

Personal health record system based on social network analysis

Mozhgan Tanhapour¹ · Ali Asghar Safaei¹ · Hadi Shakibian²

Received: 22 November 2020 / Revised: 14 February 2021 / Accepted: 9 March 2022 © The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022, corrected publication 2022

Abstract

In this paper, a health social network-based PHR model denoted as HSN-PHR (Health Social Network-based Personal Health Record), is proposed as an extended version of the integrated PHR model that benefits social network analysis to model the consumers' relationships. The proposed PHR model has benefits of all existing PHR models and more compliance with PHR definition. The HSN-PHR is a heterogeneous network with three main entities (including consumers, healthcare providers, and service provider entities) and various types of relationships. Validity of the HSN-PHR is investigated through its structural analysis. Based on consumers' requirements, four networks named "Feature-mix", "Social-family", "Social-doctor" and "Social-lab" were constructed separately concerning four relationships including profile information similarity, family relationships, refer to same doctor or laboratory. Some social network features such as assortativity, transitivity, clustering coefficient, the number of communities, average shortest path and degree distribution were compared to Wiki-vote, Facebook and a small-world network. The results of social network analysis show that the assortativity coefficient in Feature-mix network was positive and greater than other HSN-PHR networks. The degree distribution diagram for Facebook, Wiki-Vote, and Social-lab was similar to the exponential diagram, while this diagram for Feature-mix, Socialdoctor, Social-family and small-word network was similar to the normal distribution diagram. The proposed HSN-PHR provides the capabilities of serving as a PHR for the users. Developing such a social network improves consumers' relationships through a platform for propagating health information, news, and consumer education. Moreover, structural features analysis results in the examination of meeting the users' requirements more efficiently.

Keywords Patient-centered care · Personal health record · Social networking · Social network analysis

Ali Asghar Safaei aa.safaei@modares.ac.ir

Extended author information available on the last page of the article

1 Introduction

Today, individuals are interested in participating actively in their health issues such as tracking their health status, involving in health planning, and having more relationship with each other as well as healthcare providers [40, 52]. Personal Health Record (PHR) is considered as an important tool for developing patient-centered care; one of the six dimensions to achieve the high-quality healthcare introduced by the Institute of Medicine (IOM) [18, 25, 65]. National Alliance for Health Information Technology (2008) defined the PHR as follows:

"an electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared and controlled by the individuals" [81].

PHR improves healthcare cognition of consumers which in turn affected on patient-provider communication, patient knowledge, patient satisfaction and ease of care; consumers behaviours like consumers' decision making, medication management, and adherence to health behaviours; and health outcomes like physiological measures, quality of life and symptom management [8, 22]. Unlike the Electronic Health Record (EHR) which is created and controlled by healthcare providers, the PHR is controlled by consumers [81].

There are three main models for PHR including standalone, tethered, and integrated [41, 69, 77]. The information of standalone PHR is entered manually by its owner(s). Some times (that PHR is PC-based) according to patients' request its information is entered directly by healthcare providers [20, 39, 75]. The standalone PHR is controlled and managed by consumers [23, 77]. Tethered PHR is a patients' portal of EHR, thus it depends on a single healthcare provider or organization system and consumers can only access to some part of their health record [23]. In the integrated PHR, the information is collected from various sources such as insurance organizations, pharmacies, etc. [23]. Although it provides a complete view of a consumers' data, different entities including consumers, insurance companies, healthcare providers, and pharmacies contribute to the ownership and updating of integrated PHR [20, 23, 39, 64, 75]. However, these PHR models allow consumers to access their health information, but they either aren't exactly according to PHR definition (in terms of PHR ownership and controlling) or don't contain reliable information for healthcare providers' uses, as a result, it isn't possible to use them in health practices by healthcare providers.

There are different strategies to develop PHRs including online health information repository, Health Record Bank (HRB), and cloud technology [23, 70]. Furthermore, PHRs can be integrated with social networks. Some organizations such as Pew Research Center [15–17, 27] and Health Union [42] examine the social life of health information. According to the Pew Research Center's reports, the number of adults looked for health information online has increased from 61% in 2009 [15] to 72% in 2014 [27]. The health Union's survey showed that 98% of 2200 respondents used online or social media resource when they had a serious health condition [42]. Also, Pew research centre reported 70% of adults got offline or online information or support from friends and family, and 24% of them got offline or online information or support from others with the same health condition [16]. Consumers usually used social media for seeking information, esteem and social support, emotional expression and social comparison [42, 50, 76]. Some social networks such as PatientsLikeMe [63] and MedHelp [51] have created to response these consumers' needs. However, the PHR information in these social networks is entered by its owner (consumer),

thus the healthcare providers are usually concerned about the accuracy and reliability of this information [83].

Generally, two approaches are used to benefit social network analysis in the health field. In the first approach, the user's contents (like user's tweets or posts) in the social networks were analyzed to different purposes like identifying the public main thoughts, attitudes, feelings and issues about epidemics [1], tracking the disease outbreak [4, 5] and individuals contacts [45]. This knowledge can be useful for public health policymakers who must make decisions about the best measurements to response the epidemics [5]. In the second approach, the topological features of social network are analyzed to better use of health entities' relations for different purposes such as finding consumers with similar health conditions [72, 84]. These types of studies have key role in the improvement of healthcare quality and patients satisfaction [32, 59].

In this paper, our contribution falls in the second approach. We have proposed a health social network as a platform to develop the proposed PHR model. First, concerning the mentioned drawbacks for existing PHR models, a PHR model is proposed which is the extended version of the integrated PHR model with the exception that consumers have full control over their PHR. According to the PHR definition, full control means that consumers have the highest authority in entering, editing and eliminating PHR information as well as allowing access to PHR contents for others. Second, HSN-PHR is defined using graph theory to determine the main entities of HSN-PHR and their relationships. We have considered HSN-*PHR* consumers are those who join the network whether as a patient or not and was the owner of her/his PHR(s). Although, the healthcare providers and service provider systems and organizations are also considered as social networks' entities, examining their interactions is out of the scope of this paper and these entities are analyzed where they impact on consumers. HSN-PHR definition is based on the requirements elicited in [79]. Also, it is experimentally shown that the graph structural features of HSN-PHR can meet its users' requirements about health issues. Indeed, we have added PHR capabilities to social network analysis because health information analysis using social network structural features can provide valuable insights to improve healthcare quality and increase the consumers' satisfaction. The main contributions of this paper are as follows:

- A PHR model is proposed which is an extended version of the integrated model. The
 additional feature of the proposed PHR model is that it is fully controlled by its owner
 while its information is entered from various sources. Therefore, unlike the integrated PHR
 model which has multiple PHR owners, the proposed PHR model has one owner while it
 contains reliable information for both consumers and healthcare providers. In other words,
 our goal is to propose a PHR model which is more compliance with PHR definition as well
 as its content is reliable for health practices.
- Constructing a heterogeneous social network (HSN-PHR) as a platform to develop the
 proposed PHR model. This makes it possible to analyze the PHR information using the
 structural features of social networking that can provide worth intuition to improve the
 health services quality and increase the consumers' satisfaction by responding to their
 needs such as having relationships, sharing information, etc.

The rest of paper is organized as follows: Related works are summarized in Section 2. Section 3 describes HSN-PHR system. Therefore, first the proposed PHR model and its requirements are detailed and then HSN-PHR construes as a health social network. The HSN-PHR features and experimental results are discussed in Section 4. Finally, the paper is concluded in Section 5.

2 Related works

In the standalone model, the PHRs are created by commercial applications in the various forms such as PC-based, portable media (e.g. smartcard), and web-based application [23, 77]. Thus, consumers and third-party organizations are the main stakeholders of this PHR model [69]. Standalone PHRs have some advantages such as helping consumers to gather, organize and store their health information so that they can access their information anytime and anywhere they need [23, 64, 75]. The Microsoft HealthVault, Google Health and Dossia are some examples of this PHR model which have developed as an online health information repository [23]. Also, some health social network like PatientsLikeMe [63], CureTogether [19] and MedHelp [51] facilitate the consumer-consumer and consumers-physicians relationships and provide a consumer-oriented information repository which can be representative of real-world patients for research and better planning for patients' services needs [55, 58]. In these health social networks, only PatientsLikeMe provides the possibility of creating a standalone PHR [55]. Although the information can be download and stored on the storage devices, these PHRs aren't considered as a sharable record with healthcare providers, because it difficulty connects to other data sources. The key drawbacks of this type of PHR are the manual data entry that led to the uncertainty of healthcare providers about data accuracy, the possibility of don't update PHR data by consumers, and the vulnerability of non-internet-based records to damage, theft and loss [23, 64, 75]. The standalone PHR systems which are offered by third parties have privacy concerns too [21, 26].

Tethered PHR model allows patients to access some parts of their health record such as medical images, lab results, immunization record, prescription information, and so forth. This model of PHR is under the providers' control and is read-only for patients, although some allow patients to add supplements information in their record that may be used in provider's EHR [10, 20, 23, 39, 64, 75, 77]. EHR patients' portal is a common approach to create the tethered PHRs. The patients' portals interventions like patients education, using alerts for management of chronic diseases, medication refill, preventive service and secure messaging were delivered with or without healthcare providers participation. Patients portals have positive effects on psychological outcomes; controlling the blood pressure, glycemia, cholesterol and weight loss; medication adherence among HIV patients; and screening cancer patients [37]. By the population of mobile devices and an increasing tendency to m-Health, the Mobile PHRs (m-PHRs) such as My Chart in My Hand (MCMH) [61], MyHEalth Keeper [71], Health4U [67] and so forth were taken into consideration [7, 43, 44, 60, 66, 86]. MCMH is a hospital-tethered m-PHRs application started in Asan Medical Center (AMC), Seoul, Korea in 2010 [61]. Patients with chronic diseases and more hospital visits are the main consumers of MCMH; because it improves accessibility, mobility and connectivity of health information for patients who need long-term care [44]. It can be concluded that the tethered PHR model has some drawbacks such as the owner of PHR are healthcare providers (Unlike the PHR definition that the PHR must be under the consumer's control). Because this type of PHR is tightly coupled with a single provider or institution system, due to incompatibilities problems, patients cannot share their health information with other providers or institution. Also, patients don't have access to all of their health information, the patient health information is scattered on different systems and his/her data in one system isn't accessible from another [10, 20, 23, 39, 64, 75, 77].

In the integrated PHR model, typically, consumers can enter data into selected areas of the PHR. Also, they can add essential health indicators such as blood pressures, seizure history, or

weight measurements which can be useful for physicians monitoring between orderly scheduled clinic visits. An example of this model of PHR is the U.S. Department of Veterans Affairs' MyHealthVet portal that provides online access to health record for over one half million veterans. Integrated PHR allows consumers to access their records in their providers' system, omits manual re-entry of health data, reduces medical errors, omits duplication, and led to the improvement in the quality and efficiency. It allows consumers to share health information, thus it can be used as a communication channel between consumers and providers [20, 23, 39, 64, 75]. Consumer-centric HRBs created by an independent organization provides a repository to collect consumers health information from various sources and controlled by consumers [23, 30]. Therefore, HRB like Revolution Health [33] is one approach used to create the integrated PHR but it has privacy concerns; because it depends on an organization other than healthcare organizations [23, 26, 30]. OmniPHR is another integrated PHR which is cloud-based. The users of OmniPHR are patients and healthcare providers. It provides a unified view of a patients health history which is collected from health organizations; therefore it supports the distributed PHR and provides the accessibility of up-to-date information for healthcare providers [70]. Although the integrated model has more benefits compared to the previous two models, its implementation is complex (but make it usable and flexible) [20] and unlike the PHR definition, it has multiple owners [39].

In addition to mentioned disadvantages for each PHR model, all of existing PHR models have these drawbacks too: the patient-patient, patient-physicians, and physician-physician relationships aren't considered so, it is impossible to optimal use of healthcare experiences to deliver healthcare services or obtain business insights.

Some healthcare experiences such as finding proper healthcare provider [32], similar patients (to share experiences and emotional support [72-74, 84, 85]), following and preventing the epidemics [47], patient and physicians categorization (to provide the common and efficient healthcare services [35, 38]) as well as business insight like identifying the important physicians who are connected to the core of network by high mutual referral and high retention [11, 24], providing collaborative analysis to improve the acceptance of health services like pharmacy services [28] and improve the patients outcome [59] could be useful in the health systems in which the relationship analysis, community analysis and importance analysis can provide beneficial perspectives. According to a specific purpose, a social network can be considered between different entities; for example an internal social network for one hospital or between several institutions which can be used to enrich EHR information [56] or a comprehensive health social network between patients, healthcare professionals and healthcare organizations [78]. In this paper, an extended version of integrated PHR is proposed which is based on social interactions analysis between patients. In Table 1 the features of different PHR models including proposed model have been compared. This table shows that the proposed PHR model has all advantages of other models but just like the integrated model its implementation is complex.

3 The proposed health social network-based PHR system

3.1 The PHR model

In the proposed PHR model, PHR content is comprehensively entered and updated by healthcare providers. When a consumer meets a physician or any other providers like a

Table 1 Comparison the features of different PHR models	R models			
Features	Standalone	Tethered Integrated	Integrated	Proposed Model
Electronic Record Data entry from multiple resources Entering and updating information	Yes Yes consumers or providers	Y es No Providers	Yes Yes Consumers, providers, insurance company	Yes Yes Automatically by healthcare providers and insurance companies (after any meeting based on consumers' permission) also by consumers in the specific sections
Deleting information Owner(s) of PHR (managing and controlling PHR information)	Consumers Consumers	Providers	Consumers, providers, insurance company Multiple Owner (consumers, providers, insurance company)	Consumers but it is recognizable Consumers
Sharable record	No	No	Yes	Yes
Implementation complexity	No	No	Yes	Yes
Integrated view of health information	No	No	Yes	Yes
Reliability of record information for physicians	No	I	Yes	Yes

radiologist, her/his data are automatically transformed from providers' system to her/his PHR. The consumers' privacy rights to obtain reliable information for healthcare providers, are as follows:

- The PHR owner is the only person who decides on the access of others (like her/his physicians, caregivers, friend, and so on.) to her/his health information.
- The PHR owner can access health information which is entered by healthcare providers.
- The PHR owner can edit or amend the information entered by healthcare providers by sending amendment request to the related healthcare provider or in the form of annotations besides of healthcare providers' information.
- The PHR owner can also delete her/his health information entered by healthcare providers. Thus, this action is done logically by flagging information and it is logged in the PHR to be recognizable by healthcare providers. (To obtain reliable information for providers,)
- The PHR owner can enter her/his health information in a distinct section of healthcare provider information.
- PHR owner must determine how her/his PHR information could be accessed in an emergency condition. Emergency access could be requested based on the types of healthcare provider (like emergency room physicians) or the location where the care being received. These log-in types are examined at the authentication time. In the emergency condition, the PHR information would be accessible according to PHR owner permissions. PHR owners can get a report of disclosures of her/his health information.
- The PHR owner can inspect and copy her/his information and get a report from recent copies and their reasons too.

Therefore, healthcare providers (who are allowed to access one's PHR) can recognize any changes in the providers' information done by PHR owner. Figure 1 shows an overview of the proposed PHR model.

When new information is entered in the PHR, its source is saved automatically. If a healthcare provider needs to access the PHR information which is deleted by PHR owner or the PHR owner doesn't take access permission to him/her, then the PHR shows its source system and the applicant physician can send the information request to the provenance system.

This model has more compliance with PHR definition, because the consumers have full control of their PHR, and their PHR information is sharable with their thealthcare providers. Although the PHR contents are collected from various sources, it has one owner and its information is reliable for healthcare providers. In other words, the proposed PHR model is an extended version of integrated model with the exeption that it has one PHR owner and the consumers have the highest authority in the PHR controlling.

3.1.1 Functional requirements of the proposed PHR model

The functional requirements which were specified in [79] were considered to specify the proposed PHR models' properties. They proposed the requirements of a PHR model in a health social network including:

• Creating an account (which provides the possibility of entering demographic, clinical and financial information by consumers) [79]

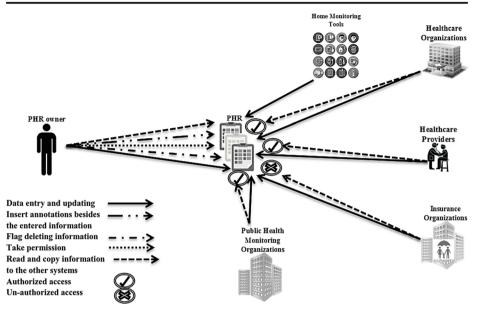


Fig. 1 The overview of proposed PHR model. Each type of arrow represents an access to the PHR which has been explained in the figure guideline. The PHR owner gives permissions to other entities to read and copy the PHR information. Thus, each requested access to read or copy of PHR information may be known as an authorized or unauthorized access based on PHR owner permission

- PHR services (such as managing medication; request prescription renewal; health calendar; entering and managing personal clinical care, observations and measurements, and so forth) [79]
- Reminder services (which may be created by consumers, healthcare providers or be in the form of provider's recommendations) [79]
- Decision support services (that provide some services like the alert warning, link to decision support services from reliable sources, proposing alternative drug in some condition such as drug allergies or drug interactions, aid to self-assessment and self-care planning, and so forth) [79]
- Providing some services about healthcare providers that can be categorized in two groups as follows:
- The first group is the services related to healthcare providers like consumer's ability to search in the provider's list; Access to a healthcare providers and organizations contact information; Taking part in the surveys about healthcare providers and organizations and so forth. [79]
- The second group is the services about the management of the meeting information. Some instances of these services are capturing and exchanging information from/with other health information systems and tools, reviewing and comparing physician²s assessments with best treatment practices, entering the care and treatment plans, and so forth [79]
- Reporting from PHR information (such as reporting the financial and administration information entered to PHR, reporting about information disclosure by secondary owner (proxy, etc.) of PHR record, and so forth) [79]
- Giving permission for accessing to PHR including giving and maintaining others permissions, surgical permissions, etc. [79]

 Social network services provided using social network capabilities including finding similar consumers; viewing other profile; sharing medical and health experiences; comment, like, and dislike other's sharing contents; creating and membership in specific disease groups; sending private messages and chatting in groups and so forth [79].

3.2 Health social networking

HSN-PHR system is a health social network which provides PHRs' functionalities for consumers. Concerning consumers' tendency to have relationships with each other and healthcare providers, a health social network was selected as a platform to develop the proposed PHR model. HSN-PHR was developed using graph theory. Graph data model is used to model networks mathematically. A graph is a set of nodes which used to represent social actors and a set of edges to represent the relations between social actors [62]. The HSN-PHR graph modelling is flexible to rapid changes due to network evolution as well as maintains data integrity. It also allows the possibility of designing relational models in which there is no semantic gap between logical and physical models. Using graphs data model of HSN-PHR various relationships can be represented which is important to create an accurate modelling of real-world domains [14, 68]. HSN-PHR has three main entities (consumers, healthcare providers, service provider systems and organizations) that are considered as networks' nodes. Also, there are different types of relations between nodes considered as networks' edges. HSN-PHR not only provides the possibility of creating PHR, but also provides the possibility of using social network capabilities such as creating relationships, sharing health information and social supporting to meet the health needs of its users.

Figure 2 shows the HSN-PHR and how the PHR information can be accessed in this network.

3.2.1 Constructing health social network model

The abbreviations used in this section are listed in Table 2.

Definition 1 A *heterogeneous graph* is a graph with k different types of nodes and q different types of edges. Thus, a heterogeneous graph is defined as follows:

$$HG = (V, E, \varphi, f)$$

Where:

V is a node-set of the heterogeneous graph which is the union of m nodes. Therefore, V is defined as follows:

$$V = \bigcup_{i=1}^{m} v_i = \{v_1 \cup v_2 \cup \ldots \cup v_m\}$$

E: $E \subset V \times V$ is an edge set of the heterogeneous graph which is the union of *n* edges. Thus, *E* is defined as follows:

$$E = \bigcup_{i=1}^{n} E_i = \{E_1 \cup E_2 \cup E_3 \cup \ldots \cup E_n\}$$

 φ : is a function which maps each node to its type in the L_1 set, where L_1 is a set of different types of nodes. Thus, if there are k types of nodes in a heterogeneous graph L_1 and φ are defined as follows:

$$\varphi: V \rightarrow L_1$$

where $L_1 = \{1, 2, \dots, k\}$

🙆 Springer

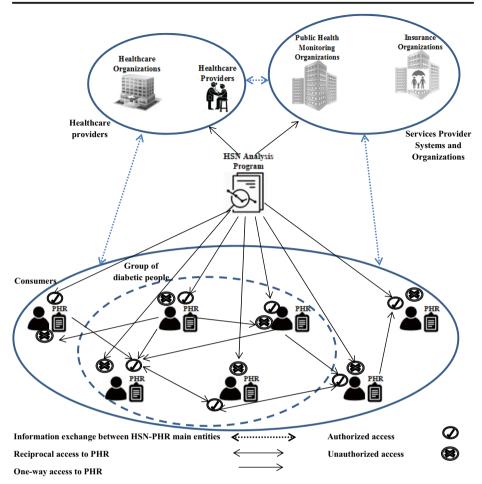


Fig. 2 Accessing to PHR in HSN-PHR. There are three main nodes in HSN-PHR which showed by oval shapes including consumers, healthcare providers and services provider systems and organization. These entities can exchange information with each other. Consumers have access to others' PHR information if the PHR owner takes permission to them. Based on consumer's request and permission, accessing to PHR can be a one-way or reciprocal relation. If PHR owner doesn't give permission to another specific consumer, the applicant access request will be unauthorized. "HSN Analysis Program" is a program that analyzes HSN-PHR entities profiles (after their permission) and HSN-PHR. This helps HSN-PHR entities to better find their health requirements (like similar consumers or healthcare providers) as well as finding proper treatments for healthcare providers, etc.

Table 2 A	bbreviations
-----------	--------------

Abbreviations	Description
HP	Healthcare providers node
SO	Service providers and Organizations node
С	Consumers node
Т	A set of edges created by consumers' treatment purposes between consumers and healthcare providers
IE	A set of edge created for information exchange between HSN-PHR entities
SU	A set of edges created to provide supportive services for consumers
SR	A set of edges created based on social relations between consumers in HSN-PHR

f is a function which maps each edge to its type in the L_2 set where L_2 is a set of different types of edges. Therefore, if there are *q* types of nodes in a heterogeneous graph L_2 and *f* are defined as follows:

$$f: E \rightarrow L_2$$

where $L_2 = \{1, 2, ..., q\}$

Thus, in a heterogeneous graph, there may be different types of relations between nodes. This showed with nodes degree (k_{vp}) . The k_{vp} for a node means that this node has k_{vp} number of a specific relation (which is determined by p) with a specific type of nodes (which is determined by v). Therefore, there are different types of degrees for each node that any of them is related to a specific relation. Thus, the degree of a node is defined as follows:

$$k_{vp} \in \mathbb{Z} | v \in V, p \in E$$

HSN-PHR has three main entities including consumers (whether was patient or not), healthcare providers, and service provider organizations and systems; as well as there are several types of relationships between each pair of HSN-PHR nodes such as information exchange, sending reminders and so on. Therefore, HSN-PHR is a heterogeneous graph (principally consists of nodes and edges) and according to definition 1. HSN-PHR graph (*H*) is defined as follows:

Where:

$$V = (V_{Hp} \cup V_{So} \cup V_C)$$
$$E = \{E_{HP-C} \cup E_{SO-C} \cup E_{SO-HP} \cup E_{C-C}\}$$
$$= \{\cup E_{(x-y)_z}\}$$

 $\mathcal{H} = (V, E).$

V is the node-set of HSN-PHR.

E is the edge set of HSN-PHR

HSN-PHR Nodes Set

As shown in Fig. 3, healthcare providers account, service provider systems and organizations account and consumers account were considered as HSN-PHR nodes. Thus, HSN-PHRs' nodes have three different types. The nodes set of HSN-PHR was defined as follows:

$$V = \left(V_{Hp} \cup V_{So} \cup V_C \right)$$

Where the *Hp*, *So* and *C* determine the nodes' types. Therefore, V_{Hp} , V_{SO} , and V_C refer to healthcare providers, service provider systems and organizations and consumers nodes, respectively. This paper focuses on consumers' requirements and expectations.

Also, the φ function is defined as follows:

$$\varphi: V \rightarrow T_1$$

where $T_1 = \{HP_x, SO_x, C_x\}$

Each specific account in the HSN-PHR has some entities. "Hp" has some entities such as physicians, nurses, laboratories, radiologists, physiotherapists and pharmacies. "C" has entities

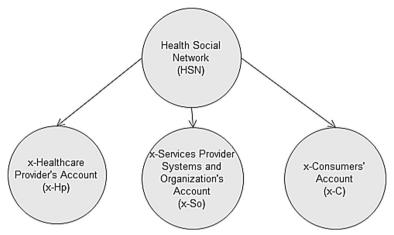


Fig. 3 General presentation of HSN-PHR nodes

including consumers and proxies. "So" has entities such as insurance companies, research organizations, disease registry organizations, public health agencies, health ministry and so forth. The "x" variable before the nodes' name in Fig. 3 and the "x" index for *HP*, *SO*, and *C* in T_1 set expresses the entity type of a specific account in the HSN-PHR. The type of each main account of HSN-PHR effects on their access to the specific parts of a consumer's PHR. For example, a physician could access to all parts of a PHR but a pharmacist only could access to consumers' drugs and allergies. However, this default access can be expended or limited by PHR owner permission too. The PHR data elements elicited in [79] are stored in the HSN-PHR nodes as a part of consumers' profile in their account.

HSN-PHR Edge Set

As shown in Fig. 4, there are various types of relationships between HSN-PHR users such as Information Exchange, Sending Reminders relationships between "Consumers' Account" and "Healthcare Providers' Account". Thus, the HSN-PHR graph has different types of edges. The edge set of HSN-PHR is defined as follows:

$$E = \{E_{HP-C} \cup E_{SO-C} \cup E_{SO-HP} \cup E_{C-C}\} = \cup E_{(x-y)}$$

As shown in Fig. 5, there are six general groups of links (or edges) in the HSN-PHR:

- 1. Relations (edges) between healthcare providers and consumers (E_{HP-C})
- Relations (edges) between service provider systems and organizations and consuemers (E_{SO-C})
- 3. Relations (edges) between consumers (E_{C-C})
- Relations (edges) between healthcare providers and service provider systems and organizations (E_{HP-SO})
- 5. Relations (edges) between healthcare providers (E_{HP-HP})
- 6. Relations (edges) between service provider systems and organizations (E_{SO-SO})

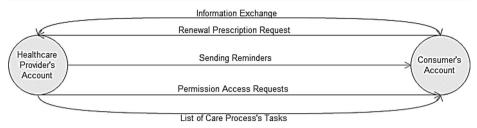


Fig. 4 An example of different types of edges in HSN-PHR graph

Where the "E" shows a link between two nodes.

Because this paper focuses on consumers' requirements, the first three links of the above list are examined in detail and the forth relation is examined to the extent that is related to consumers. The examination of other links (which were shown with dashes in Fig. 5) is out of this paper scope. The elicited requirements for developing HSN-PHR in Section 3.1.1 were used to address the HSN-PHR edges and the rules of generating each of them.

Some edges in HSN-PHR are directed and some others are undirected. Directed edges are shown by $\langle x, y \rangle$ symbol and undirected edges are shown by $\langle x, y \rangle$ symbol where "x" and "y" refer to the nodes connected with the edge. For example, sending reminders or physicians recommendations are directed edges form physicians to their consumers. However, some edges such as clinical information exchange are reciprocal, thus these edges considered as undirected edges.

The E_{HP-C} links are divided into three main categories, including *IE*, *T*, and *SU*. Each of these links can be created by different reasons listed in Table 3.

The E_{SO-C} links are divided into two main categories, including *IE*, and *SU*. Each of these links can be created by different reasons listed in Table 4.

The E_{C-C} links are divided into two main categories, including *IE*, *SR*. Each of these links can be created by different reasons listed in Table 5.

Generally, there are two main links between healthcare providers and service provider systems and organizations, including supportive services and information exchange. Reporting the results of consumers' satisfaction about providers' cares is the only E_{SO-HP} relationship that

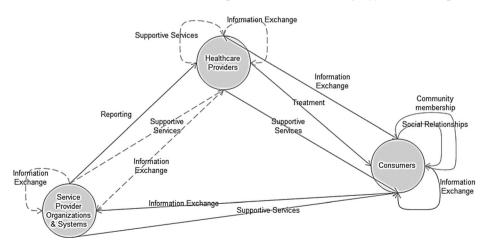


Fig. 5 The general relations between main entities in HSN-PHR

is considered because it is affected by consumers. Therefore, the reporting relationship is a kind of supportive services.

The links between two nodes in HSN-PHR are shown by $E_{(x-y)}$ where "x" and "y" refer to the entities in the relation (i.e., *HP*, *SO*, and *C*), "*E*" refers to links' category (i.e., *IE*, *SU*, *T*, and *SR*), and "z" refers to the links' name. The link name can be each of the all possible relations' names in Tables 3, 4 and 5.

The links between two nodes in HSN-PHR are defined as follows:

$$E = \{E_{HP-C} \cup E_{SO-C} \cup E_{SO-HP} \cup E_{C-C}\} \\ = \left\{ \cup E_{(x-y)_z} \right\}$$

Also, f function is defined as follows:

$$f = E \rightarrow T_2$$
where $T_2 = \left\{ E_z | ifx, y \in \{HP, C\} \land x \neq y \Rightarrow E \in \{SU, IE, T\} \\ ifx, y \in \{SO, C\} \land x \neq y \Rightarrow E \in \{SU, IE\}, \\ ifx, y \in \{SO, HP\} \land x \neq y \Rightarrow E \in \{SU, IE\} \\ ifx = y = C \Rightarrow E \in \{IE, SR\} \right\}$

As mentioned previously, each " $E_{(x-y)}$ z" relation is a set of pair nodes. For example, $IE_{(HP-C) mco}$ is a directed edge (where mco refer to the consultation message) thus, it is defined as follows:

Relation category	Relation name	Rule code	The rules of creating a relation	Directed/ undirected
Information exchange	Messaging	IE ₁	Sending the prescription renewal request from consumers to physician	Undirected
_		IE ₂	Exchange the consultation messages between consumers and healthcare providers	
	Clinical information exchange	IE ₃	Exchange any clinical information such as medical history, test results, allergic information, tasks list of care processes and so forth between PHR and other systems	
	Financial information exchange	IE ₄	Exchange any financial information such as care costs, prescriptions cost and so forth between PHR and other healthcare provider systems	
	Demographic information exchange	IE ₅	Exchange demographic information such as identification information, address and contact information and social history between PHR and other systems	
Supportive services	Reminders	Su_1	Sending reminders about meetings from healthcare providers to their consumers	Directed
	Recommendations	Su_2	Sending advice from healthcare providers to their consumers	
Treatment	Disease diagnosis	T ₁	Sending information such as discharge summary, problem list, symptoms, diagnoses and so forth to PHR	Directed
	Prescription	T ₂	Sending drug, test, radiology or physiotherapy prescription to PHR	
	Involvement in care processes	T ₃	Referring a consumer to a healthcare provider	

Table 3 The rules of E_{HP-C} relations

Table 4	The rules of E_{SO-C} relations	
---------	-----------------------------------	--

Relation category	Relation name	Rule code	The rules of create relation	Directed/ undirected
Information exchange	Messaging	IE1	Exchange messages between consumers and service provider systems and organizations	Undirected
	Participating in surveys	IE ₂	Participating in the healthcare providers' or various organizations' surveys and sending their results to participants	
	Participating in researches	IE ₃	Participating in clinical researches and sending their results to participants	
	Clinical information exchange	IE ₄	Exchange any clinical information between PHR and any service provider systems and organizations	
	Financial information exchange	IE ₅	Exchange any financial information such as care costs, and so forth between PHR and any service provider systems and organizations	
	Demographic information exchange	IE ₆	Exchange demographic information between PHR and any service provider systems and organizations	
Supportive services	Notifications	Su_1	Sending reminders about important dates of insurance services to consumers	Directed (from service provider
		Su_2	Sending alerts about critical events or situations and correct measurements in these	systems and organizations to
		Su ₃	Financial supports such as sending the advantages or facilitates of various insurance organizations to consumers	consumers)
		Su ₄	Ethical and legal supports such as creating the privacy-preserving rules and so forth	
		Su ₅	Sending education information such as news, specific educational information or the information about local and regional programs date to consumers	
	Decision support	Su ₆	Sending guides appropriate to consumers diseases and situations	
		Su ₇	Comparing the physician assessments with evidence-based guidelines and best practices	
		Su_8	Suggesting alternative drugs when there are allergy or drug interactions	
		Su ₉	List of healthcare providers concerning consumers' needs	
		$\begin{array}{c} Su_{10}\\ Su_{11} \end{array}$	Introducing resource for critical situations Sending information about improving the lifestyle	

 $IE_{(HP-C)_{mn}} = \{ < c_1, hp_1 >, < c_{10}, hp_3 >, < c_1, hp_{20} >, \dots \}$

Where C_i and $hp_j(i, j \in \mathbb{Z})$ refer to the instances of consumers and healthcare providers, respectively.

In HSN-PHR, there are different types of relations between nodes. These relations are shown by nodes degrees (k_{vp}) . Thus, a node has k_{vp} relations (which types of relation is determined by p) with a specific type of nodes (which is determined by v). Therefore, there are different types of degree for each node of HSN-PHR as follows:

Relation category	Relation name	Rule code	The rules of create relation	Directed/ undirected
Information	Messaging	IE ₁	Sending private messages between consumers	Undirected
exchange	Chatting	IE_2	Speaking out two consumers by chatting	Undirected
	Sharing information	IE ₃	Consumers share their clinical information with others	Directed
	Sharing contents	IE ₄	Sending contents such as photos, texts, sounds, clips, comments and so forth in social network	Directed
Social	Friending	SR_1	Two consumers becoming friends	Undirected
relations	Following	SR_2	One consumer following one another	Directed
	Blocking	SR3	A consumer being block by another	Directed
	Defined relations by consumers	SR_4	Defining some relations such as family members, close friends, colleagues and so forth by consumers	Directed
	Relations among more than two users	SR5	These relations are membership in a specific group, collaborative healthcare providers in a care process, users who participate in a health program, consumers who refer to the same healthcare provider and users who participate in a research program	Undirected

Table 5 The rules of E_{C-C} relations

$k_{vp} \in \mathbb{Z} | v \in V, p \in E$

This makes it possible to show the relations which are between more than two nodes such as consumers who participate in a research program. Thus, the degree of each node in these relations shows the number of consumers in them.

3.3 Network analysis

Modelling the HSN-PHR using graph theory provides the possibility of analysis the PHR information (that can be a complete version of a consumers' health information) as well as HSN-PHRs' relations using social network analysis. Graph operations (i.e. shortest path) and queries provide the possibility of operating on the graph features such as path, neighbourhood, graph statistics (i.e. diameter, centrality, etc.) at the high level of abstractions that don't need the knowledge about data structure [2, 9, 31, 34]. Thus, these results can provide worth intuition to improve the health services quality and consumers' satisfaction [32, 59]. In this section, the applications of HSN-PHR structural analysis to response the health needs were examined.

The network features of HSN-PHR can be examined in three main categories including relationship analysis, community analysis and importance analysis.

• Relationship analysis

Consumers in the HSN-PHR network needs to traverse every other consumer or healthcare provider. Thus all consumers must be reachable in HSN-PHR graph structure. This requirement could be met by examination the degree distribution of nodes in the HSN-PHR graph structure. Degree distribution measures the number of nodes with a specific degree [13]. Formally, the degree distribution of a random graph is defined by P(k) that indicate the proportion of nodes with k degree to all number of nodes in the graph as follows [53]:

$$P(k) = \binom{n-1}{k} p^k (1-p)^{n-1-k}$$
(3.1)

Where P is the probability of connecting two nodes [53].

The average shortest path is another HSN-PHR structural feature that helps to find other consumers and healthcare providers faster. The "small world phenomenon" or "six degrees of separation" in social networks means that the average shortest path in these networks is small [12, 54]. The average shortest path indicates that how many persons must be traversed on average to one person find another specific person in the network [12]. Thus, the smaller average shortest path leads to users to find each other faster. Therefore, Average shortest path can be defined as the average length of the distance between all the networks' nodes [13]:

$$L = \frac{1}{m(m-1)} \sum_{i,j \in V, i \neq j} d_{ij}$$

$$(3.2)$$

Where d_{ij} is the length of the shortest path between nodes "*i*" and "*j*" as well as "*m*" is the number of networks' nodes [13].

Importance analysis

Identification of HSN-PHR users who have more relationships with other users is useful from different purposes including business perspective for healthcare organizations, form consumers viewpoint to identify the most popular healthcare providers for a specific health issue and for healthcare policymakers to propagate health habits and measures in society, etc. identification of such nodes is important because they have high effect in the network. Structural features of HSN-PHR like betweenness, closeness, diameter and degree distribution can be used to identify these nodes.

Betweenness is defined as the number of the shortest path that passes through a node. Mathematically, betweenness for node "i" is defined as follows [13]:

$$b_i = \sum_{j,k \in V, j \neq k} \frac{n_{jk}(i)}{n_{jk}}$$
(3.3)

Where n_{jk} indicates the number of shortest path that connected "*j*" and "*k*" and $n_{jk}(i)$ indicates the number of shortest path connected node "*j*" to "*k*" and passing through node "*i*" [13].

Closeness means how much a node is near to other nodes of the graph. Precisely, the closeness of node "v" is defined as follows [29]:

$$c(v) = \sum_{w \in V} \frac{1}{d(v, w)}$$
(3.4)

Where d(v,w) is the distance length of node "v" to "w" [29].

Finally, the diameter is the maximum value among the shortest paths of a graph. In another word, if all the shortest path for graph G is represented in a matrix that d_{ij} states the length of the shortest path from node "i" to "j", then the maximum value of d_{ij} is the diameter of G [13].

Consumers may want to choose a proper healthcare provider based on the satisfaction of their previous patients. The weighted links from consumers to healthcare providers in HSN- PHR can be used to determine the healthcare providers' rank. The links' weight indicates the level of consumers' satisfaction. The average weight of a specific healthcare provider links to consumers can be used for ranking her/him. Also, the degree of a specific healthcare provider from consumers can be used to identify the most popular healthcare providers based on their referral. The degree of a node in an undirected graph is the number of edges incident it [13].

· Community analysis

Finding similar consumers in terms of their interest, health problems (based on PHR information), age, etc. is another requirement of HSN-PHRs' consumers. Thus, there is a need to suggest the consumers who more likely be friends. Also, the healthcare providers or policymakers maybe want to offer specific advice, recommendations or consultations to a group of consumers with a specific health condition. HSN-PHR structural features such as assortativity, clustering coefficient and transitivity are the indicators for the probability that two persons with a mutual friend may be friends with each other [13, 36].

Assortativity coefficient measures the connection tendency of nodes with a similar degree. Thus, the positive assortativity coefficient means that nodes tend to connect to other nodes with similar degrees and negative assortativity coefficient means that the nodes with a high degree tend to connect to nodes with the low degree and vice versa [3]. Therefore, when the assortativity coefficient is positive, there are more tendencies to create the community in the network.

Formally, the assortativity coefficient for a directed graph is defined as follows [57]:

$$\rho = \frac{\sum_{jk} jk \left(e_{jk} - q_j^{in} q_k^{out} \right)}{\sigma_{in} \sigma_{out}}$$

$$q^{in}{}_j = \frac{(j+1)p^{in}{}_{j+1}}{\sum_j jp^{in}{}_j}$$

$$q^{out}{}_k = \frac{(k+1)p^{out}{}_k}{\sum_k kp^{out}{}_k}$$
(3.5)

Where ^{*in*} and ^{*out*} are the in-degree and out-degree, respectively. e_{jk} is the fraction of links that connected a node with in-degree "*j*" to a node with out-degree "*k*". Also, σ_{in} and σ_{out} are the standard deviations of q_j^{in} and q_k^{out} , respectively. q_j^{in} is the normalized distribution of in-degree and q_k^{out} is the normalized distribution of out-degree [57].

Transitivity and clustering coefficient both measure the likelihood of connecting two persons who have a mutual friend [49]. More precisely, transitivity indicated the present triangles in the graph and defined as follows [13]:

$$Tr = \frac{3 \times number of triangles in G}{number of connected triples of vertices in G}$$
(3.6)

Also, the clustering coefficient of the graph G is defined as follows [13]:

$$C = \langle c \rangle = \frac{1}{n} \sum_{i \in V} c_i c_i = \frac{2e_i}{k_i (k_i - 1)}$$
(3.7)

Where "c_i" is the local clustering coefficient of node "i" that indicates how likely the two neighbours of node "i" ("j" and "k") connect in the subgraph G_i that created by the node "i" and its neighbours. "e_i" is the real number of edges in G_i and $2/k_i(k_i - 1)$ is the maximum number of edges that can be existed in G_i [13].

In another world, the assortativity coefficient, transitivity and clustering coefficients express the tendency to create a community in the network. However, the transitivity and clustering coefficient express the tendency to create the communities as large as three nodes.

4 Evaluation and analysis

To analyze HSN-PHR as a social network, a prototype of HSN-PHR was implemented. Some social network features such as assortativity, transitivity, clustering coefficient, the number of communities, average shortest path and degree distribution were measured and compared to these features in Wiki-vote, Facebook and a small-world network [82]. The Stanford dataset [46] was used to generate Facebook and Wiki-Vote social networks.

4.1 Evaluation setup

As mentioned earlier, HSN-PHR only concentrates on consumers' requirements and their relations. Thus, the consumers and their relations were considered in the implemented HSN-PHR. HSN-PHR network is a heterogeneous graph with different types of nodes and relations. To avoid too much complexity, some relations of HSN-PHR were examined separately; as a result, one social network was considered from the viewpoint of each relationship. In another word, to not be too far from the real-world networks, each relationship between nodes were considered as a separate network.

4.1.1 Social network datasets

To implement HSN-PHR networks, the consumers profile information was created randomly from a dummy dataset. To compare the structural features of implemented HSN-PHR by real-world networks, the small world network [82], Wiki-Vote and Facebook social networks were implemented using Stanford University datasets [46].

Consumers' profile information included first name, last name, location, allergy, main disease, insurance organization, physician name and laboratory name. Two samples of HSN-PHR with 4039 and 8298 nodes were implemented. HSN-PHR relations were considered as undirected and symmetric relations. The physicians and laboratories were considered as the most important healthcare providers who have relationships with consumers. Also, insurance organizations were considered as the most important organizations were considered as the most important organization which have relationships with consumers. The physicians, laboratories and insurance organizations were only HSN-PHR entities, instead, they considered as factors to create relations between consumers. Consumers were only HSN-PHR entities. In HSN-PHR with 4039 nodes, 100 physicians and 8 laboratories, and for HSN-PHR with 8298 nodes, 400 physicians and 20 laboratories were considered. Thus, four networks were implemented to measure the social network features of HSN-PHR. The characteristics of implemented networks were listed in Table 6.

Networks name	Networks' relations	Nodes numbers	Edges numbers
Feature-mix	A network of consumers who have similar profile	4039	407,739
	information including location, allergy, main disease, or insurance organization	8298	344,243
Social-family	A network of consumers who have a family	4039	407,739
•	relationship with each other	8298	3,442,425
Social-doctor	A network of consumers who refer to same physician	4039	407,739
		8298	3,442,425
Social-lab	A network of consumers who refer to same laboratory	4039	407,739
		8298	3,442,425
Small World [82]		4039	88,234
[.]		8298	414,900
Wiki-Vote [46]	_	8298	103,689
Facebook [46]	-	4039	88,234

Table 6 The statistical characteristics of the implemented networks

4.2 Structural features analysis

Using the analysis of HSN-PHR features, it is shown that how HSN-PHR network features can be used to meet the health requirements of its users. Tables 7 and 8 show some measured social network features in HSN-PHR networks, Wiki-Vote, Facebook and small-world network. Also, Figs. 6 and 7 respectively exhibit the degree distribution for HSN-PHR networks with 4039 nodes and 8298 nodes compare to Facebook, Wiki-Vote and a small-world network.

• Analysis of the assortativity, transitivity, clustering coefficient and the number of communities

As shown in Tables 7 and 8, the assortativity coefficient in Feature-mix network was positive and greater than its value in other HSN-PHR networks. Therefore, the tendency to create communities in this network was greater than other networks. As shown in Table 7, the number of community in Feature-mix was greater than other networks (the threshold of minimal valid size for community detection was considered 3). It can be concluded that consumers with similar profile and PHR information were more interested in being friends with each other. Thus, when the friend suggestion is based on consumers' profile and PHR information similarities such as location, allergy, main disease, or insurance organization, the

Social network name	Assortativity	Transitivity	Clustering coefficient	Number of communities	Average shortest path
Facebook	0.06	0.52	0.605	15	3.69
Wiki-Vote	-0.083	0.125	0.120	10	3.69
Small world	0.00	0.54	0.545	13	2.56
Feature-mix	0.35	0.79	0.871	20	2.74
Social-family	-0.03	0.09	0.189	9	2.02
Social-doctor	-0.06	0.08	0.219	9	2.01
Social-lab	-0.04	0.09	0.203	9	2.22

Table 7 The measured features in networks of HSN-PHR with 4039 nodes

Social network name	Assortativity	Transitivity	Clustering coefficient	Number of communities	Average shortest path
Facebook	0.06	0.52	0.605	15	3.69
Wiki-Vote	-0.083	0.125	0.120	10	3.69
Small world	0.003	0.543	0.543	17	2.56
Feature-mix	0.323	0.805	0.514	16	2.74
Social-family	0.055	0.074	0.358	22	2.02
Social-doctor	-0.003	0.061	0.371	22	2.01
Social-lab	-0.043	0.022	0.020	6	2.22

Table 8 The measured features in networks of HSN-PHR with 8298 nodes

HSN-PHR consumers more likely become friends with each other. Concerning the assortativity coefficient of the other three networks, after the profile and PHR information similarity, HSN-PHR consumers who have family relations were more interested in becoming friends with each other. Besides, referring to the same laboratory and physician nearly had the same effects on consumers' interest in being friends with each other.

Also, by decreasing the value of assortativity coefficient the transitivity value decreased too. In other words, when the tendency of creating communities in HSN-PHR decreased, the tendency of creating triangle relations decreased too. The changes of clustering coefficient were similar to transitivity with an exception that the clustering coefficient of Social-doctor network was more than its value for Social-family although the transitivity value of Social-doctor was less than Social-family. But this difference was negligible (0.013). As expected, the clustering coefficient of Feature-mix network was greater than other networks. Therefore, it can be concluded that two HSN-PHR consumers were more interested in being friends with each other when they had a mutual friend as well as they had similarity in profile or PHR information with her/his mutual friend.

Concerning the assortativity coefficient, in Table 7, the number of communities for Featuremix network was greater than the other three networks. Also, the number of communities for

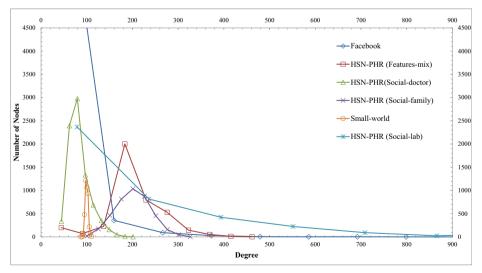


Fig. 6 Degree distribution in HSN-PHR networks with 4039 nodes and Facebook

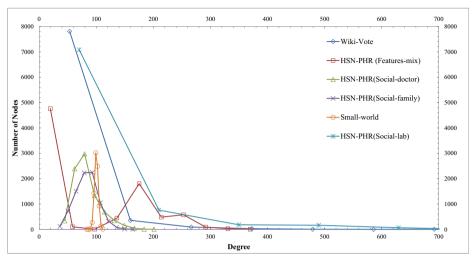


Fig. 7 Degree distribution in HSN-PHR networks with 8298 nodes and Wiki-Vote

Social-family, Social-doctor and Social-lab were equal. It would be expected since the difference between the clustering coefficient in these networks was small.

In Table 8, the number of communities for Social-Family and Social-doctor was equal. This result is acceptable, due to the small difference between the assortativity coefficients of these networks. Concerning that Social-lab had the smallest value of assortativity coefficient; the number of its communities was less than other networks too.

Therefore, as shown in Table 8, the analysis of assortativity, clustering coefficient and transitivity features can be used to identify users who are more likely interested in being friends with each other.

Analysis of the average shortest path

As shown in Tables 7 and 8, the average shortest path for Social-family, Social-doctor and Social-lab approximately was 2; also for Feature-mix and implemented Small-world approximately was 3. This shows the small world phenomenon in HSN-PHR networks. As a result, in Social-family, Social-doctor and Social-lab networks HSN-PHR consumers could faster find each other than Feature-mix. However, the clustering and assortativity coefficients of Feature-mix were more than other networks. Thus, in Feature-mix the tendency of creating communities was more than other networks but its users later found each other.

The average shortest path can be an important feature that determines how fast news, rumours and information are spread on the network. The fewer average shortest path, the faster spreading new, rumours, and information in a network.

Analysis of degree distribution

As shown in Figs. 6 and 7, the degree distribution diagram for Facebook, Wiki-Vote, and Sociallab was similar to exponential diagrams. While, the degree distribution for Feature-mix, Socialdoctor, Social-family and small-word network was similar to normal distribution diagrams.

Name of social network	Social network users	Possibility of creating PHR	Using network for general or special diseases	Consumers- healthcare providers relations and vice versa	Consumers-service providers organizations relations and vice versa
PatientsLikeMe	Consumers	1	Generally	×	×
MedHelp	Consumers	×	Generally	×	х
TuDiabetes	Consumers	×	Diabetics	×	х
AlcoholHelpCenter	Consumers	×	Alcoholism	×	×
CureTogether	Consumers	×	Generally	×	х
DailyStrenght	Consumers	×	Generally	×	×
MDJunction	Consumers	×	Generally	×	×
HSN-PHR	Consumers, healthcare providers, service provider organizations	1	Generally	1	\checkmark

Table 9 Comparing Proposed HSN-PHR with Similar Health Social Networks

In networks with exponential degree distribution diagram, there are few nodes with a high degree as well as many nodes with a low degree. Therefore, it can be concluded that some nodes in these networks have a hub role which means some nodes directly connect to many other nodes in the network. Usually, hub nodes are popular users who can influence on many social network users.

In networks which the degree distribution diagram is similar to the normal distribution, the degree of most nodes is close to each other. The difference of nodes degree in these networks is much less than the difference of nodes degree in exponential degree distribution. Hub users in the networks with normal degree distribution are a few nodes in the right point of diagrams. Although the hub nodes in these networks compared to networks with exponential degree distribution are connected to fewer other nodes (the degree of hub nodes is less than hub degree in exponential degree distribution), generally, users of these networks are more connected to each other.

In addition to finding a hub user in a network who have a key role to spread issues, diseases, etc. degree distribution can be an important feature to examine the reachability of nodes. If a node has zero-degree then it isn't reachable from others. Thus, if a network is a connected network (there is no node with zero-degree) then each node can be reachable from other nodes.

5 Concluding remarks

PHR approaches like the health record banks or cloud provide only the possibility of creating PHR for consumers. Concerning the increasing need of consumers to have relationships with others (consumers or healthcare providers) about health issues, in this paper, social network was selected to develop the proposed PHR model. For this purpose, a PHR model proposed that was extended version of integrated model. Two main goals of proposing new PHR model include its' compatibility with PHR definition (that PHR must be controlled and managed by consumers) as well as the reliability of its information for consumers and healthcare providers and organizations. Then a heterogeneous social network (which provides the possibility of creating a PHR for its consumers) was designed to response the consumers' needs to have relationships about health issues. HSN-PHR construed based on PHR functional requirements.

Thus, a formal model of social network-based PHR was designed with graph theory. The HSN-PHR entities were consumers, healthcare providers and service provider systems and organizations. The structural analysis of HSN-PHR was done to use the social network beneficiaries in response to the health needs like treatment decisions, health business plans and response to consumers' needs like finding similar consumers, emotional supports, and finding best healthcare providers for their health issues which are based on having relationship with other entities like other consumers, healthcare providers and insurance organizations.

As shown in Table 9, the proposed HSN-PHR provided the possibility of creating PHR for consumers. The HSN-PHR is a public and disease-independence social network. All HSN-PHRs' consumers can have relationships with healthcare providers and service provider organizations. However, in other health social networks only PatientsLikeMe provides the possibility of creating PHR for its consumers. In PatientsLikeMe, consumers are responsible for entering, updating, and accuracy of their PHR information. While, in the proposed HSN-PHR the information entry and update is performed by healthcare providers, consumers and some organizations such as insurance and payers. Thus, HSN-PHR information is reliable for consumers, healthcare providers and other organizations. Also, developing a PHR in the social network makes it possible to use social network capabilities in the health field such as suggesting the proper physicians to consumers, suggesting the similar consumers to each other, the possibility of traversing HSN-PHR users to find the new friends, etc. However in this paper, we have focused on consumers and their relations. HSN-PHR can improve consumers' relations with healthcare providers and related organizations. Therefore, it can improve health information access, reduce the healthcare costs, providing the right care to the right person, improve consumers' satisfaction and healthcare quality.

The social network analysis can be used concerning health policies. For example, there is a desire to create communities of users in the health social networks such as HSN-PHR; since it can facilitate finding similar consumers, information exchange, emotional supports and so forth. Concerning the results of this paper, consumers with a mutual friend who has a similar profile or PHR information with her/his friend, are more likely interested in being a friend. After profile or PHR information similarity, friend suggestion based on consumers' family relations has more effects on becoming friends and creating a community in a health social network. On the other hand, considering some factors such as referring to the same physicians or labs led to health social network consumers find each other faster. Besides, the popularity of hub nodes and their power in the health social networks can be used to health purposes such as rapid dissemination of news and health information, dissemination of correct behavioural habits and healthy lifestyle and improving the level of social health. Thus, hub node identification is very important.

In order to privacy issues and the sensitivity of the health information records, there is no public dataset contains the health record of individuals [48, 80]. Therefore, inaccibility to the exact dataset to simulate the HSN-PHR network is one of the limitation of this paper. However, like the other studies that they need PHR information [6], a dummy dataset has been used with the similar information. In this paper, it was assumed that all of the health information systems can be connected to the internet and exchange information with HSN-PHR. Analysis the social network characteristics of proposed HSN-PHR showed that how the social network characteristics of health social networks can be used for health purposes such as accelerating the propagation of health news and educations. More health requirements can be responded by network features analysis in each graph analysis category which are proposed for future works. Relationship analysis can be used for finding similar consumers. This makes it possible by analysis the edges between users where their weight indicates how much two users

are similar. Community analysis can be used to find the best communities for each consumer according to the similarity of her/his PHR information with most of the consumers in each community in the network. Importance Analysis can be used to finding more valuable PHR for each disease. This can be important to help decision making for new consumers. Valuable PHRs for a specific disease are determined according to some metrics like the number of users' request to access these PHRs, duration of creating them, PHR owner age and gender for specific diseases which are prevalent in a specific age range or gender. Each PHP in each disease community has an importance weight according to each metric. Different metrics for the different disease have various importance that is determined by its coefficient. Also, data mining techniques can be used to detect the pandemic disease outbreak and prevent the more prevalence of them in futures works. Also, developing HSN-PHR from the viewpoint of other entities as well as for specific diseases can be considered in future works.

Funding The study was funded by Tarbiat Modares University.

Declarations

Conflict of interest The authors declare that they have no competing interests.

Ethical approval This article does not contain any studies with animals performed by any of the authors.

Informed consent This article contains a study by authors that involves humans. Informed consent was obtained from all individual participants included in the study.

References

- Abd-Alrazaq A, Alhuwail D, Househ M, Hamdi M, Shah Z (2020) Top concerns of tweeters during the COVID-19 pandemic: infoveillance study. J Med Internet Res 22(4):e19016
- Abiteboul S 1997 Querying semi-structured data. In: International Conference on Database Theory, Springer, pp 1–18
- 3. Alderson DL, Li L (2007) Diversity of graphs with highly variable connectivity. Phys Rev E 75(4):046102
- Alessa A, Faezipour M (2018) A review of influenza detection and prediction through social networking sites. Theor Biol Med Model 15(1):1–27
- Al-Garadi MA, Khan MS, Varathan KD, Mujtaba G, Al-Kabsi AM (2016) Using online social networks to track a pandemic: a systematic review. J Biomed Inform 62:1–11
- Alhaddadin F (2020) Privacy-aware cloud-based architecture for sharing healthcare information. Doctoral dissertation, Auckland University of Technology
- Allaert F-A (2010) Quantin C Patients' empowerment of their personal health record requires strong traceability to guarantee patients health care security. EFMI-STC, In, pp 43–47
- Andrikopoulou E, Scott P, Herrera H, Good A (2019) What are the important design features of personal health records to improve medication adherence for patients with long-term conditions? A systematic literature review. BMJ Open 9(9):e028628
- Angles R, Gutierrez C (2018) An introduction to graph data management. In: Fletcher G, Hidders J, Larriba-Pey J (eds) Graph Data Management. Data-Centric Systems and Applications. Springer, Cham, pp. 1–32
- Anoshiravani A, Gaskin G, Kopetsky CS, Longhurst CA (2011) Implementing an interoperable personal health record in pediatrics: lessons learned at an academic children's hospital Journal of participatory medicine 3
- Appel AP, de Santana VF, Moyano LG, Ito M, Pinhanez CS (2018) A social network analysis framework for modeling health insurance claims data. arXiv preprint arXiv:180207116
- 12. Bakhshandeh R, Samadi M, Azimifar Z, Schaeffer J (2011, July) Degrees of separation in social networks. In: International Symposium on Combinatorial Search 2:1

- Boccaletti S, Latora V, Moreno Y, Chavez M, Hwang D-U (2006) Complex networks: structure and dynamics. Phys Rep 424(4–5):175–308
- 14. Carson MB, Scholtens DM, Frailey CN, Gravenor SJ, Kricke GE, Soulakis ND (2016) An outcomeweighted network model for characterizing collaboration. PLoS One 11(10):e0163861
- Center PR (2009) The social life of health information. https://www.pewresearch.org/internet/2009/06/11/ the-social-life-of-health-information/. Accessed 2 Feb 2021
- 16. Center PR (2013) Pew Internet & American Life Project: health online 2013. https://www.google.com/url?sa=t&rct= j&q=&esrc=s&source=web&cd=&ved=2ahUKEwjYuaKFiMzuAhWRo3EKHdN7BYoQFjABegQIAhAC&url= https%3A%2F%2Fwww.pewinternet.org%2Fwp-content%2Fuploads%2Fsites%2F9%2Fmedia%2FFiles% 2FReports%2FPIP_HealthOnline.pdf&usg=AOvVaw07skU0Od4R-OAa3TKpMLTd. Accessed 2 Feb 2021
- 17. Center PR (2018) Social media fact sheet. http://www.pewinternet.org/fact-sheet/social-media/. Accessed 2 Feb 2021
- 18. Corrigan JM (2005) Crossing the quality chasm. Building a better delivery system 89
- 19. CureTogether (2021) CureTogether. http://curetogether.com/home/conditions. Accessed 2 Feb 2021
- Daglish D, Archer N 2009 Electronic personal health record systems: a brief review of privacy, security, and architectural issues. In: 2009 world congress on privacy, security, Trust and the Management of e-Business, IEEE, pp 110–120
- 21. D'Amore JD, Mandel JC, Kreda DA, Swain A, Koromia GA, Sundareswaran S, Alschuler L, Dolin RH, Mandl KD, Kohane IS (2014) Are meaningful use stage 2 certified EHRs ready for interoperability? Findings from the SMART C-CDA collaborative. J Am Med Inform Assoc 21(6):1060–1068
- Davis S, Roudsari A, Raworth R, Courtney KL, MacKay L (2017) Shared decision-making using personal health record technology: a scoping review at the crossroads. J Am Med Inform Assoc 24(4):857–866
- 23. Detmer D, Bloomrosen M, Raymond B, Tang P (2008) Integrated personal health records: transformative tools for consumer-centric care. BMC medical informatics and decision making 8(1):1–14
- Dong X, Tang D, Tang C (2021) Social network analysis in China's hospital healthcare. Physica A: Statistical Mechanics and its Applications 565:125546
- Epstein RM, Fiscella K, Lesser CS, Stange KC (2010) Why the nation needs a policy push on patientcentered health care. Health Aff 29(8):1489–1495
- Ford EW, Hesse BW, Huerta TR (2016) Personal health record use in the United States: forecasting future adoption levels. J Med Internet Res 18(3):e73
- Fox S (2011) The social life of health information 2011. Pew research Center's internet and American life project. https://www.pewresearch.org/internet/2011/05/12/the-social-life-of-health-information-2011/. Accessed 2 Feb 2021
- Franco-Trigo L, Marqués-Sánchez P, Tudball J, Benrimoj S, Martínez-Martínez F, Sabater-Hernández D (2020) Collaborative health service planning: a stakeholder analysis with social network analysis to develop a community pharmacy service. Res Soc Adm Pharm 16(2):216–229
- Golbeck J (2013) Chapter 3-network structure and measures. Analyzing the social web Boston: Morgan Kaufmann:25–44, Network Structure and Measures
- Gold JD, Ball MJ (2007) The health record banking imperative: a conceptual model. IBM Syst J 46(1):43– 55
- Graves M, Bergeman ER, Lawrence CB A 1995 Graph-theoretic data model for genome mapping databases. In: Proceedings of the Twenty-Eighth Annual Hawaii International Conference on System Sciences. IEEE, pp 32–41
- Groenen CJ, van Duijnhoven NT, Faber MJ, Koetsenruijter J, Kremer JA, Vandenbussche FP (2017) Use of social network analysis in maternity care to identify the profession most suited for case manager role. Midwifery 45:50–55
- 33. Group RH (2021) Revolution health. http://www.revolutionhealth.com/. Accessed 2 Feb 2021
- 34. Güting RH 1994 GraphDB: Modeling and querying graphs in databases. In: VLDB. Citeseer, pp 12–15
- HaCohen-Kerner Y, Dilmon R, Hone M, Ben-Basan MA (2019) Automatic classification of complaint letters according to service provider categories. Inf Process Manag 56(6):102102
- Han X (2015) Mining user similarity in online social networks: analysis, modeling and applications. Evry, Institut national des télécommunications
- Han H-R, Gleason KT, Sun C-A, Miller HN, Kang SJ, Chow S, Anderson R, Nagy P, Bauer T (2019) Using patient portals to improve patient outcomes: systematic review. JMIR human factors 6(4):e15038
- Hung M, Lauren E, Hon ES, Birmingham WC, Xu J, Su S, Hon SD, Park J, Dang P, Lipsky MS (2020) Social network analysis of COVID-19 sentiments: application of artificial intelligence. J Med Internet Res 22(8):e22590
- Israelson J, Cankaya EC A 2012 Hybrid web based personal health record system shielded with comprehensive security. In: 2012 45th Hawaii International Conference on System Sciences, IEEE, pp 2958–2968

- Khan FA, Rahman A, Alharbi M, Qawqzeh YK (2020) Awareness and willingness to use PHR: a roadmap towards cloud-dew architecture based PHR framework. Multimed Tools Appl 79(13):8399–8413
- Koskinen J, Rantanen MM 2020 What is a PHR? Definitions of Personal Health Record (PHR) Used in Literature—A Systematic Literature Review. In: International Conference on Well-Being in the Information Society, Springer, pp 24–49
- Lawhon L (2016) New health union survey reveals importance of online health communities. Health union. https://health-union.com/news/online-health-experience-survey/. Accessed 2 Feb 2021
- Lee J 2011 Smart health: Concepts and status of ubiquitous health with smartphone. In: ICTC 2011, IEEE, pp 388–389
- 44. Lee G, Park JY, Shin S-Y, Hwang JS, Ryu HJ, Lee JH, Bates DW (2016) Which users should be the focus of mobile personal health records? Analysis of user characteristics influencing usage of a tethered mobile personal health record. Telemedicine and e-Health 22(5):419–428
- 45. Lee K, Polson D, Lowe E, Main R, Holtkamp D, Martínez-López B (2017) Unraveling the contact patterns and network structure of pig shipments in the United States and its association with porcine reproductive and respiratory syndrome virus (PRRSV) outbreaks. Preventive veterinary medicine 138:113–123
- Leskovec J KA (2014) SNAP DAtasets: Stanford large network dataset collection. https://snap.stanford.edu/ data/. Accessed 2 Feb 2021
- Ljubic B, Gligorijevic D, Gligorijevic J, Pavlovski M, Obradovic Z (2019) Social network analysis for better understanding of influenza. J Biomed Inform 93:103161
- Lokhandwala S, Rush B (2016) Objectives of the secondary analysis of electronic health record data. Secondary Analysis of Electronic Health Records:3–7
- Lönnqvist J-E, İtkonen JV, Verkasalo M, Poutvaara P (2014) The five-factor model of personality and degree and transitivity of Facebook social networks. J Res Pers 50:98–101
- Lu Y, Luo S, Liu X (2021) Development of social support networks by patients with depression through online health communities: social network analysis. JMIR Med Inform 9(1):e24618
- 51. MedHelp (2021) MedHelp. http://www.medhelp.org/. Accessed 2 Feb 2021
- Menichetti J, Libreri C, Lozza E, Graffigna G (2016) Giving patients a starring role in their own care: a bibliometric analysis of the on-going literature debate. Health Expect 19(3):516–526
- 53. Mislove AE (2009) Online social networks: measurement, analysis, and applications to distributed information systems.
- Mislove A, Marcon M, Gummadi KP, Druschel P, Bhattacharjee B 2007 Measurement and analysis of online social networks. In: Proceedings of the 7th ACM SIGCOMM conference on Internet measurement. pp 29–42
- 55. Narducci F, Lops P, Semeraro G (2017) Power to the patients: the HealthNetsocial network. Inf Syst 71: 111–122
- 56. Nasiri S, Dornhöfer M, Fathi M (2013) Improving ehr and patient empowerment based on dynamic knowledge assets. INFORMATIK 2013–Informatik angepasst an mensch, organisation und umwelt
- Noldus R, Van Mieghem P (2015) Assortativity in complex networks. Journal of Complex Networks 3(4): 507–542
- Nyman E, Vaughan T, Desta B, Wang X, Barut V, Emmas C (2020) Characteristics and symptom severity of patients reporting systemic lupus erythematosus in the PatientsLikeMe online health community: a retrospective observational study. Rheumatology and therapy 7(1):201–213
- Ostovari M, Steele-Morris C-J, Griffin PM, Yu D (2019) Data-driven modeling of diabetes care teams using social network analysis. J Am Med Inform Assoc 26(10):911–919
- Ozdalga E, Ozdalga A, Ahuja N (2012) The smartphone in medicine: a review of current and potential use among physicians and students. J Med Internet Res 14(5):e128
- 61. Park J-Y, Lee G, Shin S-Y, Kim JH, Han H-W, Kwon T-W, Kim WS, Lee JH (2014) Lessons learned from the development of health applications in a tertiary hospital. Telemedicine and e-Health 20(3):215–222
- 62. Pastor-Satorras R, Castellano C, Van Mieghem P, Vespignani A (2015) Epidemic processes in complex networks. Rev Mod Phys 87(3):925–979
- 63. PatientsLikeMe (2021) PatientsLikeMe https://www.patientslikeme.com/. Accessed 2 Feb 2021
- 64. Pirtle B, Chandra A (2011) An overview of consumer perceptions and acceptance as well as barriers and potential of electronic personal health records. Am J Health Sci 2(2):45–52
- Reti SR, Feldman HJ, Ross SE, Safran C (2010) Improving personal health records for patient-centered care. J Am Med Inform Assoc 17(2):192–195
- Ricciardi L, Mostashari F, Murphy J, Daniel JG, Siminerio EP (2013) A national action plan to support consumer engagement via e-health. Health Aff 32(2):376–384
- Ro HJ, Jung SY, Lee K, Hwang H, Yoo S, Baek H, Lee K, Bae WK, Han J-S, Kim S (2015) Establishing a personal health record system in an academic hospital: one year's experience. Korean journal of family medicine 36(3):121–127

- Robinson I, Webber J, Eifrem E (2015) Graph databases: new opportunities for connected data. "2nd edn. O'Reilly Media, Inc. The United States of America. pp 1–10
- Roehrs A, Da Costa CA, da Rosa RR, De Oliveira KSF (2017) Personal health records: a systematic literature review. J Med Internet Res 19(1):e13
- Roehrs A, Da Costa CA, da Rosa RR (2017) OmniPHR: a distributed architecture model to integrate personal health records. J Biomed Inform 71:70–81
- Ryu B, Kim N, Heo E et al (2017) Impact of an electronic health record-integrated personal health record on patient participation in health care: development and randomized controlled trial of MyHealthKeeper. J Med Internet Res 19(12):e401
- 72. Shakibian H, Charkari NM (2017) Mutual information model for link prediction in heterogeneous complex networks. Sci Rep 7(1):1–16
- Shakibian H, Charkari NM (2018) Statistical similarity measures for link prediction in heterogeneous complex networks. Physica A: Statistical Mechanics and its Applications 501:248–263
- 74. Shakibian H, Charkari NM, Jalili S (2016) Ensemble link predictor for heterogeneous complex networks. International Journal of Information & Communication Technology Research 8(1):9–14
- 75. Studeny J, Coustasse A (2014) Personal health records: is rapid adoption hindering interoperability? Perspect Health Inf Manag 11(Summer):1e
- Swan M (2009) Emerging patient-driven health care models: an examination of health social networks, consumer personalized medicine and quantified self-tracking. Int J Environ Res Public Health 6(2):492–525
- Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ (2006) Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 13(2):121–126
- Tanhapour M, Safaei AA (2015) Specification of requirements for health social-network as personal health record (PHR) system. Tehran Univ Med J 73(6):431–441
- Tanhapour M, Safaei AA (2018) Specification of a social network-based PHR. Int J Electron Healthc 10(4): 249–274
- Tu Y, Zhou H, Lang W, Chen T, Li X, Xu B (2020) A novel cross-sensor calibration method to generate a consistent night-time lights time series dataset. Int J Remote Sens 41(14):5482–5502
- 81. Wager KA, Lee FW, Glaser JP (2017) Health care information systems: a practical approach for health care management. John Wiley & Sons
- 82. Watts DJ, Strogatz SH (1998) Collective dynamics of 'small-world'networks. Nature 393(6684):440-442
- Witry MJ, Doucette WR, Daly JM, Levy BT, Chrischilles EA (2010) Family physician perceptions of personal health records. Perspectives in health information management/AHIMA, American health information management association 7 (winter)
- Yan L, Peng J, Tan Y (2015) Network dynamics: how can we find patients like us? Inf Syst Res 26(3):496– 512
- Yoo M, Lee S, Ha T (2019) Semantic network analysis for understanding user experiences of bipolar and depressive disorders on Reddit. Inf Process Manag 56(4):1565–1575
- Young-Mason J (2013) Information and knowledge is power: the online personal health record. Clin Nurse Spec 27(2):105–106

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Affiliations

Mozhgan Tanhapour¹ · Ali Asghar Safaei¹ · Hadi Shakibian²

Mozhgan Tanhapour m.tanhapour@modares.ac.ir

Hadi Shakibian H.shakibian@alzahra.ac.ir

- ¹ Department of Medical Informatics, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, Iran
- ² Department of Computer Engineering, Faculty of Engineering, Alzahra University, Tehran, Iran