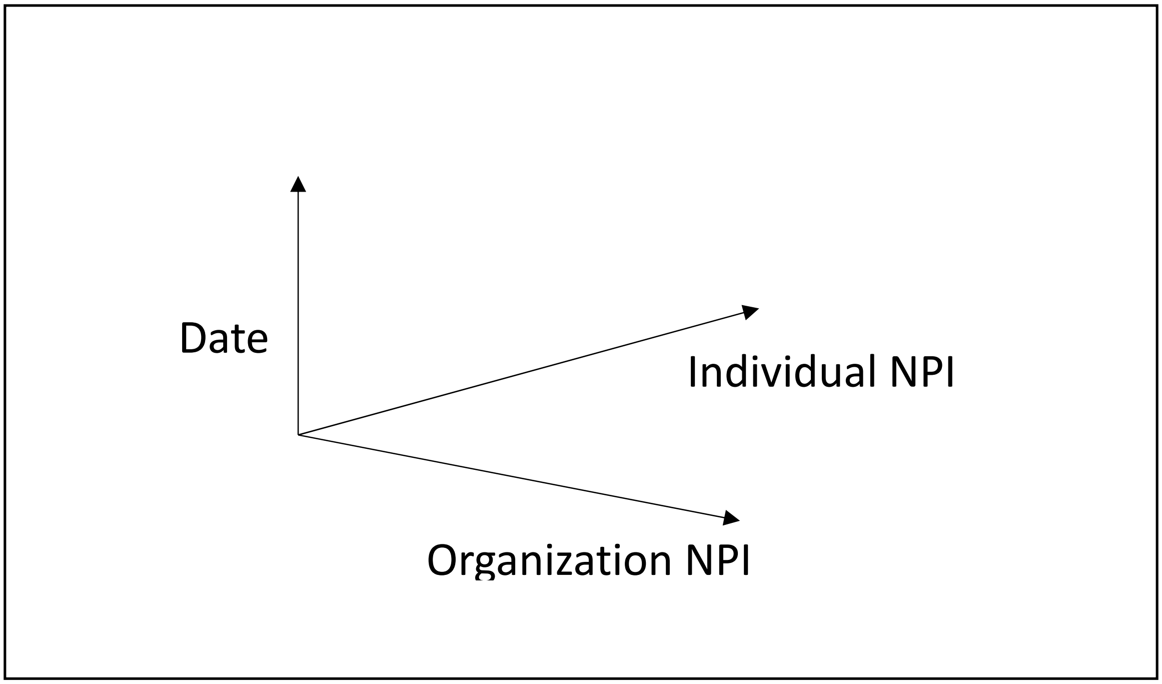

Figure 4.5: How date, NPI for organization and NPI for individual represented by integrated dimensional space.

an individual, and a date. We may think of the patient record as being represented by a 3 dimensional space where axis 1 is a date, axis 2 is the National Provider Identifier for an individual, and axis 3 is the National Provider Identifier for an organization. We consider each point in this 3d space to represent a patient encounter.

Each encounter may be more or less documented, and may or may not be accessible to the decision maker. We mark each encounter point with "x" if the associated documentation is available, and mark it "o" otherwise. The proportion of "x"s to all encounters is the information density of the record, a value from 0 to 1.

We may set the date range to some modulus N, restrict the organization to some geographic region or corporate domain, restrict the organization to some specific type, and restrict providers to some set of specialties. In all of this we use the National Provider Identifier system (NPI) and its associated taxonomies for organization and specialties.

Allowing for such restrictions sets aside the impossible problem of realizing the LPR in its logical fullness. It does however allow us to make statements like (1):

1. We have Mr. Smith's longitudinal record for 2 years beginning July 2, 2014 to present, for Wisconsin, for Aurora clinics, for family medicine.

In addition, we can add qualifiers regarding the information density of the LPR, as in (2):

2. We have Mr. Smith's longitudinal record for 2 years beginning July 2, 2014 to present, for Wisconsin, for Aurora clinics, for family medicine with information density 1.

Of course, it is important that the LPR for an individual be accessible to decision makes in an organization. We must implement methods for retrieving as much of the clinical encounter documentation as possible and needed. In the next section we discuss challenges and methods for implementing the model.

A suggested workflow for LPR to be implanted is summarized in the following steps:-

1. Create a new record related to a patient for a visit.
2. Link with NPI.
3. If not linked or found, patient needs to fill paper work.
4. Display group of records that is linked with NPI.

5. If it's not available, LPR is created for new patients.
6. Display group of records
7. Display an LPR timeline
8. Input temporal identifier for data
9. Locate associated documents
10. Mark each encounter point with "x" if the associated documentation is available.
11. Mark each encounter point with "o" if the associated documentation is NOT available.
12. Access Patient encounter
13. Review all patient linked EMRs
14. Determine a problem based on the group of records and the visit.
15. Create a relationship based on the "date" and data visualized.
16. Create a treatment plan based on the problem.
17. Document additional problems
18. Update/Edit LPR
19. Close each record of each visit
20. Repeat steps for a subsequent visit if needed.
21. Allow transporting data from one system to another.
22. Close LPR

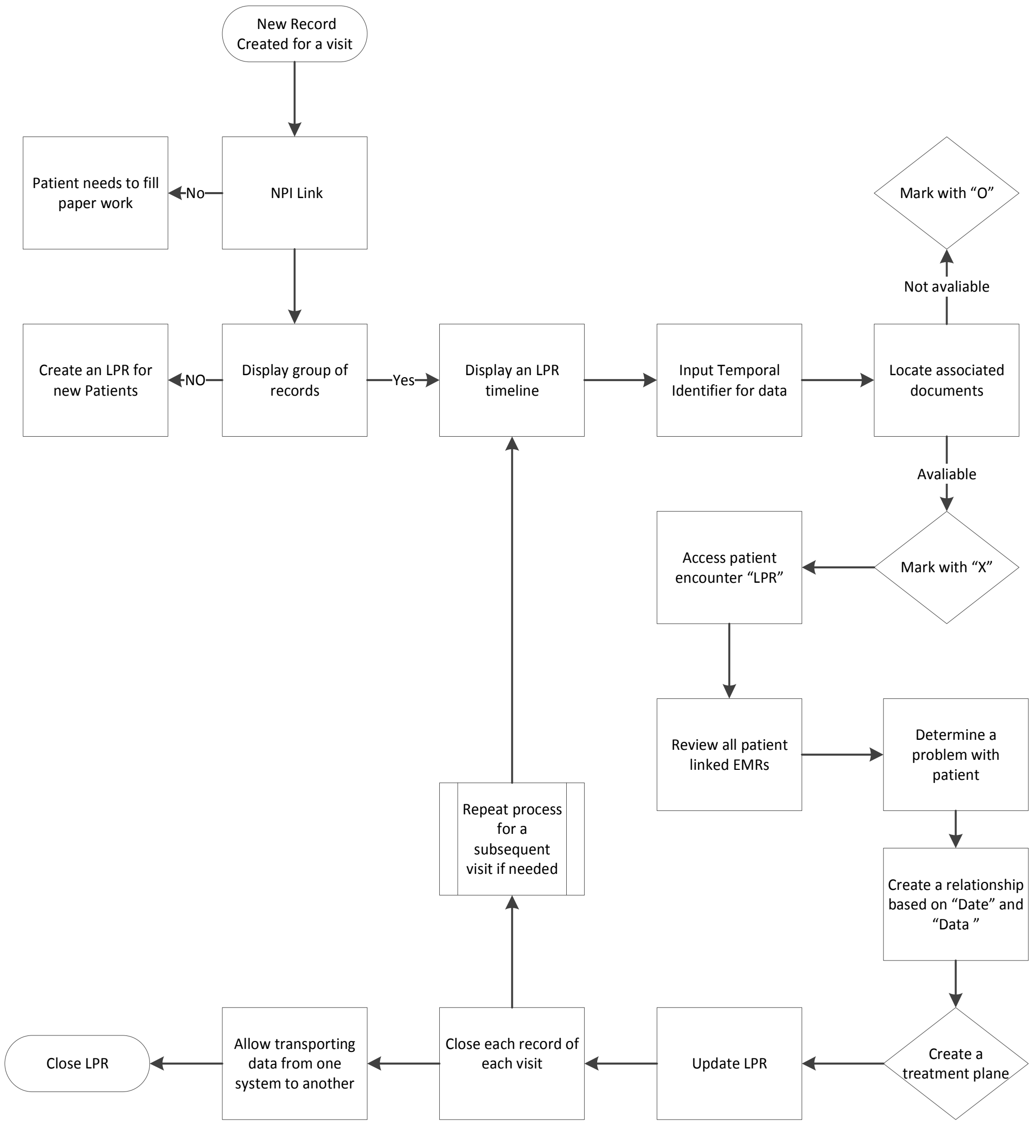

Figure 4.6: A Diagram illustrate the workflow of an LPR

<u>Challenges for Implementing the Model</u>

There are multiple challenges to face in implementing the model. First and foremost is an epistemological challenge—How can a given provider in a given organization know what encounters with providers and organizations over time a patient has had? This epistemic challenge is one that cannot be solved in the absence of either a universally unique patient identifier or patient held-records. A typically practice is to collect historical information f4rom patients by self-reports, which may or may not be accurate.

For small projects like small health centers link to exchange data between computers may be easy since only a little document of the specification is required. However, for larger organizations like big hospitals it may be very tedious to implement system interoperability, for such organizations a rigorous implementation program is needed. Since a vast and complex specification of implementation is involved, errors always bound to arise. Domain experts may not understand the lengthy and complex specifications (Kwok, 2007).Errors may subsequently increase due to different implementation involved; some option permitted and difficulty in understanding the language involved. These misunderstandings lead to mistakes that reduce quality and increase costs.

An additional challenge is The risk of multiple EMR use is the risk of missing data and any corresponding decision support that impact patient safety. Some of the features of EMRs that are cited as making care safer, such as improving communication, providing access to patient information, and stopping mistakes at the ordering process may be more difficult to achieve if more than one EMR is used without appropriate integration. (Bates DW, 2003)

Perhaps the most meaningful use of EMRs and the one that may be most problematic when more than one EMR is used is communication between providers who share care of a patient. Sending documents or messages across the boundary of different EMR systems presents a challenge when performed within a given EMR message center. It requires more than just transmitting the message – it should also be possible that when the message is removed from one system, it is also deleted from the other. Otherwise, the list of notes or messages to be reviewed will grow quickly, and the review process will become much more burdensome. It is difficult to communicate between EMRs initially, and difficult to synchronize message management between two systems. (T. Payne, 2012)

Another challenge to look at is due to multiple chronic conditions that require care for older patients by several providers at different location would aggregate information of patient although all EHRs are needed to provide Continuity of Care Document not all EHRs are open and not all formats are easily collected, that would conclude a challenge to a Medicare ACO or any collaborative care organizations.

We need to provide a platform for implementation of care guidelines and management, for sure with clinical decision support tools to permit LPR function and can be utilized for evaluating and assessing the care delivered and the process by which it is delivered. In the following chapter, we will discuss the strategies and suggested a model for an LPR to work.

Chapter 5: Discussion and Conclusion

Discussion

At least every caregiving department in a health facility requires to have and keep the patient's medical history before and after administering medication. Information about Longitudinal patient health condition is of significance when it comes to understanding the history of the illness of the patient. A good example is; the emergency department in health facilities mark the transition of the care provided for patients. In the emergency department, the understanding of longitudinal health condition of the patient such the patient's allergies, problems, diagnoses, medications, results from recent laboratory test and procedures are necessary for the formation of an appropriate plan of the care to be given. Most of the patients who make visits to the emergency department are unplanned and in many cases urgent hence their medical history may be unavailable to the physicians in the emergency department.

Time constraint is another factor that can restrict the availability of the patient's information for the physicians to pursue. A recent survey that was carried out by the American medical informatics association which showed that despite the belief by the majority of the emergency department physicians that their clients would benefit from the kept longitudinal health records, they tend to obtain the information in less than 10% of the required time. Studies also show that a good number of care providers and patients are always not ready to provide such information which results in a lack of crucial information about the patient for the physicians. This lack of information does not only to lead to poor services but also inefficiency in care provision due to redundant testing, ineffective treatment procedures and delay in care provision (DONABEDIAN, 2005).

Research evaluation by Lloyd and Stirling (2015) (Lloyd, 2015), indicates that the development of integrated health service delivery models could be a necessity to ensure the improvement in efficiency and effectiveness of healthcare service delivery. As such, through the report, there is an indication of a need for integrated healthcare systems to enable the realization of superior performance regarding the quality and safety of patients. On the other hand, the integration of health systems could be attributable to effective communication and improvement in the standardization of protocols. Additional research articles indicate that health integration would be a necessity to facilitate patient safety

Interoperability denotes the capacity of computerized systems to share information, construe, and employ the data by its significance, instead of just its clear appearance (Basch, 2014). Setbacks occur when given information presents numerous meanings or when different terms signify a similar perception but are not easily identified as synonyms. In this regard, scores of multi-stakeholder organizations are presently endeavoring to handle interoperability. On the other hand, a longitudinal patient record represents the systemized details of patients that are electronically stored in a mechanized design. There is a great necessity for the establishment of interoperability values that can allow computerized medical systems to store and share the patients' data while maintaining the clinical significance of the information within them staunchly.

If the LPR is to have the capacity of maintaining a thorough record of patients across their life spans and facilitate interoperability, it calls for the ability to preserve all the necessary facets in a consistent and rigorous manner to make sure that all future requesting medical systems can understand the information comprehensively. The healthcare industry increasingly necessitates clinicians to access the recorded data of the patients that might be shared across different sites, captured in a range of paper or digital formats, and conveyed as a set of the narrative of well thought-out, multimedia, and implicit entries. Longitudinal electronic patient records offer much-awaited solutions to such needs of the clinicians (Coorevits et al., 2013). The data for the LPR ought to be complemented by a proper technique of identifying and conveying the required hierarchical frameworks with electronic health records, the form of data, the extent of the values that the entries might hold, and other limitations with the intention of guaranteeing interoperability, information consistency, and quality of care.

With respect to interoperability and LPR, if there is the first occurrence, there is a need for the second as the combination of varied and at times discipline-anchored and culturally defined form of medical data is necessary for the composition of an all-embracing electronic health record that can safely, lawfully, and fittingly substitute paper records in an apparent challenge. The presently crucial factors on LPR entail the specification, standardization, and implementation of constituents to demonstrate completeness and interoperability (Coorevits et al., 2013). In LPR, the dissimilar endeavors seek to handle slightly differing features of the interoperability difficulty, and in the occurrence of overlaps, there is an excellent working rapport amid the groups, encompassing cross-membership and coordination. The provision of quality care relies on the occurring triad of information systems regarding medical records, clinical knowledge, and procedures of care. It is evident that personal and institutional aspects have a critical influence on the level of reception of medical informatics improvements. A vital constituent of the LPR operation is the capability of nurturing the essential proficiencies within the healthcare personnel to adopt the electronic health record as an element of the contemporary and incorporated clinical service. This demands dedication to training, and most significantly, the acknowledgment that key changes are usually best executed gradually.

The majority of the averted outlays associated with longitudinal patient records are the cause of efficiencies generated by the electronic accessibility of the information of the patients. Such encompass the augmented use of assessments, decreased staff capital dedicated to the management of patients, lessened costs associated with supplies required to replace paper records, and minimal expenses on transcription. The implementation of longitudinal electronic patient records prevents the unnecessary application of tests or the requirement to mail copies of medical examination results on paper to diverse providers (Basch, 2014). Through ensuring that the information of a patient is readily accessible, longitudinal patient records decrease the huge amount of money spent on paper records and studies have established that the application of electronic health records saves time and avoids flaws by offering ordered documentation practices. A wide pool of studies has also established a connection involving the implementation of LPR, interoperability, and the satisfaction of health professionals with their present practice, in addition to patient approval. The satisfaction of the patients and health professionals ought to be precedence in health care since it is linked to the quality of care, improved prescribing conducts, and enhanced retention in health practices, especially the ones in underserved regions.

The data that is provided by the longitudinal patient records enables the health care workers to determine the medical history of the patient to provide informed care services.

There is an increasing purpose of the patient's records ensuring compliance with documents with governmental, institutional and professional regulation (Michael, 2010). Failure by the care practitioner to check on the longitudinal Patient records before administering treatment is highly likely to give ineffective results.

Conclusion

In this paper, we proposed a generic, logical and temporal Longitudinal Medical Record. The function of LPR is to collect patient data from various EMRs and takes clinical decisions to aid healthcare personnel to make clinical decisions.

EMR remains the principal source of patient clinical data, and the desire to own that data source, and expand the platform by adding LPR would be a great solution offering, yet remains a strategic imperative for the healthcare industry to initiate such a functional tool to improve patient care.

Essential for care coordination, patient engagement, public health and quality reporting – just to name a few, LPR would allow EMR systems to send, receive, and use a standard set of electronic clinical information at the nationwide level.

Bibliography

(NDC), T. N. (2016). *National Drug Code Directory*. Retrieved from FDA U.S. Food and Drug Administration: https://www.accessdata.fda.gov/scripts/cder/ndc/

ASTM.org. (1996). *ASTM*. Retrieved March 15, 2016, from http://www.astm.org/ABOUT/overview.html

Babbott, S., Manwell, L. B., Brown, R., Montague, E., Williams, E., Schwartz, M., . . . Linzer, M. (2014). Electronic medical records and physician stress in primary care: results from the MEMO Study. *Journal of American Medical Informatics, 21*, e100–e106.

Bates DW, G. A. (2003). Improving safety with information technology. *N Engl J Med , 348*, 2526–2534.

Begoyan, A. (2007). AN OVERVIEW OF INTEROPERABILITY STANDARDS FOR ELECTRONIC HEALTH RECORDS. *Society for design and process science.*

Benson, T. (2012). *Principle of Health interoperability HL7 and SNOMED.*

Bouhaddou, O., Warnekar, P., Parrish, F., Do, N., Mandel, J., Kilbourne, J., & Lincoln, M. (2008). Exchange of Computable Patient Data between the Department of Veterans Affairs (VA) and the Department of Defense (DoD): Terminology Mediation Strategy. *Journal of the American Medical Informatics Association, 15(2)*, 174-183.

Christensen, B., & Gunnar, E. (2016). Evaluating Model-Driven Development for large-scale EHRs through the openEHR approach. *International Journal of Medical Informatics, 89*, 43-54.

DONABEDIAN, A. (2005). Evaluating the Quality of Medical Care. 32.

Eichhorst, B. (2002). Patient-centric HIS - A Healthcare information system based on a longitudinal patient record provides benefits to patients and clinicians. *Health Management Technology, 23(4)*, 40-42.

Frank Naeymi-Rad, R. C. (2008). *US Patent No. 20080065452 A1.*

Frank Naeymi-Rad, R. J. (2013). *US Patent No. 20130080191 A1.*

Fung, V., Cheung, N. T., Ho, E., Cheung, C., Chan, H., Tsang, K., . . . Sek, A. (2007). Building a Womb-to-Tomb Health Record in Hong Kong - an Application of Information Architecture. *MEDINFO, 129*, 474-477.

Gabrieli, E. R. (1997). Longitudinal Electronic Patient Records. *Computers in Nursing , 15*, S48-S52.

Green, M., & Bowie, M. (2005). *Essential of Health Information Management* . New York .

Hripcsak, G., Sengupta, S., Wilcox, A., & Green, R. A. (2007). Emergency Department Access to a Longitudinal Medical Record. *JAMIA , 14(2)*, 235-238.

Jacobs, L. (2009). Interview with Lawrence Weed, MD— The Father of the Problem-Oriented Medical Record Looks Ahead. *The Permanente Journal, 13(3)*, 84–89.

Khan WA, H. M. (2012). Saas based interoperability service for semantic mappings among health-care standards. 8th International Conference on Innovations in Information Technology.

Konver, A. R., & Knickman, J. R. (2011). *Jonas and Kovner's Health Care Delivery in the United States* (Tenth ed.). New York: Springer Pub.

Kotze, E., & McDonald, T. (2012). A longitudinal patient record for patients receiving antiretroviral treatment. *New Generation Sciences , 10(1)*, 49-60.

Krist, A., Beasley, J., Crosson, J., Kibbe, D., Klinkman, M., Lehmann, C., . . . Mitchell, J. .. (2014). Electronic health record functionality needed to better support primary care. *JAMA Med, 21*, 764–771.

Kristina Star, S. W. (2015). Longitudinal medical records as a complement to routine drug safety signal analysis. *pharmacoepidemiology and drug safety, 24*, 486–494.

Kwok. (2007). Wirless Internet and Mobile Computing Interoperability and Performance. .

Lloyd, B. &. (2015). A tool to support meaningful person-centred activity for clients with dementia – a Delphi study.

Malolepszy, A. (2008). *USA Patent No. US20080262868 A1.*

MCDONALD, T. (2008). longitudinal patient record for patient receiving antiretriovial treatment . 14.

Michael, K. (2010). *Johns Hopkins family health book.* New York: HarperCollins.

Naeymi-Rad, F., Charlot, R., OGANESOVA, A., HAINES, D., BODAL, A., YOUNG, A., . . . MALDONADO, J. (2013). *US Patent No. US8589400 B2.*

NIH. (2009). *Unified Medical Language System® (UMLS®)*. Retrieved from U.S. National Library of Medicine: https://www.nlm.nih.gov/research/umls/

NPI Application. (1998-2004). *NPI Application Help* . Retrieved from National Plane and Provider Enumeration System : https://nppes.cms.hhs.gov/NPPES/Help.do?topic=SelectEntity

OpenEHR. (2005). *Aims of the openEHR Architecture*. Retrieved from OpenEHR.org: http://www.openehr.org/releases/1.0.1/html/architecture/overview/Output/aims.html

Rouse, M. (2011). *RxNorm*. Retrieved from Search Health IT : http://searchhealthit.techtarget.com/definition/RxNorm

Seven, H. L. (2006-2017). *HL7 Standards*. Retrieved from HL7.org: http://www.hl7.org/about/index.cfm?ref=nav

Shalini Bhartiya, D. M. (2014). Challenges and Recommendations to Healthcare Data Exchange in an Interoperable Environment. *Electronic Journal of Health Informatics, 8(2)*, 16.

Sriram, R. (2009). The Role of Standards in Healthcare Automation . *5th IEEE Conference on Automation Science and Engineering*, (pp. 79-82). India.

Star, K., Watson, S., Sandberg, L., Johansson, J., & Edwards, I. (2015). Longitudinal medical records as a complement to routine drug safety signal analysis. *Pharmacoepidemiol Drug Saf, 24(5)*, 486-494.

Steven Linthicum, S. F. (2010). *US Patent No. 20100131293.*

T. Payne, J. F. (2012). Use of more than one electronic medical record system within a single health care organization . *Appl Clin Inform., 3(4)*, 462–474.

Takuva, S., Maskew, M., Brennan, A. T., Sanne, I., MacPhail, A. P., & Fox, M. P. (2013). Anemia among HIV-Infected Patients Initiating Antiretroviral Therapy in South Africa: Improvement in Hemoglobin regardless of Degree of Immunosuppression and the Initiating ART Regimen. *Journal of Tropical Medicine, 1(1)*, 6.

U.S. Department of Health & Human Services (HHS). (n.d.). *HITECH Act*. Retrieved from HHS.gov: http://www.hhs.gov/hipaa/for-professionals/special-topics/HITECH-act-enforcement-interim-final-rule/index.html

Welch, C., Bartlett, J., & Petersen, I. (2014). Application of multiple imputation using the two-fold fully conditional specification algorithm in longitudinal clinical data. *The Stata Journal, 14(2)*, 1-13.

WHO. (2016). *ICD*. Retrieved from Who.int: http://www.who.int/classifications/icd/en/

William R. Braithwaite, M. P. (2004). *Continuity of Care Record (CCR)* . Retrieved from HL7.org: https://www.hl7.org/documentcenter/public_temp_A66034AC-1C23-BA17-

0CED43783504936A/calendarofevents/himss/2004/presentations/ContinuityofCareRecord.pdf

WILLIAM W. STEAD, M. B. (2005). Achievable Steps Toward Building a National Health Information Infrastructure in the United States. *ournal of the American Medical Informatics Association, 12*, 2.