

Analysis of Research in Adoption of Person-Centred Healthcare Systems: The Case of Online Personal Health Record

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Abstract

Although the personal health record (PHR) has enormous potential to ameliorate both documentation of health-related information and care of individuals, it has not been adopted as originally expected. The purpose of this paper is to analyse research studies in PHR adoption and provide a comprehensive taxonomy of the factors affecting PHR adoption. We searched three categories of key terms across nine academic databases and identified an initial set of 7,468 research studies. We filtered papers on the basis of their title, abstract and full text (91 remaining papers) to have relevant PHR adoption research studies. Based on the conceptualisation of adoption factors in the 91 included papers, a list of factors that impacted on PHR adoption was identified and we categorised them into six main clusters. This review is a good starting point for researchers who are interested in adoption of PHR systems. Furthermore, it provides valuable information for healthcare practitioners and PHR system developers.

Keywords

Personal health record, PHR, health information systems, person-centred healthcare systems

INTRODUCTION

Many studies have conducted research on the use of technology and its impacts (Ghapanchi 2012a; Ghapanchi 2012b; Ghapanchi 2012c; Zarei 2010). Health information systems (HIS) offer one of the most important means of modernising and improving healthcare delivery. In the United States, the HIS market grew from \$23 billion in 2005 to \$38 billion in 2009 (Tong 2009). Furthermore, there have been the increasing demands for HIS in developing countries. For example, a major Chinese hospital invested almost \$1.5 billion in developing an electronic patient record system. Among the various HIS applications in healthcare, the electronic medical record (EMR), electronic health record (EHR) and PHR are thought to have the potential to bolster healthcare quality and facilitate communication between users and healthcare providers (Najaforkaman 2013; Tavara 2015). The EMR is an electronic record of an individual's health-related information that is created within a single healthcare organisation, where health data can be gathered, managed and consulted by authorised healthcare practitioners such as clinicians and staff (Hsiao et al. 2010). The EHR, conversely, is a record of an individual's health-related information which conforms to nationally recognised interoperability standards (Häyrinen 2008; Najaforkaman 2014a). The EHR, therefore, can be created, managed and consulted by authorised healthcare practitioners across more than one healthcare organisation (Najaforkaman 2014b; Randeree 2007). The PHR is an electronic system through which individuals themselves can access, manage and share their health-related information with healthcare practitioners (Baird 2011; Chan 2009). This definition shows that individuals can use the PHR system to collect their own personal health information and medical history in one integrated system which is accessible from anywhere by authorised persons.

Although some research studies have shown the benefits of PHR systems in healthcare (Baird 2011; Chan 2009), other research suggests that PHRs have not been adopted as originally expected. For example, Kim

(2009) conducted a study over a 33-month period on the public health issue management system (PHIMS). They evaluated use and user adoption through system logs, questionnaire surveys and user group meetings. Despite PHIMS being available for free and personal assistance and computers with Internet connections provided without any cost to individuals, only 13 per cent of residents applied the system in their health care. Almost one-half of the users only applied the PHIMS on a single day. Furthermore, in Australia in 2009, the National Health and Hospitals Reform Commission (NHHC) suggested an individual-controlled EHR for every person to improve healthcare productivity and safety (Mooranian 2013; Xu 2014). Although it has been claimed that the Australian healthcare system is one of the best in the world, it has nonetheless faced challenges such as medication errors, fragmented sources of health information, repetition of tests, and growth in chronic illness and health workforce resource constraints; the source of these problems was that individuals' expectations were changing towards technology.

If users are to benefit from the application of PHRs, it is crucial to understand the factors impacting on PHR adoption. While there are various studies on PHR adoption that describe some of the PHR adoption factors, none of them provide a comprehensive review of factors in PHR adoption. In response to this, the purpose of this study is to analyse research studies in adoption of PHR and provide a comprehensive taxonomy of the factors affecting PHR adoption.

METHOD

This study was conducted in accordance with a systematic literature review to explore factors impacting on PHR adoption. A systematic literature review focuses on a topic or research question, and aims to identify, evaluate and interpret available empirical research studies (Kitchenham and Charters 2007). We had following steps: (1) finding appropriate research resources; (2) identifying search terms; (3) identifying of relevant studies; (4) study selection; (5) data synthesis; and (6) collating, summarizing, and reporting results. Many studies have applied this method to conduct systematic review (Amrollahi 2013; Ghanbarzadeh 2014; Ghapanchi 2011a; Ghapanchi 2011b; Ghapanchi 2008; Kosman et al. 2013).

Resources Searched

Science Direct, Scopus, ProQuest, PubMed, IEEE Xplore, ACM Digital Library, Association for Information Systems electronic library, SpringerLink, and Thomson Reuters' Web of Science became nine databases of choice in this systematic review. They provided access to studies from various fields, including engineering, healthcare, health informatics, human-computer interaction, computer science, psychology, and other areas.

Search Terms

We applied three major categories of search terms. The first category emphasizes different PHR terms and definitions such as "personal health record", "PHR", "personal electronic health record", "personal medical record", "individual health record", "patient-held medical record", and "personally controlled health record". The second category focuses on adoption terms and concepts such as "adoption", "acceptance", "use", and "behavioural intention". The last category is based on impact terminologies such as "impact", "influence", "effect", "affect", and "impress". In fact, we were looking for relevant studies that assessed different factors affecting PHR adoption.

Inclusion/Exclusion Criteria

The following selection criteria were applied: (1) we selected papers have been published before June 2014; (2) we included research studies that were published in English-language; (3) articles, conference papers were included in our searches; (4) reports, business articles, and news media reports were excluded from our study; (5) we included papers focused on PHR systems, and other studies related to computerized systems in healthcare such as EMR and EHR were excluded from this systematic review; (6) we included PHR studies that focus on factors that affect adoption of PHR systems.

Study Selection Process

The first phase included searching for keyword terms on nine databases. Consequently, 7,468 primary papers were recognized for initial screening. Following this, we excluded papers on the basis of their titles (6,253 papers excluded; n=1,215). For instance, in the PubMed database, we applied the Advanced Search section of the online database and inserted the three groups of keyword terms and hit the search button. We read the titles of all the articles and excluded them on that basis. Phase 3 involved excluding papers on the basis of their abstracts (666 papers excluded; n=549). In this phase, we read all the abstracts of the downloaded studies and

retained all relevant papers. In the final phase, duplicated papers were omitted and we read the full texts of the remaining papers (458 articles excluded; N=91). As a result of these phases, we had 91 relevant articles based on factors affecting PHR adoption.

Data Analysis

Based on definitions and terminologies of adoption factors in the 91 selected studies, a list of factors impacting on PHR adoption was identified. At this stage, some of the factors were merged according to their meaning and explanation of adoption. Following this, we attempted to categorize the adoption factors, extracted from the literature, into meaningful clusters in order to produce a comprehensive taxonomy. To complete this stage, the authors went through the review sources in various research areas such as PHR development, policy and standard, PHR usage in healthcare, and medical research. The authors assigned a suitable label to each identified factor according to its terms and terminologies in the previous research studies. After finishing the labelling process, we had three iterative rounds to achieve a better classification of adoption factors impacting on PHR adoption. Some labels were renamed or merged in the second and third rounds to arrive at the final taxonomy. Finally, we identified six labels: individual, psychological, health-related, legal, environmental, and technological.

RESULTS

In this section, we present the demographic characteristics of the research studies in PHR adoption and also propose six clusters of factors affecting PHR adoption.

Theories

From 91 included studies in the final assessment, only 24 papers applied one or more theories to frame the research or clarify their results. Many research studies on PHR adoption have not used any theories. The theories and model that have been used in PHR adoption studies are: social cognitive theory, integrated model of behaviour prediction, unified theory of acceptance and use of technology (UTAUT), individual and family self-management theory, the systems development life cycle, the systems research organizing model, technology acceptance model (TAM), theory of reasoned action (TRA), theory of planned behaviour (TPB), motivational model, model of personal computer utilization, innovation diffusion theory, self-determination theory, DeLone and McLean's model, grounded theory, protection motivation theory, task technology fit, self-regulation theory, and the information systems continuance model. According to Figure 1, the majority of researchers that used theories in their paper, applied TAM, UTAUT, grounded theory, and social cognitive theory.

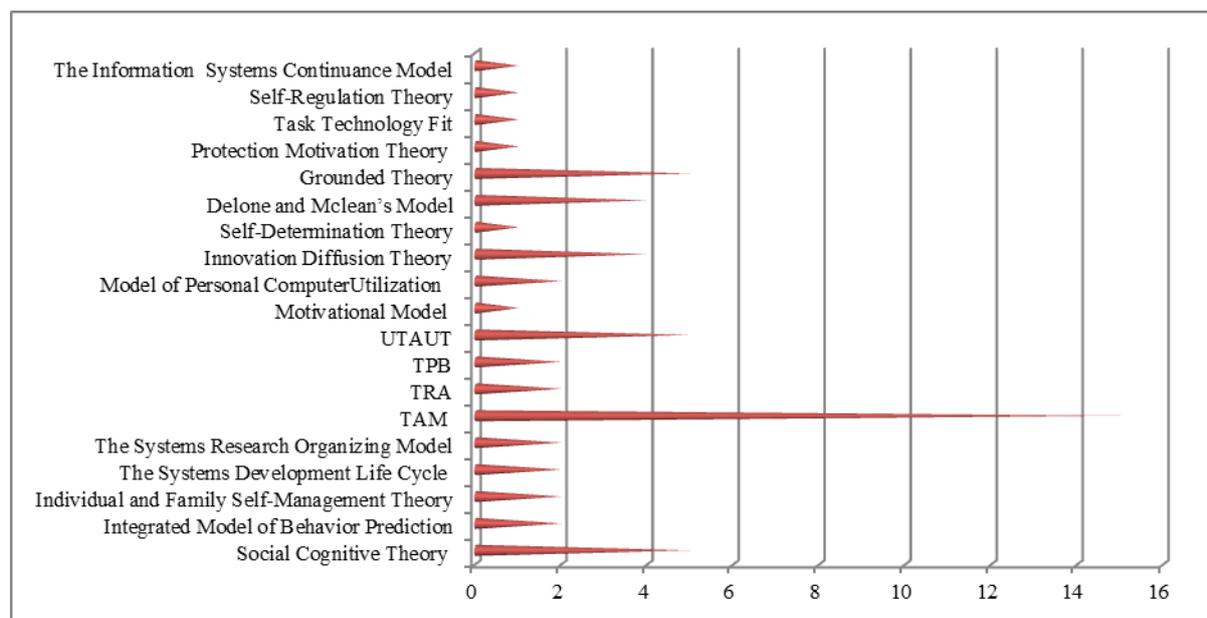


Figure 1: Distribution of papers over different theories

Different PHR Terminologies

From 91 extracted papers, we found different terminologies for PHR systems. The term ‘personal health record’ was used in 73 PHR adoption papers. Furthermore, various terms were found that reflected PHR systems, such as ‘personally controlled electronic health records (PCEHR)’, ‘integrated personal health record’, ‘interactive preventive health record (IPHR)’, ‘personal health information management system (PHIMS)’, ‘electronic symptom reporting (ESR)’, ‘interpersonal health record’, ‘electronic patient records (EPR)’, ‘patient-held health records’, ‘web-based self-referral system’, ‘patients’ electronic personal health records’, ‘personal electronic health records’ and ‘health self-management system’.

Year of Publication

This section provides the statistical trend of literature on adoption of PHR systems among users. Figure 2 shows the distribution of relevant papers per year. The trend line presents an increasing interest from the academic community in the PHR adoption research area, in particular after 2007. It suggests that the adoption of PHR as a major person-centred healthcare system has caught the attention of researchers as a major concern in healthcare. In spite of annual fluctuations in the number of studies, the overall trend is strongly positive and this shows the increasing interest in this field. This interest is reflected in the literature which is gradually outlining innovative approaches in individuals’ healthcare and the potential benefits for consumers.

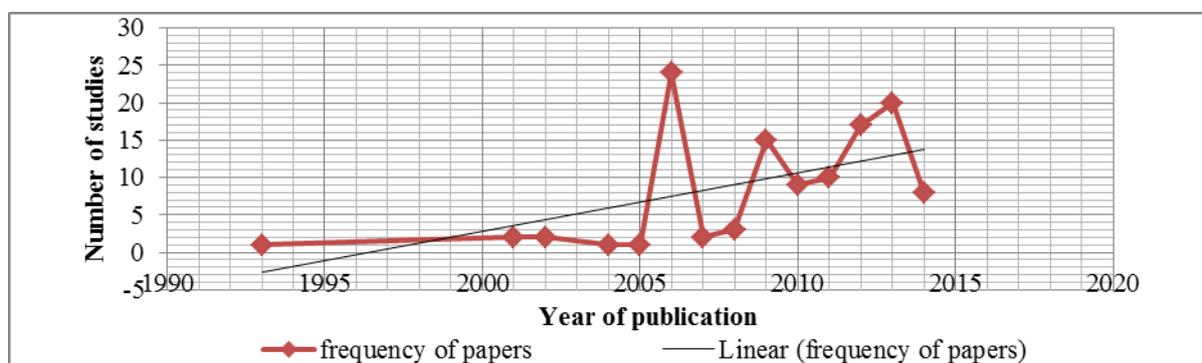


Figure 2: Frequency of papers per year

Research Approaches

Out of 91 studies included in this paper, 69 conducted experimental research. Among them, 19 studies applied qualitative research approaches and 38 papers used quantitative methods. Twelve research studies used mixed methods approaches (combination of qualitative and quantitative approaches) (see Figure 3). It can be shown that studies in this research area mainly concentrate on individual characteristics and cause-effect relationships which is why quantitative research approaches are very popular in PHR adoption research.

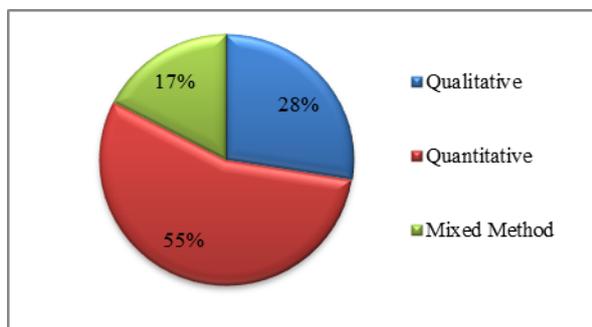


Figure 3: Research approaches

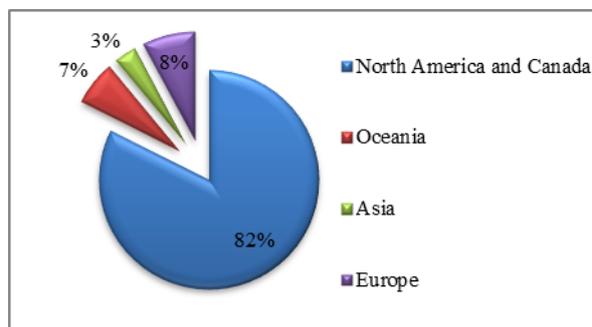


Figure 4: Frequency of papers per continent

Geographic Distribution of Studies

Figure 4 gives a breakdown of the frequency of papers published in different continents. Most of the research studies in PHR adoption are conducted in North America and Canada with 82%. Europe is the next most prolific source of research studies with 8%, followed by Oceania with 7% and Asia with 3%. While the affiliation of a

research study to a specific university or organisation in a country does not necessarily mean that the context of the study concerns the same country or even continent, it might provide insights to a limited extent.

Main Clusters of Factors Affecting PHR Adoption

In this section, we identify facilitators and barriers that have impacted the adoption of PHR systems and categorise these factors into six categories: individual, psychological, health-related, legal, environmental and technological.

Individual Factors

Individual factors clarify individual attributes that consist of some important factors such as: age, gender, marital status, race/ethnicity, higher education level, employment status, higher income, higher e-health literacy, higher health numeracy, higher skills and higher verbal ability. Figure 5 shows the frequency of individual factors that were evaluated in the included studies.

For example, e-health literacy plays an important role in PHR adoption. The results of 27 studies evaluated the e-health literacy factor. E-health literacy includes traditional literacy, health literacy, information literacy, scientific literacy, media literacy, computer literacy and Internet literacy (Logue 2012). Health literacy completely depends on a user’s ability to understand and act on health-related information. PHR users should be able to obtain, process and understand at least an elementary level of health education. Computer and Internet literacy is another important ability which enables users to update PHRs and interact with the PHR system (Wen 2010). Therefore, users with greater computer literacy are more likely to adopt PHR systems (Kahn 2009; Noblin 2012; Wen 2010). Moreover, Tulu (2012) applied mixed methods research and identified that, overall, PHR systems are used more frequently by older patients than younger ones. On the other hand, Wen (2010) concluded that patients aged 65 and over perceived less value in PHR usage and therefore less likely to apply a PHR system in their health care than younger patients.

Psychological Factors

The next category, psychological factors, is composed of various factors such as self-efficacy, attitudes, outcome expectations, self-management perception, technology anxiety, autonomy, lack of trust, personal innovativeness, information-seeking preferences, concerns about sharing information, perceived complexity of treatment and incentive motivation. Figure 6 shows the frequency of psychological factors that were evaluated in the studies included.

For example, self-efficacy is one of the most important psychological factors impacting on PHR adoption (Liu 2013). Studies have shown that PHR users who demonstrated a higher level of confidence in managing their health (activated users) were more likely to adopt the system. Self-efficacy is a key factor for behavioural change. Behavioural change in social science is not an easy task. In PHR adoption, change management concepts involve healthcare providers and consumers (individuals). There must be enthusiasm for change. Individuals need to understand how PHR systems can improve their quality of health care by offering various functions to facilitate information management. Providers need to trust the information in PHRs, adjust their workflows and develop different mind-sets (Kahn 2009).

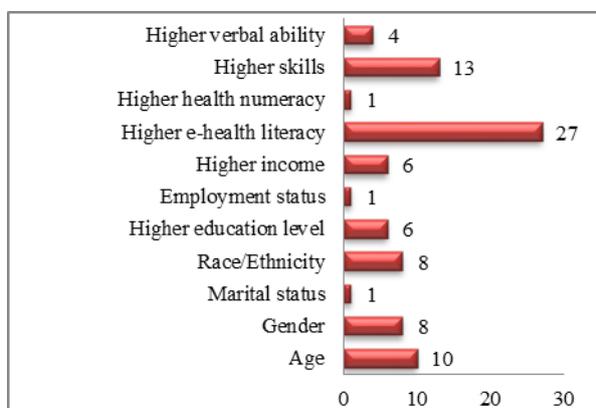


Figure 5: Frequency of the individual factors in the PHR adoption studies



Figure 6: Frequency of the psychological factors in the PHR adoption studies

Moreover, PHR users paid a lot of attention to the perception of autonomy and welcomed better access and control of their health-related information (Liu 2011). Though autonomy was highly valued, it was perceived as a double-edged sword: there were concerns about the responsibility of maintaining the accuracy and integrity of health-related information. PHR consumers wanted assurances that inaccurate and outdated medical information that they identified and modified in their digital PHR would be updated in all relevant data sources. PHR users also expressed concerns about the consequences of intentionally or inadvertently altering PHR contents and were additionally worried about applying the system's tools for annotation when adding their own health-related information. The concerns around individual annotation among PHR consumers was echoed by health providers who framed this anxiety in terms of risk for data liability, accuracy, completeness and quality of care (Weitzman 2009).

Health-Related Factors

The third category, health-related factors, is composed of three factors: health consciousness, health status (limited physical and cognitive abilities) and health management training. It focuses on factors impacting on the health status and health behaviour of individuals. Figure 7 shows the frequency of health-related factors that were evaluated in the studies included.

For example, health consciousness is one of the important factors that impact on PHR adoption (Lafky 2008). Users who have a 'wellness-oriented' lifestyle worry about nutrition, fitness, stress, environment, medical history and their treatment processes (Assadi 2009). These kinds of consumers take responsibility for their health and are excellent users of PHR systems. They believe that a specific health problem can be potentially life-threatening (perceived severity). In general, if individuals are susceptible to a specific health problem, they try to behave healthily to decrease the risk of the health problems. Individuals are more likely to have healthy behaviours if they perceive a particular health problem as serious. Therefore, it is claimed that PHR users who believe that the severity of the health threat is high are more likely to adopt the system (Assadi 2009; Laugesen 2013). In addition, the majority of studies claimed that individuals' health status has a direct impact on PHR adoption. For example, individuals with physical and cognitive impairments may recognise the value of gathering, organising, monitoring and managing health-related information, but may be unable to complete a particular task without assistance. Lober (2006) claimed that cognitive function is a major problem for many users over the age of 65 and impacted on their PHR usage. Memory problems impacted on 11 per cent of women over the age 65; 15 per cent of male users in that age group had a moderate to severe disability.

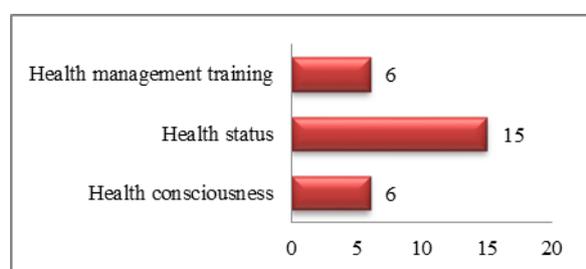


Figure 7: Frequency of the health-related factors in the PHR adoption studies

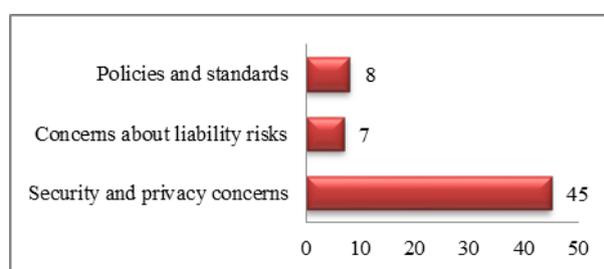


Figure 8: Frequency of the legal factors in the PHR adoption studies

Legal Factors

Health-related information is managed by individuals in the PHR system, and this information could therefore be vulnerable in terms of confidentiality, integrity and availability concepts. This category is composed of legal issues such as security and privacy concerns, concerns about liability risks, and policies and standards. Figure 8 shows the frequency of legal factors that were evaluated in the included studies.

Security and privacy concerns are one of the main barriers to PHR adoption (Panchal 2013). Privacy threats concern the disclosure and subsequent use of an individual's information. Individuals rely on the perceived control over their health-related data disclosure as a signal to evaluate the benefits and potential privacy threats they may achieve from using the PHR system. The privacy invasion experience from using PHR reflects a user's direct experience of being a victim of privacy attack. These kinds of privacy invasions impact on PHR users' context-specific privacy beliefs and PHR adoption. PHR users who regularly experience threats to their privacy may apply trust as the major basis to evaluate privacy risks, and give less consideration to perceived privacy control. A high level of privacy control over information in the PHR system could assure individuals that healthcare providers are less likely to behave opportunistically, causing them to make more satisfactory judgments about the advantages of PHRs. For instance, individuals perceived PHRs as a useful system if they

had control over sharing health-related information with their physicians and family members. Conversely, they perceived high privacy risks if they felt that they had little control over health-related information collated in the PHR system (Li 2014).

Environmental Factors

The environmental category is composed of various factors such as social influence, physician–patient relationship, market forces, workflow models, insurer issues (private insurers) and geographic location. Figure 9 shows the frequency of environmental factors that were evaluated in the included studies.

For example, social influence is an important factor that identifies social power to change the attitudes or behaviour of an individual in a particular direction. In fact, an individual’s actions, reactions and thoughts can be impacted by other individuals. In this case, communication tactics can play an important role in motivating people to adopt PHR. Communication tactics are the ways in which a person hears about the PHR system through various channels such as Internet web pages, email messages, posters and television advertisements (Agarwal 2013). Healthcare providers and policymakers often provide marketing messages to raise awareness of the values of PHRs to increase adoption rates of the systems. Individuals who claim to have been more exposed to communication tactics should be more aware of the advantages of PHR systems (Agarwal 2013). If individuals perceive that PHR systems’ functionality have value and they are aware of PHR benefits to their health care, higher intention to use the system should result.

Furthermore, an individual’s insurance status at the time of using a PHR is important. Insurance status can be grouped into Medicare, Medicaid, private and self-pay. Individuals with Medicare and Medicaid insurers were less likely to adopt PHR systems. They had concerns about privacy because of unclear privacy policies, the fact that insurers' employees could access an individual’s self-reported data, and concerns about how insurers might use that information to restrict coverage, raise premiums or limit benefits. Patients also had concerns about insurers’ sponsorship of PHR systems. In general, patients do not trust sharing personal health-related information with insurers, especially Medicare and Medicaid (Grossman 2009). On the other hand, patients that use private insurers are more likely to adopt a PHR and share their health-related information because of greater feelings of trust compared with Medicare and Medicaid, the existence of more security and privacy principles in private insurance systems and comprehensive policies and standards (Yamin 2011).

Technical Factors

The final category, technological factors, is composed of various factors such as usefulness, ease of use, alternative strategies, interoperability, trialability, observability, availability, functionality, lack of access to the Internet and technical support. Figure 10 shows the frequency of technological factors that were evaluated in the included studies. For example, a majority of researchers found that perceived usefulness and ease of use of PHR systems are important factors that can have a positive impact on PHR adoption. If consumers believe that applying PHRs in their healthcare can help them to improve their quality of care, they are more likely to adopt the system (Logue 2013).

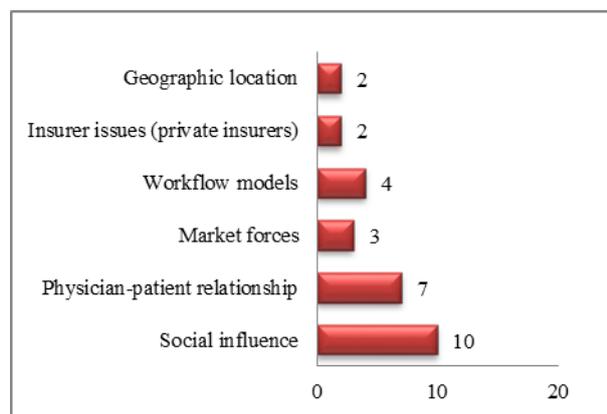


Figure 9: Frequency of the environmental factors in the PHR adoption studies

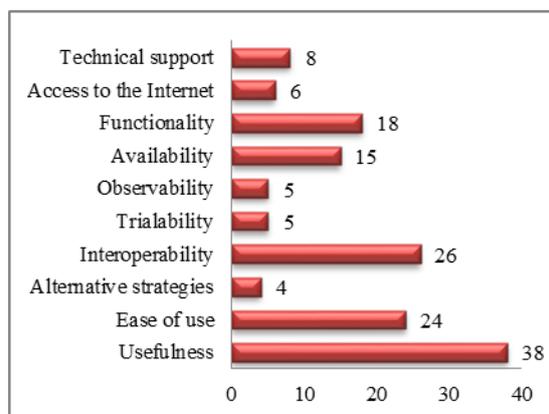


Figure 10: Frequency of the technical factors in the PHR adoption studies

PHR systems should bring various benefits for individuals such as reducing the amount of time spent completing documentation, facilitating communication between individuals and doctors, improving the accuracy

and integrity of health-related information, increasing the overall safety of individual care, reducing the complexity of individual treatment and reducing the number of times that an individual asks the same question (Witry 2010). According to the literature, ease of use or the level of complexity of a PHR system has a significant impact on system adoption. For example, medical jargon and advanced language used in some PHR systems can be so complex that patients are unable to interpret the medical information (Liu 2011). Additionally, interoperability is an important technological factor that impacts positively on PHR adoption. It refers to the capacity of PHR systems to communicate with other health-related systems (EMR/EHR) and to connect healthcare providers with individuals through a shared information network (Lafky 2008).

DISCUSSION

Adoption of PHR systems is a dynamic research area and this systematic literature review indicated that interest in this research area is growing. While we admit that the increase in the number of papers in adoption of PHR systems might have happened because of the general increase in the number of publications, we refer to the applications of these systems in real settings that have been analysed through realist review. The majority of research studies have not used a theoretical framework. In order to address PHR adoption factors more precisely, future research studies will need to be conducted which are based on sophisticated statistical techniques. There are some major adoption theories in the field of information systems that could provide significant antecedents to improve system adoption. There are some theories from different research concepts that can be applied to adoption, such as the health belief model (HBM) which comes from psychology and health concepts; it elaborates on some important factors such as perceived risk, perceived seriousness, motivation and cues to action. Consequently, future studies should seek to include additional theoretical constructs in PHR research.

This review identified six major clusters of factors that impact on PHR adoption. Research in each of these areas is at diverse levels of maturity and the theoretical framework adopted and the research paradigm used will naturally differ accordingly. Based on prior literature and the results of this review, there is a clear emerging need for a research agenda regarding the effects of environmental and health-related factors on PHR adoption such as level of user involvement, environment uncertainty, social network effects, competition, vendor efforts, task-fit issues, geographic location (poor/rich countries), healthcare cultural changes and effects of chronic disease conditions. In addition, more research is needed to assess additional behavioural factors such as user attitude towards information systems, technology readiness, user scepticism, user expectations and interest, behavioural changes, confirmation, feelings of imposition and continuance intention. However, despite the existence of various qualitative and quantitative studies that focus on PHR adoption factors, further research is needed to gain a more detailed understanding of what motivates individuals not only to adopt but to continue using PHRs. Long-term sustainability of PHR system use by individuals is an important subject that was not covered in any of the literature we studied. Sustainability issues include not only positive outcomes from concepts such as adoption, acceptance, satisfaction and usability, but positive individual, behavioural and organisational impacts. Therefore, research should focus on post-adoption (continued use) beliefs and attitudes toward PHR systems.

Finally, this systematic review is a good research source to inform healthcare practitioners about facilitators and barriers to PHR adoption. For instance, PHR papers in the literature have revealed the significant impact of healthcare providers' endorsements and engagement in an individual's use of PHR systems. While PHR systems are created as individual-oriented tools aimed at engaging and empowering consumers, research articles have suggested that engagement should be a reciprocal process: productive interactions between consumers and healthcare providers such as physicians and nurses. Healthcare practitioners and individuals (patients) should apply PHR systems together as partners. In the case of the patient-physician relationship, there are concerns that current health-related documentation would make it problematic for patients to successfully understand and suitably interpret their health-related data. Patients were able to access their health records based on a PHR concept, but most patients were unable to fully understand its content. This can generate substantial anxiety and concerns in patients and have a direct negative impact on the physician-patient relationship. Moreover, this review informs PHR system developers and IT professionals about the technological factors impacting on PHR adoption. Various functions should be integrated into comprehensive PHR systems. For example, health-related information functions that measure weight, height, blood pressure, diabetes information, allergies, medication etc. Moreover, some PHR functions focus on connections with EMR systems, health devices, social networks and third-party applications. Complete functionality and data entry, data sharing, data validation and information display features motivate patients to adopt PHR systems. Therefore, system developers and IT can develop various functions for PHRs to make the systems more accessible for users.

CONCLUSION

Although there have been many research studies on the benefits of PHR systems in healthcare and health self-management, some research suggests that PHRs have not been adopted as originally expected. In this review, we provided a systematic literature review of 91 research studies and identified adoption factors that impact on PHR use. These factors were categorised into six clusters. We understand that applying citation-based analysis can lead to a more comprehensive knowledge about PHR. However, due to the large number of papers on PHR, this was beyond the authors' time and resources. Therefore, we chose to use systematic review method suggested by Kitchenham and Charters (2007). The proposed PHR adoption taxonomy can be applied as a valuable guideline for researchers and practitioners, and also has wider implications for policymakers, healthcare providers, PHR system developers, health insurers and IT professionals. The discussion of each category given above offers a comprehensive overview of PHR studies for new researchers in the field of health information systems. Furthermore, healthcare practitioners and PHR system developers may find it helpful to take note of and apply the proposed suggestions in this study to better understand the relevant research studies that could help them solve problems with adoption of healthcare self-management systems.

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