Analyzing Collective Knowledge Towards Public Health Policy Making

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Abstract. Nowadays there exists a plethora of diverse data sources producing tons of healthcare data, augmenting the size of data that finally is stored both in Electronic Health Records (EHRs) and in Personal Health Records (PHRs). Thus, the great challenge that emerges is not only to gather all this data in an efficient and effective manner, but also to extract knowledge out of it. The latter is the key factor that enables healthcare professionals to take serious clinical decisions both on individual and on collective level, finally forming representative public health policies. Towards this direction, the current paper proposes a system that supports a new paradigm of EHRs, the eXtended Health Records (XHRs), which include the majority of the health determinants. XHRs are then transformed into XHRs Networks that capture the clinical, social and human context of diverse population segmentations, producing the corresponding collective knowledge. By exploiting this knowledge, the proposed system is finally able to create multi-modal policies, addressing various facts and evolving risks that arise from diverse population segmentations.

Keywords: EHRs, PHRs, Collective Knowledge, Data Analysis, Public Health Policies.

1 Introduction

Nowadays there is a tremendous amount of data that is generated from various sources. Those sources belong to many different domains such as health, business, governance, finance, insurance, etc. [1]. The great challenge that has emerged is not only to gather this data in an efficient and effective manner, but also to extract knowledge from this. Especially when it comes to the healthcare domain, dealing with the aforementioned challenge becomes of vital importance because of the nature of health data and the knowledge that this data is able to offer if manipulated correctly. Based on a recent research [2], 92% of healthcare providers have already begun to address this challenge by promoting the use of digitalization in healthcare facilities. This digitalization includes the introduction of storing, previously paper-based, health data in digital formats. By doing so, it becomes feasible to perform computational tasks upon this data, extracting useful knowledge and information. Characteristic examples of such initiatives represent both the Electronic Health Records (EHRs), where healthcare professionals are able to store patients' data, and the Personal Health Records (PHRs), where patients are able to store their personal healthcare data by themselves. Based on [3], there has been continuous growth in the adoption of national electronic health record (EHR) systems over the past 15 years, while the 46% of this growth took place in the past 5 years.

However, those initiatives do not currently offer the opportunity to perform more complex computational tasks on healthcare data, such as big data analytics, in order to generate collective knowledge [4]. Even though there have been put various research efforts for combining the diverse and heterogeneous data coming from EHRs and PHRs, and thus generating collective knowledge, none of these has reached a fully mature level of functionality. This fact relies mainly on the lack of the usage of a universal standard that would enable the interoperability of such diverse healthcare data, regardless of its origin, nature, and format. Collective knowledge is the key factor that enables healthcare professionals to take serious clinical decisions not only on an individual, but also on a collective level [5]. Especially the collective level plays a major role, where a specific type of healthcare professionals, namely policy makers, are responsible for creating protocols, interventions and policies for the well-being of the general population. It is quite obvious that finding a way to combine EHRs and PHRs data and analyzing it would have a tremendous constructive impact on public health [5].

In order to contribute to the aforementioned area, this paper proposes a system that supports a new kind of EHRs and PHRs, namely eXtended Health Records (XHRs), which are able to integrate different kinds of healthcare data coming from both EHRs and PHRs. As soon as the system successfully constructs these XHRs, it exploits them in order to build discrete XHRs' networks based on common characteristics that the XHRs may have. The XHRs networks are then analyzed using top-notch algorithms finally assisting policy makers in creating protocols, interventions and policies for the public health. To achieve that, the system follows a two-phases process, where in the first phase it develops the proposed XHRs, whilst in the second phase it proceeds with the formulation of the XHRs networks, and the generation of collective knowledge.

This paper is organized as follows. Section 2 thoroughly analyzes the related work regarding the general concepts of EHRs, PHRs, as well as public health policies, outlining the innovations that the proposed system provides towards these directions, highlighting its importance for solving known issues that healthcare information systems currently have. Section 3 describes the general architecture of the proposed system, as well as its supported functionalities. Finally, Section 4 summarizes our overall work and provides insights regarding the following steps.

2 Literature Review

2.1 Electronic Health Records & Personal Health Records

The usage of Electronic Health Records (EHRs) and Personal Health Records (PHRs) in the healthcare domain is indisputable. Whereas an EHR is a computer record that originates with and is controlled by health professionals, including diverse kinds of clinical tests (e.g., hematological, imaging, biochemical), a PHR can be generated by physicians, patients, hospitals, pharmacies, and other sources, being controlled by the patient, containing information such as nutrition, sport activity, as well as user-generated biosignals [6]. Finding correlations between those two (2) types of records promotes disease prevention, risk management, and rational resource allocation, whilst favors the development of strategies for their efficient management [7]. Their unified form can be stored in cloud computing infrastructures for their rapid and efficient exploitation, while it can be regularly updated with new flows in order to capture the changes of the environment regarding new health data and new characteristics of the populations of interest. Updating this data provides the possibility of improving the quality of the exported knowledge, while maintaining the performance of the prediction tools at high levels.

In the literature there is often the tendency to consolidate health data of different types in order to exploit it in two (2) main pillars of development, Personalized Medicine and Population Health [8]. Personalized Medicine is related to the provision of personalized care to patients in the form of targeted recommendations and suggestions [9], which are based on standards derived from specific genetic traits, as well as diseases and allergies of the patient, in contrast with traditional methods that extract knowledge about the average patient [10]. On the other hand, Population Health refers to the provision of generalized care in the form of recommendations and predictions based on knowledge extracted from population data. This data is used to find population, environmental and social factors that affect the health of the masses and aim at the efficient management of resources and large-scale risk [11].

In addition to the value of healthcare data (primary and secondary) that is stored by health professionals for the acquisition of collective knowledge, in recent years the importance of collecting and utilizing health data generated by the user through mobile phones and mobile devices (wearables) is highlighted [12]. That is why Information Technology (IT) business giants such as Apple, Microsoft, and Samsung are taking advantage of the knowledge generated by this data in order to create applications that will guide users towards self-improvement of their health. Applications such as Runtastic [13], Runkeeper [14], Fitbit [15], Garmin Connect Mobile [16], Strava running and cycling [17], MisFit [18], and devices such as Withings [19] and iHealth [20] extend their functionality to health data collection by investing in the storage of PHRs to extract useful knowledge. Consequently, the aggregation of large volumes of data in combination with the technological developments of recent years in software and hardware has made great strides in the transformation of heterogeneously produced information into usable knowledge.

In this context, heterogeneity of data is necessary in order to be able to codify and interpret the mechanisms, as well as to predict the effects of pathogens, which are not affected by isolated factors, but their patchwork. In this patchwork of factors, connections and interactions are identified, the understanding of which is the key for further analyzing the data and extracting useful knowledge. At the same time, the simultaneous identification of specific characteristics of the data for a particular record may signal an event of medical interest, while the correlation of data between the records may be linked to the disclosure of empirical medical knowledge. Identifying facts, experience, and correlations between health records is critical for extracting usable knowledge.

However, data diversity also raises challenges regarding the high degree of curse of dimensionality, which inevitably leads to sparse data, lack of records and noise content [27]. The above elements are a major obstacle to the efforts of prediction tools to extract standards with effective resolution that can be generalized to different data. In order for an information system to gain in-depth knowledge of the data subsets within EHRs and PHRs, which are responsible for revealing medical empirical knowledge, interactions and events, the creation of EHRs and PHRs networks is a prerequisite. The extraction of solid representations or phenotypes from heterogeneous features contained in the underlying EHRs and PHRs, can be achieved by using clustering techniques such as K-Means [28], Hierarchical [29], and Spectral Clustering [30], as it is proposed in the literature in order to create similar networks. The main purpose of these networks is to create multidisciplinary cooperation, taking as sectors the different sources of data, in order to identify new factors of influence, facts and empirical knowledge across the sectors. Initiatives such as the Hitech and Patient Protection and Affordable Care Act (PPACA) are moving towards similar links that form networks of EHRs and PHRs [31]. Based on the same logic for creating networks of EHRs and PHRs, Electronic Medical Records and Genomics and Scalable Precision Medicine Oriented Knowledge Engine initiatives discover internal knowledge structures between EHR and DNA data [32], [33].

2.2 Public Health Policies

Public health is defined in several different ways [34], [35] all of them agreeing to the general concept that public health is the science and art of preventing disease, promoting health and prolonging life through an organized effort of society. Moreover, in the modern literature there is a reference to the term “new public health”, which stems from the need to consider the health issues of the population as a problem that is not solved only by medical care. In this light, primary health care has been recognized as a key factor in achieving improved health of the population [36].

Based on that, every modern state must ensure that the health system provides every citizen with the highest possible level of physical, mental and social health and well-being [37]. Achieving this goal requires structured planning of public health policies, which have to be constantly updated and evaluated, based on the ever-changing needs of the population. The current era is characterized by the existence of a wealth of data that relates to various areas of public health, such as data coming from official organizations, public and private hospitals, primary healthcare providers, research data related to risk factors and health problems of populations (either as a whole or specific groups), electronic prescription data, as well as data from wearable devices that more and more people use and provide information about their state of health. The value of this enormous amount of health data is limited by their fragmentary nature and non-interconnectedness, resulting in their difficult, incomplete and fragmentary utilization to identify the main health problems of the populations and the consequent design of public health policies.

In order to properly form such public health policies, the key point lies in the utilization of health data in its electronic form in order to improve the relevant policies. The whole process from finding the sources of electronic health data, to integrating them into the system, analyzing and evaluating them in order to formulate public health policies, should be based on a specific methodology, which will focus on the basic principles of Epidemiology and Public Health. In short, the starting point for investigating and prioritizing the health problems of a population is the study of routine statistical series. Regular statistical series contain data of epidemiological and medical-social interest which are collected for other purposes (legal, economic, demographic) but can be used to study health issues [38]. Finding the health problems of the population from various sources, would lead to the second step, which is the prioritization of these problems as well as the risk factors, in order to design appropriate health policies and interventions. This process presupposes the existence of criteria for the evaluation of these problems (e.g., based on the incidence, mortality, burden of disease and finally the cost of health coverage). Prioritization is particularly important at this stage, as the problems that need to be addressed are multiple and at many different levels, and their prioritization is done according to the possibilities and the special needs of each time period. Finally, in the third step, the public health researcher, having identified the required data and having focused on the specific problem she wants to address, should look for past and existing public health programs, on the specific subject.

2.3 Advancements of Proposed System

To go beyond the aforementioned aspects, being capable of forming public health policies based on collective knowledge, the proposed system allows the recording and differentiation of similar health-related information from different sources. Therefore, it is able to collect data from healthcare providers and patients, from medical monitoring devices, mobile devices, wearables, etc. To achieve that, it is based on a scalable model of information integration, the XHRs, which is able to be enriched with new entities regarding health information that is also included in EHRs and PHRs. XHRs are designed and implemented based on the HL7 FHIR standard [39], which is widely used and easily implemented. In addition, the proposed system isolates the logic of information exchange from the logic of information storage and data analysis.

As for the XHRs networks, existing information systems for extracting knowledge from EHRs and PHRs do not take full advantage of all the heterogeneous data being processed. This is because they handle health records in isolation and independently.

This approach ignores the existence of hidden connections and interrelationships. It therefore leads to the creation of independent and fragmented services, to the limited exploitation of data and, ultimately, to the export of knowledge of limited value, which is reflected in spasmodic health strategies and ineffective provision of personalized medical care. In contrast to this approach, the proposed system seeks to exploit all the heterogeneous data that reside inside the diverse EHRs and PHRs, by searching for clusters with important health interactions among them, penetrating the different domains of the data source. Taking advantage of advanced clustering and classification techniques, it identifies empirical knowledge and correlations as well as noise and sparse data layout.

With regards to health policies, as stated in the literature review, in order to properly form public health policies, the key point lies in the utilization of health data in its electronic form in order to improve the relevant policies. Thus, the whole process from finding the sources of electronic health data, to integrating them into the system, analyzing and evaluating them in order to formulate public health policies, is based on a specific methodology, which adopts the basic principles of Epidemiology and Public Health. Towards this direction, the proposed system is able to integrate data from different sources so that the available information is in a detailed and editable format, in order to take a holistic approach to health data and draw conclusions. An important problem is that the above data, although available for study and processing, is fragmentary, comes from many different sources, expresses different populations and requires great care in processing and comparing. As a first step, the proposed system provides a centralized repository where the researchers can enter and locate information about the most important data concerning the health of a population. At the same time, the system always ensures that the data is updated from the abovementioned sources, since they are updated on a regular basis. The ability to search for older files within the system is also legitimate, in case long-term comparisons are desired. In case that the data from the existing regular statistical series are not sufficient for the purposes of the respective research activity, the public health researcher is able to seek data from specific epidemiological surveys.

3 Proposed System

3.1 System Architecture

The proposed system, aims at the development of innovative mechanisms and services for achieving integrated health data management and successful formulation of public health policies. The methodology that is followed in the system improves the possibilities of utilizing health data through the integration of technologies that allow its holistic analysis, based on knowledge and experience from similar databases, and their continuous evolution through integration of data. This system can add value to health policymaking by shaping populations with similar characteristics. To achieve that, it applies a three (3) phases process of data collection and management that directly or indirectly relates to the health of the citizen-patient, as depicted in ***Fig. 1.*** In short, the suggested system consists of three (3) separate pillars. In the first pillar, XHRs, the required information is derived from the data sources' exploration, in order to correlate and interpret heterogeneous data sources and environmental information of the individuals. In the second pillar, XHRs Networks, diverse groups of XHRs are created, so as to create opportunities for personalized health, disease prevention and health promotion. Finally, the third pillar, offers all the means for achieving both creation and co-creation of multi-modal policies, by incorporating mechanisms for risk analysis, as well as for compilation of predictions, addressing various evolving risks that are realized from diverse population segmentations.

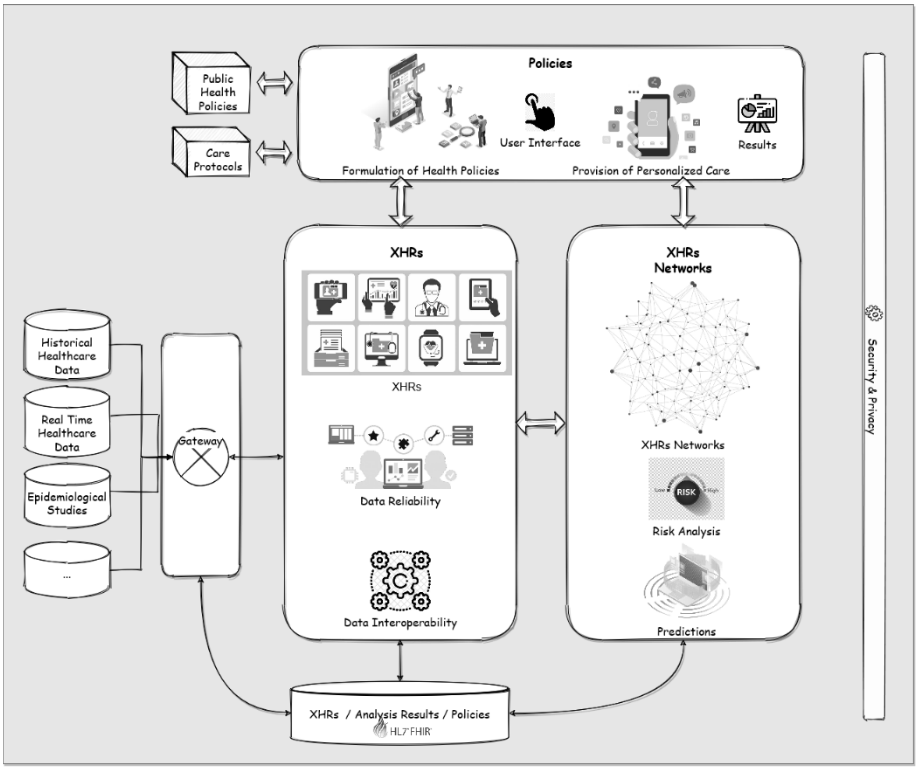

Fig. 1. Proposed system architecture

In deeper detail, the first pillar (i.e., XHRs) refers to the development of the XHRs, which include all health determinants, in order to form a complete picture of the individuals. Towards this direction, each dataset that is fed into the XHRs must contain fully cleaned, reliable and interoperable data. To achieve that, the system includes (i) the Data Reliability component, which is responsible for identifying and removing possible errors and inconsistencies of the data, and (ii) the Data Interoperability component that is responsible for the reception of different types of data that may use diverse international standards and convert it to the most commonly used HL7 FHIR standard. Hence, XHRs include cleaned, reliable and interoperable data related to the health of individuals / patients, incorporating not only prevention (e.g., vaccinations, diet and lifestyle) and care data (primary and secondary), but also additional data identified as determinants of health (e.g., social security data, environmental data, data from social networks). Thus, an XHR contains four categories (4) of data: (i) health and social data recorded by the patient and her environment, (ii) social care data collected by social actors, (iii) objective data in which clinical signs recorded and transmitted in the form of biomarkers by medical devices connected to the individual and / or patient (such as activity trackers, smartwatches, wearables, etc.), and (iv) health and care data (primary and secondary) including data stored by health professionals.

The second pillar (i.e., XHRs Networks) refers to the export of knowledge from the XHRs networks. To this context, the system creates interconnected XHRs, which are created based on the previously constructed XHRs. Thus, the latter include features such as identifying and disseminating events that affect the individual and / or patient, disseminating knowledge and experience, and establishing relationships through interaction and interoperability with other XHRs. This means that XHRs are able to create fully interoperable ecosystems in an automated way based on various criteria related to lifestyle and potential symptomatology and exchange data and experiences. Moreover, the system offers machine learning mechanisms for predictions and risk analysis on XHRs.

Finally, in the third pillar (i.e., Policies), the system offers its web interface that is responsible for presenting all the produced analytical results, coming from the second pillar. More specifically, a user is able to visualize the results of Risk Analysis, Predictions and XHRs Networks, through the provided interface. After processing the results, policy makers are able to model and evaluate their policies through this pillar. It should be noted that there exists an extra component outside of the abovementioned pillars, covering the whole system, namely the Security and Privacy component.

3.2 System Functionalities

The proposed system provides several mechanisms with specific functionalities in order to support the creation of XHRs, Networks of XHRs and the formulation of Public Health Policies.

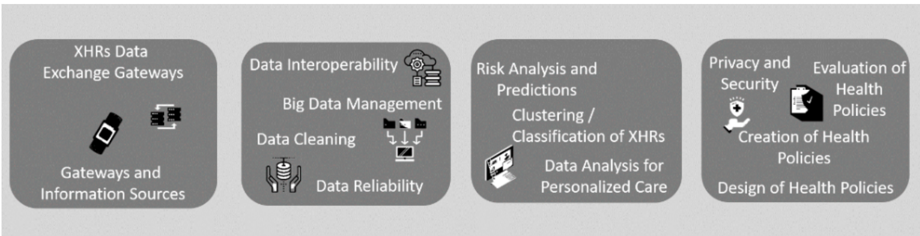

Fig. 2. Supported system functionalities

As depicted in ***Fig. 2,*** the system offers certain capabilities. More particularly, through Gateways and Information Sources, the system is able to support various diverse information sources that generate health data of different formats. In the same context, XHRs Data Exchange Gateways are responsible for managing the integration of heterogeneous health data sources, allowing the efficient connection of heterogeneous sources with the system.

Regarding Data Cleaning, all the collected data are evaluated in terms of their quality, being processed by a series of mechanisms, in order to be successfully corrected and verified. On top of that, a sequence of actions are performed for ensuring the reliability of all the cleaned data. Hence, a key functionality of the system is the Data Reliability, which is performed based on the compliance rules that the system's data should follow. As for the Data Interoperability functionality, this refers to the ability of the system to create appropriate mechanisms that are able to encode all the collected information from one structure to another through appropriate rules and transformations, trying to give a more indicative design step of the HL7 FHIR standard. In order to manage all this data, the system exploits the Big Data Management functionality, by using a non-relational database (i.e., MongoDB). Thus, the system is able to receive a large amount of data and manage it properly.

With regards to the XHRs Networks, those are generated by utilizing advanced clustering and classification techniques, through which the system aims at identifying empirical knowledge and interrelationships among the different XHRs that have been constructed and stored into the system. Those networks are supported by two (2) additional functionalities, namely the Data Analysis for Risks and Predictions and Data Analysis for Personalized Care. The first one has to do with the appliance of appropriate feature extraction or feature selection techniques, as well as state of the art machine learning algorithms. The second one refers to the ability of providing personalized care by analyzing healthcare data on an individual level.

Concerning the Public Health Policies, the system provides the policy makers with the suitable tools for designing, creating and evaluating them. Thus, the information is made available in the most possible explanatory form, leading the healthcare professionals to safely draw conclusions. Last but not least, the Privacy and Security of data is essential. As a result, one of the main priorities of the system is to accomplish real-time anonymization of XHRs in order to ensure the anonymity of the patients during the operational processes of analysis and management of big data. Moreover, it is also crucial to protect the system's resources and that is why an access control-based system has been developed for verifying the role of each user entering the system.

4 Conclusions

Today, at a time when data is being produced in huge quantities and their exploitation is considered priceless, it is imperative that health information systems manage this data effectively. Healthcare systems currently in use, have several loopholes in managing different data from different sources. They also experience performance issues when handling big data. The system proposed in this paper offers a solution for the productive handling of diverse health datasets towards the extraction of collective knowledge out of it, and the formulation of effective public health policies. Specific processes take place in each pillar of the system in order to make the best possible use of this data.

The proposed system is still a work in progress and many design iterations have to be done, taking into consideration the evolving challenges in the field of big data in the healthcare domain. It should be also noted that the main functionality of each component has already been implemented and we are currently working on a first evaluation and testing of the proposed system architecture, utilizing healthcare data from different data sources. Based on the results we have recorded so far, it is within our future goals to add new data sources to the system. We also want to improve the design of XHRs to include more attributes and types of healthcare data. In addition, we aim to enrich the data reliability component by using state-of-the-art algorithms to clean up primary data from different sources, as well as upgrade the techniques used by XHRs networks. Finally, we aim to use all the appropriate machine learning and deep learning algorithms in order to achieve top results in defining and evaluating health policies.

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