Journal of Information Technology Management

Print ISSN: 2008-5893

Online ISSN: 2423-5059

Identification of Stakeholders in Personal Health Records Using Blockchain Technology: A Comprehensive Review

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Abstract

Leveraging supplementary technology such as Blockchain has the potential to alter the stakeholders involved in a system. Paying attention to stakeholders is one of the main pillars of developing a system. Evidence has shown that Blockchain can solve existing challenges and add new capabilities. These actions will change the stakeholders of PHR. If a value is different for everyone, at the first stage, stakeholders should be identified, and that is our goal in this study. The research adhered to the guidelines outlined in the PRISMA statement. To this end, the study utilized databases including MEDLINE, ScienceDirect, and Google Scholar for English language articles, while the "iranjournals.nlai.ir" database was accessed for Persian language articles. Finally, 35 articles were chosen from searching databases, and six extra articles were selected from reviewing the final articles' references. Stakeholders were categorized into 15 groups. The patient (individual) was identified as the most frequent

stakeholder (41 times), and infrastructure providers and the token exchange market were mentioned once each. The usage type is categorized into four groups: direct user interaction, data user, impact user, and financial beneficiaries, comprising six, eight, four, and four stakeholders, respectively. Patients (individuals) use the four groups, and health care providers, policymakers, hospitals, and the government each use two groups. Intelligent contracts are neglected in PHR, which can significantly impact the motivation and creation of incentives for using different stakeholders. The grouping presented here can be used in the preparation of the business model of PHR based on Blockchain. Data has the most usage for stakeholders and strengthens and supports investments in technologies such as Blockchain as an infrastructure for creating data markets, new business models, and creating value.

Keywords: Personal Health Record, Stakeholder Theory, Blockchain Technology

Journal of Information Technology Management, 2024, Vol. 16, Issue 2, pp. 181-205
Published by the University of Tehran, College of Management
doi: https://doi.org/ 10.22059/JITM.2024.366017.3498
Article Type: Research Paper

Received: September 30, 2023
Received in revised form: February 27, 2024
Accepted: March 16, 2024
Published online: April 30, 2024

Introduction

Healthcare stakeholders are very interested in adopting and using electronic Personal Health Records (PHR) due to their potential benefits (Gagnon et al., 2016). PHR has been praised for its potential to improve healthcare efficiency and support patients (Cushman et al., 2010). It is expanding due to its ability to improve healthcare and control healthcare costs. Research shows that the value of PHR tools may come from three broad areas: reducing direct medical costs, improving efficiency, and improving healthcare quality. The costs and benefits, and thus the ultimate value of PHR, will likely differ for different stakeholders, including patients, payers, providers, and employers (Johnston et al., 2007).

Although PHR adoption has increased in recent years, there are still obstacles. PHR is facing obstacles like poor integration and sharing of health records between providers or patients (Heart et al., 2017; Pussewalage & Oleshchuk, 2017), lack of interoperability in the absence of common health data standards (Alyami & Song, 2016), and security issues such as confidentiality and privacy of health records (Alyami & Song, 2016; Ford et al., 2016). As a result, patients often have to inform their health records and repeat lab tests. Some countries have initiated integrating PHRs, but this integration usually occurs only at the organizational level, and it does not result in patients' access to their digital records (Chiauzzi et al., 2015).

One of the solutions facing organizations/companies to solve the existing problems and obstacles is to modernize the technological infrastructure (Warren & Treat, 2019). When a

company adopts new technology, its goal is to create value or maintain a competitive advantage (Peppard & Ward, 2004). Incentives and perceived value are key factors in implementing, accepting, and using a new technology. If the implementation of a new technology is accompanied by incentives that affect the intended users, the adoption and use of the technology will be facilitated (Nazi, 2013). The Internet of Things (IoT), Artificial Intelligence (AI), and Blockchain are unprecedented technologies for the private and public sectors (Oracle, 2018). Blockchain technology is widely used in healthcare, manufacturing, legal, government, retail, real estate, tourism, and media (Marr, 2018). In practical terms, Blockchain's popularity may be simple: "Financial services and other applications need modernization, and blockchain technology seems to offer a solution" (Levine, 2015).

The most common use of blockchain technology in the healthcare industry is electronic health records (EHRs)(Agbo et al., 2019; Chukwu & Garg, 2020; Drosatos & Kaldoudi, 2019; Hasselgren et al., 2020). Given that one of the inherent characteristics of Blockchain is its decentralized nature, where data ownership is placed in the hands of individual users, some have suggested that Blockchain may be more suited to PHR specifically rather than the EHR in general (Angeles, 2019; Lee et al., 2020a). Smart contracts can lead to increased transparency of the entire treatment environment, access control management, and data integration based on defined patient-provider relationships and data privacy policies (Sookhak et al., 2021). Smart contracts can reduce transaction, legal, operational, and infrastructure costs without intermediaries. In addition, smart contracts can replace trust with automatically implemented terms and conditions according to personal data privacy policies, health data registration policies, and third-party participation policies (Esmaeilzadeh, 2022). Specifically for PHR applications, Blockchain can also decentralize control and incorporate incentive mechanisms through smart contracts, further attracting public use and increasing adoption (Xuan et al., 2020). These advantages, among others, have motivated efforts to test the feasibility and implementation of blockchain-based PHR (Lee et al., 2020b; Park et al., 2019).

Current stakeholders are interested in adopting and using PHR due to its potential benefits (Gagnon et al., 2016). As PHR's low adoption rate is due to some obstacles, Trustees of the health sector use new technologies to resolve the barriers. Blockchain is one of the selected technologies for this purpose. The point here is that the use of new technology leads to the addition of new capabilities and the removal of barriers, which can change the current stakeholders and the relationships between them. Therefore, in this research, we intend to identify Blockchain-based PHR stakeholders (abbreviated from here on as Bb_PHR). A systematic review will be used for this. Looking at the stakeholders here is comprehensive, and the theory of stakeholders is used for this purpose.

The importance of paying attention to stakeholders will be mentioned in the definition of stakeholder's theory section. We will define the term stakeholder and the stakeholder theory in the following. Then, the definition of PHR will be presented. Finally, in the results

and conclusion section, we will introduce the stakeholders of Bb-PHR with a stakeholder theory approach.

Literature Review

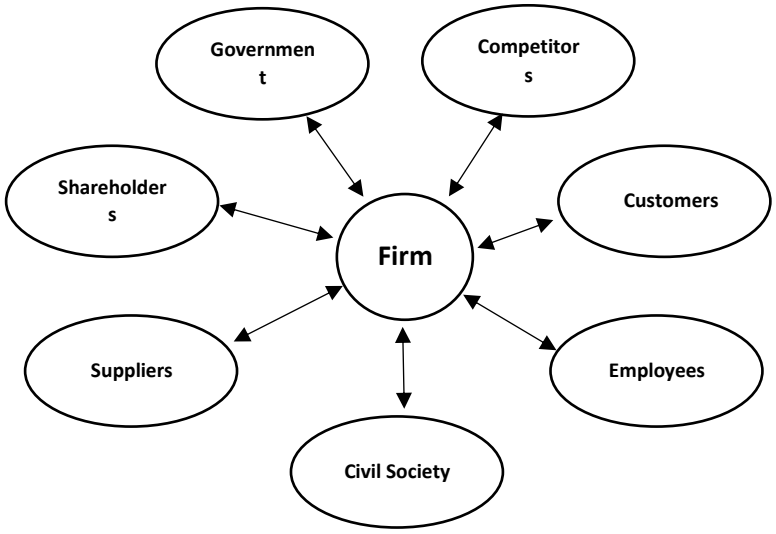
Stakeholder theory

Stakeholder theory is rooted in management literature and is one of the emerging tools in management research. Donaldson and Preston (1995) believe stakeholder theory has been advanced and justified in management literature based on its descriptive accuracy, instrumental power, and normative validity. The term stakeholder covers a wide range of definitions. Although many articles refer to the same definitions, the concept of stakeholders is still disputed (Miles, 2011). The word "stakeholder" has a relatively recent history (Pouloudi, 1999) and has become a trendy word in the management vocabulary, "almost a cliché". Freeman (1984) found its origin in 1963 when this term was used to define "a group without whose support the organization would perish". Freeman discussed stakeholders in corporate planning, systems theory, corporate social responsibility, organization theory (Pouloudi, 1999), and later integration with strategic management and approaches to help managers improve their strategic position (Mishra & Mishra, 2014). Researchers have defined the stakeholder concept differently according to their views and roles. In general, the most well-known definition is provided by Freeman (1984): "A stakeholder in an organization is any group or individual who can influence the achievement of the organization's goals or be affected by those goals ".

Freeman introduced the stakeholder model as a map with the organization at the center of a wheel, surrounded by various stakeholders. The original model by Freeman comprises eleven stakeholders. However, the most commonly used version of the model consists of seven stakeholders (Figure 1) (Freeman, 1984). Using the Stakeholder theory in business models can help us understand the interaction between partners and the impact of the different interests of actors involved in the ecosystem. Stakeholder theory is increasingly critical in business model research because business models, by definition, span boundaries and involve external partners in the value-creation process. Gnatzy and Moser (2012) studied political, economic, socio-cultural, and technological stakeholder approaches to show how stakeholder theory can be used to develop business models for health insurance markets in rural India (Gassmann et al., 2016). In addition, stakeholder theory can be applied to internal processes. Implementing innovative business models in companies requires the management of all internal stakeholders to promote this idea. Which stakeholders and with what tools these stakeholders should be managed to achieve success are essential aspects of business model research, both practically and theoretically (Gassmann et al., 2016).

Figure 1

Freeman's stakeholder model (1984)



PHR based on Blockchain technology

Blockchain distributed ledger technology offers a new alternative to traditional data management methods that rely on internal data servers or third-party cloud services. Blockchain could address privacy and security concerns surrounding EHR (Fang et al., 2021), decentralize control, and incorporate incentive mechanisms for PHR (Xuan et al., 2020). These benefits led to increased adoption of PHR, increased value gained by current stakeholders, and added new stakeholders to this set.

Healthcare stakeholders are very interested in adopting and using PHRs due to their potential benefits (Gagnon et al., 2016). The PHRs have been praised for their potential to improve healthcare efficiency and support patients (Cushman et al., 2010). A definition of the issue should be provided first for a more detailed examination. Defining a PHR is difficult due to its nature. In various studies, the field or nature of information or content, the source of information, the features and functions provided, the custodian of the file, the location of information storage, technical methods, and the persons authorized to access the information of this file have been mentioned as its characteristics (Hayavi-Haghighi et al., 2019). According to the different features and capabilities, several definitions have been provided, and the following three commonly used definitions are mentioned:

- The American Health Information Management Association (AHIMA) considers a personal health record as an electronic source with national accessibility, which consists of health information throughout people's lives and can be used to make health-related decisions. This organization considers the ownership and management of the data in the PHR (even if care providers create it) related to the patient. However, it does not consider

it a legal position nor a substitute for the EHR (*Role of the Personal Health Record in the EHR (2010 Update) - Retired*, 2010).

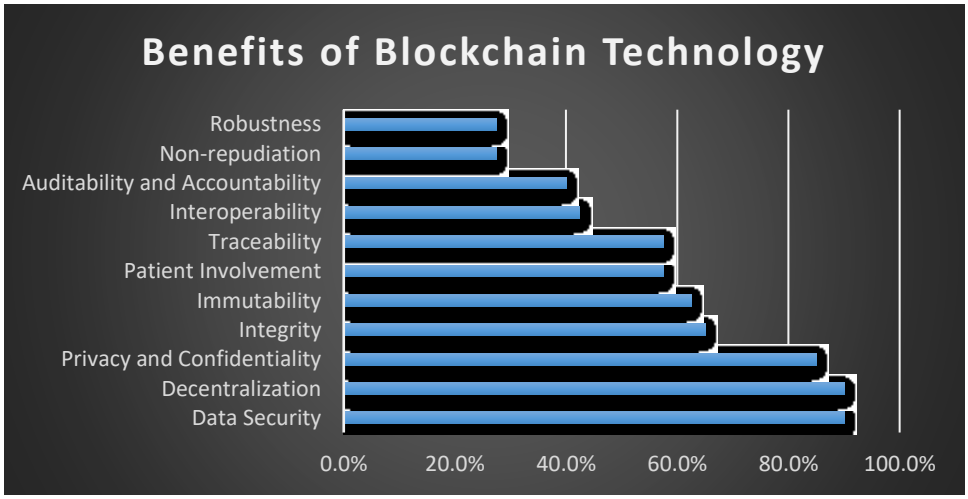
- The Markel Foundation, to connect the group of health innovations, classifies PHR as part of the set of internet tools. It considers its primary capability to be the possibility of accessing and coordinating health information throughout the life of patients and increasing access to information. It believes that PHR is a separate system. It is based on the person, which provides a comprehensive and integrated view of people's health information and is designed to track and support health activities throughout life (Scott et al., 2006).
- The National Alliance for Health Information Technology (NAHIT) also considers the PHR a personal electronic file of health-related information that follows interoperability standards. Its data is collected from various sources. A person can manage, share, and control it (Alliance et al., 2008).

To summarize, a PHR is a set of Internet-based tools that allow people to access lifelong health information, coordinate it, and make appropriate parts available to those needing it. It can be said that being patient-centered, individual ownership and management, collecting information during the life cycle, and helping self-care are among the indicators of PHR mentioned in all three definitions. In various studies, the characteristics of PHR have been mentioned as specifying the scope or nature of the information or content, the source of information, the features and functions provided, the custodian of the file, the location of the information, technical methods, and the persons authorized to access the information of this file (Hayavi-Haghighi et al., 2019).

Based on Alhabidi's research (2021), the most important benefits of using Blockchain in healthcare are information security, decentralization, privacy, and confidentiality. The complete list of identified benefits is shown in Figure 2.

Figure 2

Benefits of blockchain technology (Alhabidi, 2021)



Sun et al. (2021) also proposed Blockchain as a promising solution for data sharing while maintaining security and privacy due to its immutability benefits. According to Cunningham and Ainsworth (2017), a Blockchain technology based on an Ethereum smart contract can create a verifiable, secure, and open auditable environment that is very important for developing health information systems (Cunningham & Ainsworth, 2017).

EHR is the most common use of Blockchain technology in the healthcare industry (Agbo et al., 2019; Chukwu & Garg, 2020; Drosatos & Kaldoudi, 2019; Hasselgren et al., 2020). Given that one of the inherent characteristics of Blockchain is its decentralized nature, where data ownership is placed in the hands of individual users, some have suggested that Blockchain may be more suited to PHRs specifically rather than EHRs in general (Angeles, 2019; Lee et al., 2020a). Smart contracts can lead to increased transparency of the entire treatment environment, access control management, and data integration based on defined patient-provider relationships and data privacy policies (Sookhak et al., 2021). Smart contracts can reduce transaction, legal, operational, and infrastructure costs without intermediaries. In addition, smart contracts can replace trust with automatically implemented terms and conditions according to personal data privacy policies, health data registration policies, and third-party participation policies (Esmaeilzadeh, 2022).

Methodology

This systematic literature review was conducted based on the guidelines described in the PRISMA1 statement (Moher et al., 2009; PRISMA Flow Diagram, 2020). This type of literature review was chosen because our purpose in conducting this research was to identify the stakeholders of Bb_PHR. According to the research questions and objective, unlike a meta-analysis, there was no need to synthesize the data. Also, a quality assessment was not performed because we only sought to identify the stakeholders and characteristics of Bb_PHR. For this systematic literature review, the following steps were performed:

- Specifying the research questions
- Preparation of search strategy
- Selection of articles
- Summarize the data

Research question

This research seeks to answer the question of "Who are the stakeholders of Bb_PHR?"

[1] Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Search strategy

To find related articles combining the keywords "stakeholder," "electronic health record," "personal health records," and "PHR" and their Persian equivalents using AND and OR operators, they were used in MEDLINE, ScienceDirect, and Google Scholar databases. And for Persian language articles in the "www.iranjournals.nlai.ir" database. Because Blockchain is a technology that, with its features, can add new stakeholders to current PHR stakeholders or create unique benefits for existing stakeholders, we avoid limiting the search to the word "blockchain" and act more broadly to identify stakeholders. Also, articles related to EHRs were used for analysis due to their similarity with PHR. Since Blockchain is still in its infancy, Google Scholar was included as a search database to include relevant gray literature in this review. According to Paez's (2017) research results, gray literature or evidence not published in commercial journals can contribute to systematic reviews. Gray literature can include academic articles, theses, research and committee reports, government reports, conference papers, and ongoing research. Therefore, gray literature can reduce publication bias, increase the comprehensiveness and timeliness of reviews, and strengthen the presentation of a balanced picture of the available evidence (Paez, 2017).

Article selection

After the articles were obtained, criteria for inclusion and exclusion were applied in the final review. The criteria for inclusion are Articles in which users, ecosystem, and stakeholders of PHR or EHR are mentioned. The exclusion criteria are 1) duplicate articles, 2) review articles, 3) articles whose full text was unavailable, and 4) articles whose full text was not in English or Persian. The selection of articles was made in several stages (in order). First, duplicate articles were removed. Then, the titles of the articles were reviewed, and those that were not related to the topic were discarded. In the next step, the abstracts of the articles were reviewed, and those whose primary focus was not on PHR and did not mention the stakeholders and review articles were excluded from the study. Finally, the full text of the remaining articles was reviewed. At this stage, articles whose full text could not be accessed and those whose full text was not in English or Persian were also removed.

Summarizing data

Microsoft Excel software created a data collection form to summarize the data. Two reviewers with experience in the health and information technology field reviewed the full text of selected articles independently. To solve discrepancies in abstracted data, both individuals re-reviewed the articles together to reach an agreement. A total of four data elements were extracted from each article. Table 1 provides a complete list of extracted data elements and describes each.

Table 1

List of data elements extracted from selected articles

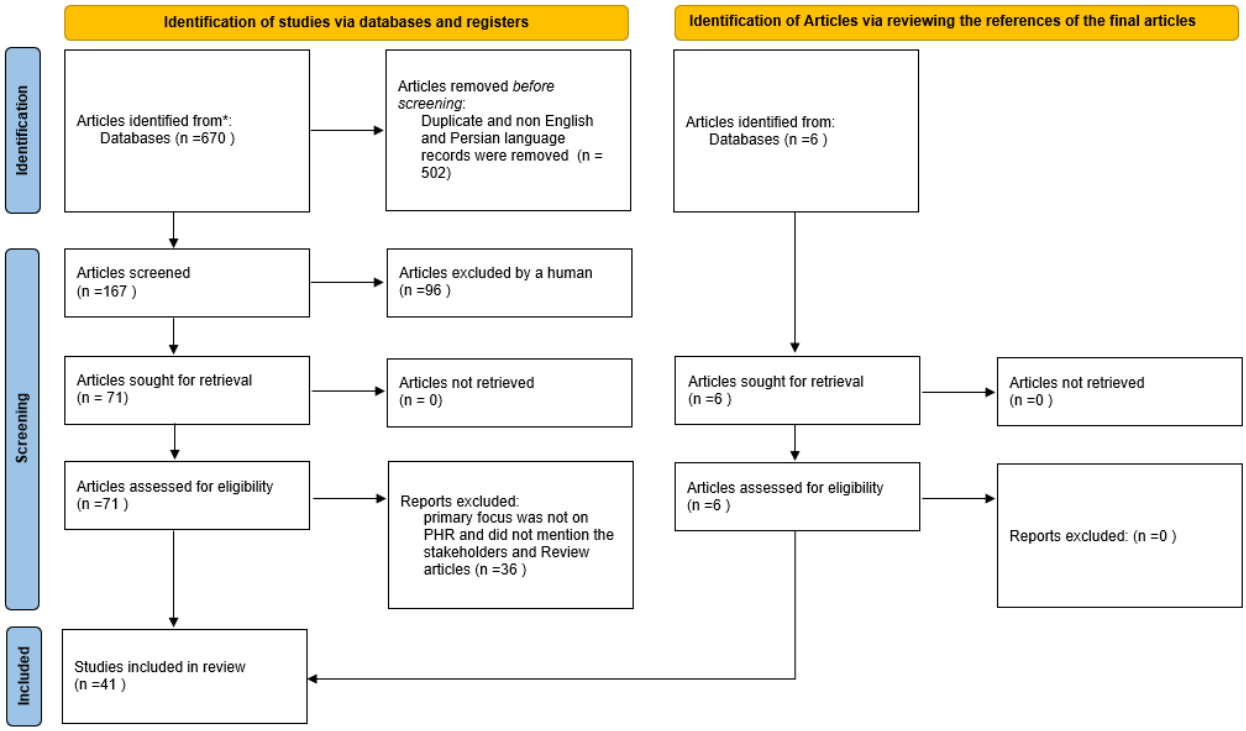
Row	Data type	Data description
Author and Date	General	Last name of the first author and Year of publication of the article
The main subject of the article	Specialized	What does each article search for
Stakeholders	Specialized	Who/which stakeholders are
Expected Value/benefit	Specialized	Which value or benefit is expected via adding blockchain technology

Results

A search for articles was conducted on February 17, 2022, which resulted in 670 articles, among which 168 were non-duplicated. According to the article selection process, 35 articles were selected for review. Another six articles were added to the study using the snowball method (reviewing the references of the final articles) in reviewing the full text of the articles (Figure 3).

Figure 3

PRISMA diagram for the process of selecting articles



A total of 41 articles were included in the final review stage. The complete list of articles is shown in Table 2.

Table 2

List of articles for final review

Article identifier	Author and Date		The main subject of the article	Stakeholder identified	Expected Value/benefit from Blockchain
A01	Johnston et al., 2007	(Johnston et al., 2007)	Assessing the Value of Personal Health Records (PHRs)	Patients, payers, providers, and employers.	Not mentioned
A02	Idri et al., 2016	(Idri et al., 2016)	Evaluating the Software Product Quality of Pregnancy Monitoring Mobile Personal Health Records	Patients, medical institutions, hospital, laboratory	Not mentioned
A03	Ruotsalainen & Blobel, 2018	(Ruotsalainen & Blobel, 2018)	Calculating Privacy and Trust in pHealth Ecosystems	Users (patients), service providers such as regulated healthcare providers, unregulated healthcare providers, ICT service providers, researchers, and industry organizations.	Not mentioned
A04	Gagnon et al., 2016	(Gagnon et al., 2016)	Adoption of Electronic Personal Health Records in Canada	Six groups: patients, ePHR administrators, health care professionals (nurses and physicians), organizations interested in health technology assessment and development, government health agencies, and researchers.	Not mentioned
A05	Dixon et al., 2009	(Dixon et al., 2009)	Assessing HIE stakeholder readiness for consumer access	Patients, policymakers, developers, providers	Not mentioned
A06	Lopes et al., 2015	(Lopes et al., 2015)	Challenges and Opportunities for Exploring Patient-Level Data	Patients, pharmaceutical companies, researchers, commercial stakeholders	Not mentioned
A07	Hübner et al., 2020	(Hübner et al., 2020)	Clinical Information Systems	Patients, researchers, government, institutions providing medical services	Not mentioned
A08	Ennis et al., 2014	(Ennis et al., 2014)	electronic Personal Health Record for people with severe and enduring mental health problems	Government (England Department of Health), researchers, patients,	Not mentioned
A09	Van Brunt, 2017	(Van Brunt, 2017)	Establishing a systematic approach to improving social and physical determinants of health	Community planners, beneficiaries of healthcare and insurance services, public and private organizations, and non-governmental organizations	Not mentioned
A10	Cimino et	(Cimino et	Consumer-mediated	Patient, payer, service	Not mentioned

	al., 2014	al., 2014)	health information exchanges	provider,	
A11	Staunton et al., 2021	(Staunton et al., 2021)	Data protection, data management, and data sharing	Health data has these stakeholders: government, policymakers, investors, health professionals, researchers, and patients.	Not mentioned
A12	Vlahou et al., 2021	(Vlahou et al., 2021)	Data Sharing Under the General Data Protection Regulation	Patients, legislators, legal officers, scientists	Not mentioned
A13	Wynia & Dunn, 2010	(Wynia & Dunn, 2010)	Practical and Ethical Issues for Patients and Physicians Using Personal Health Records	Patients, doctors, buyers, policymakers, large companies for their employees	Not mentioned
A14	Siek, 2018	(Siek, 2018)	Understanding User Needs in the Design Process of Personal Health Systems	The patient, the patient's family, health professionals	Not mentioned
A15	Cijvat et al., 2021	(Cijvat et al., 2021)	Finding Factors for the Development and Implementation of Patients' Access to Electronic Health Records	Patients, health professionals, doctors, policymakers, health organizations	Not mentioned
A16	Abd-alrazaq et al., 2019	(Abd-alrazaq et al., 2019)	Factors that affect the use of electronic personal health records among patients	Patient, researchers	Not mentioned
A17	Fernández-Alemán et al., 2013	(Fernández-Alemán et al., 2013)	An Analysis of Functionality of Free Web-based Personal Health Records	Patients, doctors, laboratories, radiology	Not mentioned
A18	Ruotsalainen & Blobel, 2021	(Ruotsalainen & Blobel, 2021)	Service User View of the Level of Privacy and Trust in pHealth Systems	The user (patient), platform operators, and unregulated health service providers,	Not mentioned
A19	Bloomrosen & Detmer, 2010	(Bloomrosen & Detmer, 2010)	Implications for Informatics, evidence-based care, and research national policy	Academic and pharmaceutical industry researchers, community researchers, health care providers, patients, policymakers, consumers and caregivers, and the health information technology industry.	Not mentioned
A20	Dixon et al., 2018	(Dixon et al., 2018)	Information technologies that facilitate care coordination	Patients, providers, caregivers, and other patients	Not mentioned
A21	Detmer et al., 2008	(Detmer et al., 2008)	Transformative Tools for Consumer-Centric Care	Public and private sector stakeholders, hospitals, doctor's offices, laboratories, pharmacies and other organizations, patients	Not mentioned
A22	Kim et al., 2019	(Kim et al., 2019)	Investigating data accessibility of personal health apps	Patients, healthcare providers, researchers, third-party developers, and the general public	Not mentioned

A23	Adeleke et al., 2011	(Adeleke et al., 2011)	Knowledge, attitudes, and practice of confidentiality of patient's health records	Patients, health professionals, government medical centers	Not mentioned
A24	Jung et al., 2021	(Jung et al., 2021)	Mechanism Design of Health Care Blockchain System Token Economy	Participants (not only patients but anyone who wants to share their information), compensation institutions (insurance), researchers, infrastructure providers, token exchange markets	can be applied to compensate entities participating in the blockchain data-sharing platform appropriately reducing gaps between the needs of companies, hospitals, and participants (patients) concerning data utilization , with high security and privacy
A25	Bietz et al., 2016	(Bietz et al., 2016)	Opportunities and challenges in the use of personal health data for health research	Personal (individual) data applies to these stakeholders: early adopters who track data about their health, researchers who may use the data as part of their research, and companies who develop devices, applications, or services. They market the tracking itself and collect and manage the data generated.	Not mentioned
A26	Fricton & Davies, 2008	(Fricton & Davies, 2008)	Improve Health Information Exchange and Patient Safety via Personal Health Records	Patients, caregivers, and health providers	Not mentioned
A27	Huh et al., 2013	(Huh et al., 2013)	Wellness self-monitoring tools for older adults	Patients, health care providers	Not mentioned
A28	Heidel et al., 2021	(Heidel et al., 2021)	To study under which circumstances wearable and health app users would accept a compensation payment, namely a digital dividend, to share their self-tracked health data	Patients, health insurance, pharmaceutical or medical device companies, universities	Not mentioned
A29	Curtis et al., 2011	(Curtis et al., 2011)	Adoption, usability, and research for personal health records in Canada	Patients, care providers, and physicians	Not mentioned
A30	Dexheimer et al., 2019	(Dexheimer et al., 2019)	Sharing personal health record data elements in protective custody	Caseworkers, community members and other foster youth, and health care	Not mentioned

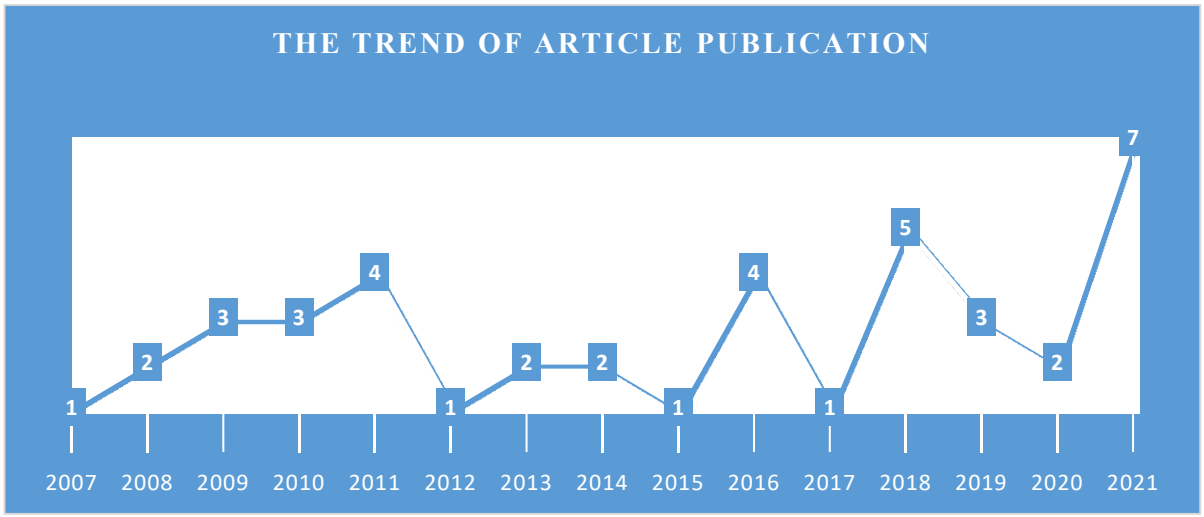
				providers	
A31	Ruiz et al., 2016	(Ruiz et al., 2016)	Use of and Skills Using an Online Personal Health Record in Outpatient Veterans	Patient, doctor, pharmacy	Not mentioned
A32	Eccher et al., 2020	(Eccher et al., 2020)	Integrated and evolving care model for patients' empowerment and data repository	Patients, research institutes, private IT companies, pharmacies, hospitals	Not mentioned
A33	Stroetmann et al., 2011	(Stroetmann et al., 2011)	Role of device-level interoperability in promoting health	Policymakers, regulators, suppliers, health care providers, health professionals, patient representatives, industry, researchers	Not mentioned
A34	Wilcox et al., 2009	(Wilcox et al., 2009)	Using Personal Health Records for Automated Clinical Trials Recruitment	Researchers, patients, doctors treating the patient,	Not mentioned
A35	Hargreaves , 2010	(Hargreaves, 2010)	Benefits of electronic personal health records for providers and patients in rural America	Patient, Labs, Radiology, Pharmacies, Other PHRs, Medical Devices, Physicians, Hospitals, Claims Companies	Not mentioned
A36	Weitzman et al., 2012	(Weitzman et al., 2012)	Sharing personal health record data for care improvement and public health	Patients, providers of health services outside the hospital,	Not mentioned
A37	Sobhkhiz Koozeh kanan et al., 2021	(Sobhkhiz Koozeh kanan et al., 2021)	Determining the needs of the beneficiaries of the athletes' medical information management system	Athletes, sports health service providers, sports medicine research centers	Not mentioned
A38	Hayavi-Haghighi et al., 2019	(Hayavi-Haghighi et al., 2019)	Requirements and challenges of using personal health records	Patients, managers, and care providers	Not mentioned
A39	Moeil Tabaghdehi et al., 2018	(Moeil Tabaghdehi et al., 2018)	Determining the specification of Data Set for Major Thalassemia Patients	Patients, health professionals, doctors	Not mentioned
A40	Ahmadi et al., 2011	(Ahmadi et al., 2011)	The Role of Personal Health Records and information technology in the Future health care System	Patients, doctors, and nurses	Not mentioned
A41	Tanhapour & Safaei, 2017	(Tanhapour & Safaei, 2017)	Design and modeling of personal health record system based on health social network	Patients or regular network users, care providers and organizations, service delivery systems	Not mentioned

The trend of published articles

The publication trend of the selected articles for the final review is illustrated in Figure 3. The search for articles was conducted within the time range from 2010 to 2022. However, for the richness of the evaluation, six other articles were added to the study using the snowball method (reviewing the references of the final articles) in the review of the full text. As shown in Figure 4, the most significant number of articles is related to 2021. Generally, the published articles have no clear trend (upward or downward). Nevertheless, every few years, attention has been paid to the discussion of stakeholders (years 2011, 2016, 2018, and 2021).

Figure 4

The trend of published articles



Identified Stakeholders

In all the reviewed articles (n=41), the patient or individual was mentioned as the primary stakeholder. Table 3 lists the terms found in the articles to refer to it. In most PHR definitions, the word "individual" is used, but as seen in Table 3, researchers used the term "patient" in their articles. According to the definitions, we use "individual" to indicate other titles with the same meaning. The following stakeholders are "researchers" and "research centers." The next stakeholder mentioned in the articles is the "health care provider." To define the scope of this group, better to define this term first: "Medical or osteopath doctor, podiatrist, dentist, chiropractor, clinical psychologist, optometrist, nurse practitioner, nurse-midwife, or a clinical social worker who is authorized to do so by the state and to practice within the scope of his practice as defined by state law or a Christian Science practitioner (Who Is Considered a Health Care Provider/Practitioner? | People & Culture, n.d.). According to this definition, the stakeholders mentioned in the articles under the titles of "health care providers, health services," "health experts," and "doctors and nurses" are all included in the "health care provider" category.

Other groups mentioned in the articles include policymakers and macro decision-makers, which were referred to in nine articles and will be categorized as "policymakers" in Table 3. Health IT service providers and developers were mentioned 12 times as another group of stakeholders. Public and private medical institutions and hospitals were referred to as "hospitals" nine times. The government and pharmaceutical companies were each mentioned twice. Compensation institutions and insurance were cited four times collectively. Additionally, the patient's family, representatives, and caregivers were mentioned five times, pharmacies four times, and laboratories and radiology three times. Finally, business stakeholders, ePHR managers, infrastructure providers, and the token exchange market were mentioned once each. The results from Table 2 indicate that only one study (A24) discussed the values Blockchain can bring to stakeholders.

Table 3

Categories of identified stakeholders

Stakeholder	Indicator	Abundance in articles	Articles that have referred to it
Patient	Individual	35	All articles except the following articles
User		3	A03, A18, A41
Participants (not only patients but anyone who wants to share their information)		1	A24
Early adopters tracking their health data		1	A25
Athletes		1	A37
researchers and research centers	Researchers	17	A03, A04, A06, A07, A08, A11, A12, A16, A19, A22, A24, A25, A28, A32, A33, A34, A37
Health care providers, health services	Health care provider	16	A01, A03, A10, A18, A19, A20, A22, A26, A27, A29, A30, A33, A36, A37, A38, A41
Health professionals		7	A04, A11, A14, A15, A23, A33, A39
Doctors and nurses		11	A04, A13, A15, A17, A18, A29, A31, A34, A35, A39, A40
Policymakers and macro decision-makers	Policymakers	9	A05, A09, A11, A12, A13, A15, A19, A33, A38
Institutions providing medical services	Hospitals	4	A02, A07, A09, A15
hospitals		5	A02, A21, A23, A32, A35
Government and government agencies	Government	5	A04, A07, A08, A09, A11
Health IT service providers and developers	PHR software providers	12	A03, A04, A05, A09, A19, A21, A22, A25, A32, A33, A35, A41
pharmacy	Pharmacy	4	A21, A31, A32, A35
Insurance company	Insurance company	4	A35, A09, A24, A28
Laboratory and radiology	Laboratory and radiology	3	A02, A21, A35
Business stakeholders	Business	1	A06

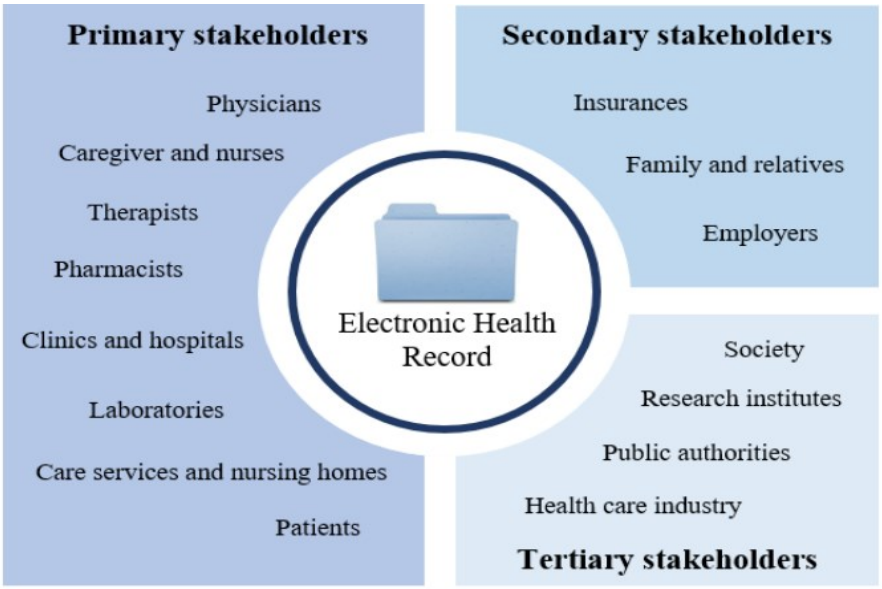
	stakeholders		
The family and representative of the patient and caregiver,	Representative of the patient	5	A14, A19, A20, A26, A33
Society and other patients	Society	4	A20, A21, A22, A30
PHR managers	PHR managers	1	A04
Pharmaceutical companies	Pharmaceutical companies	2	A06, A28
Infrastructure provider	Infrastructure company	1	A24
Token exchange market	Token and cryptocurrency service providers	1	A24
Employers	Employer	1	A01

Beinke et al. (2019) identified and grouped the stakeholders of EHRs. This article can use a similar category since PHR is similar to EHR. The authors of this article got an idea from the categorizing of Beinke et al. (2019) (Figure 5).

The first category is the stakeholder who uses it directly and is its user somehow. The second category is mediated and influenced by usage results, and the third group indirectly benefits from this possibility. Perhaps it would have been better if Figure 4 was drawn as circles around the electronic health record. Efforts have been made to classify stakeholders and simplify their identification and management. According to Mainardes et al. (2012), stakeholders can be classified based on the levels of an attribute, such as power, legitimacy, and urgency, or based on the stakeholder's potential to harm or cooperate with the organization (Savage et al., 1991). Stakeholders can also be divided into primary or secondary groups (Cleland, 2008).

Figure 5

Overview of stakeholder groups (Beinke et al., 2019)



In the research of Beinke et al. (2019), the providers of EHRs were excluded from the study because their interests are seen in the needs of their customers (other stakeholders). Software companies that provide these services receive their fees directly (producers of PHR software). However, we consider this group as a stakeholder. Due to blockchain technology, PHRs and overcoming health record problems will lead to greater acceptance and, consequently, more benefits for these software producers. To better show the categorizing, instead of drawing a figure, we used a table (Table 4). As shown in Table 3, in the "Indicator" column, there is a title representing several stakeholder groups. Among the items mentioned under the title of stakeholder in this table, "employer" was removed from the final list because it somehow includes the hospital or the government (private or public sector). "ePHR Administrators" was also removed from the definitive list of stakeholder because it is in the system users category. "Commercial stakeholders" were also removed from the final list because they are companies providing software and infrastructure services and are another part of the stakeholders (for example, private hospitals). In the final list, we distinguished between the stakeholders who directly benefit from the Bb_PHR implementation (they are the users of this system) and those who indirectly have such a relationship (the group that uses the information of this system and the group that is benefited from its effects).

Table 4

Bb_PHR stakeholder grouping

No	Stakeholder	User and direct relation	User of data	User of effects	Financial benefits
1	Individual	✓	✓	✓	✓
2	Researchers		✓		
3	Health care provider	✓	✓		
4	Policymakers		✓	✓	
5	Hospitals	✓	✓		
6	Government		✓	✓	
7	Bb_PHR software providers				✓
8	Pharmacy	✓			
9	Laboratory and radiology	✓			
10	Patient representative	✓			
11	Society			✓	
12	Insurance company		✓		
13	Pharmaceutical companies		✓		
14	Infrastructure companies				✓
15	Token and cryptocurrency service providers				✓
Sum		6	8	4	4

Conclusion

According to the research conducted by the authors of this article, this is the first systematic review on identifying stakeholders of PHR based on Blockchain. An extensive search was born for this purpose, and gray literature was also used in the analyses. In this systematic review, the stakeholders of PHR were found according to the mentioned articles.

The only stakeholder that is recognized in this review and is exclusively related to blockchain technology is "token and cryptocurrency service providers," so as the final goal of improving the PHRs system is to increase adoption based on excluding barriers and adding incentives, we propose for future research to investigate the relation between "token and cryptocurrency service providers" and other stakeholders, a business model for health data market. Meanwhile, studying such a market's legal and ethical issues is essential.

The results show that despite the use of Blockchain in EHR and PHR, little attention has been paid to the way the benefits of this technology are related to those who benefit from it. As shown in Table 4, eight stakeholders use the data. Blockchain leads to better data protection and the provision of more complete and better quality data by improving data interoperability and integrity for the stakeholders of that area (Individuals, researchers, health care providers, policymakers, hospitals, government, Insurance companies, and Pharmaceutical companies). The same is the case with financial interests. Four stakeholder groups will benefit from economic benefits (in the form of cost reduction or buying and selling of individual health data), all due to the use of Blockchain in personal health records.

Using blockchain technology in PHRs can overcome some challenges facing the acceptance and use of this type of health record. Knowing the stakeholders of the PHRs based on blockchain technology can effectively increase the approval of PHRs. By paying attention to all the stakeholders simultaneously and creating benefits/values (visible and invisible) for them, it is possible to achieve such a system's maximum efficiency and effectiveness.

Conflict of interest

The authors declare no potential conflict of interest regarding the publication of this work. In addition, the ethical issues including plagiarism, informed consent, misconduct, data fabrication and, or falsification, double publication and, or submission, and redundancy have been completely witnessed by the authors.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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Bibliographic information of this paper for citing:

Khajouei, Hamid; Taghavifard, Mohammad Taghi; Amiri, Maghsoud & Raeesi Vanani, Iman (2024). Identification of Stakeholders in Personal Health Records Using Blockchain Technology: A Comprehensive Review. *Journal of Information Technology Management,* 16 (2), 191-205. https://doi.org/10.22059/JITM.2024.366017.3498