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# **Personal Health Records: Beneficial or Burdensome for Patients and Healthcare Providers?**

*by Melissa Lester, MSW, MS; Samuel Boateng, MS; Jana Studeny MSHI, RN-BC, CP-HIMS and Alberto Coustasse, DrPH, MD, MBA, MPH*

## **Abstract**

Personal health records (PHRs) have been mandated to be made available to patients to provide increased access to medical care information, encourage participation in healthcare decision making, and enable correction of errors within medical records. The purpose of this study was to analyze the usefulness of PHRs from the perspectives of patients and providers. The methodology of this qualitative study was a literature review using 34 articles. PHRs are powerful tools for patients and healthcare providers. Better healthcare results and correction of medical records have been shown to be positive outcomes of the use of PHRs. PHRs have also been shown to be difficult for patients to use and understand, and providers had concerns about correct information transferring to the portals and patients eliminating information from the record. Concerns regarding patient understanding of medical records, legal liability, and the response time required of providers were also identified. For the PHR to succeed in the US healthcare system, assurance that the information will be protected, useful, and easily accessed is necessary.

**Keywords:** electronic health records, healthcare decisions, meaningful use, personal health records (PHRs)

## **Introduction**

The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 encouraged the use of electronic health records (EHRs) through incentives for hospitals in the United States.<sup>1</sup> The goals of EHRs have been promotion of quality healthcare, cost containment, and safety for patients. Personal health records (PHRs), in conjunction with EHRs, are new technological tools that have promoted patients' participation in their healthcare decisions, correction of medical record errors, and increased access to medical care.<sup>2</sup>

For many years, patients have kept paper copies of their medical records, but with this new technology, patients can have their records maintained electronically.<sup>3</sup> PHRs are electronic portals through which patients can acquire and superintend their health records and share this information with authorized persons in a confidential, protected environment.<sup>4</sup>

PHRs became well known through the Meaningful Use (MU) mandate<sup>5</sup> supported by the HITECH Act. This act mandated that EHRs should operate reciprocally throughout the nation's healthcare system and be used in a meaningful manner.<sup>6</sup> MU, which has three stages of objectives, emphasized the use of EHRs to improve quality, safety, efficiency, and health inequality. PHRs were optional in MU stage 1,

and then MU stage 2 mandated that PHRs be offered to patients by their providers. MU stage 3 has an objective to improve health outcomes through quality, safety, efficiency, and access to PHRs as a health management tool.<sup>7</sup> PHRs were included in the second stage under the objective of commissioning patients and their families to be involved in their healthcare.<sup>8</sup> Patients who have accessed their medical records have reported a broader knowledge base of their own health concerns, the ability to communicate more effectively with their physicians, initiation of efforts to improve their health, and decreased utilization of healthcare services.<sup>9</sup> PHRs can help make patients aware of their health conditions, which could initiate changes in their healthcare plan.<sup>10</sup>

PHRs can be tethered or untethered.<sup>11</sup> Tethered PHRs are connected with EHRs, meaning that patients can see data that providers have placed into the PHR. Conversely, untethered PHRs are not connected with EHRs.<sup>12</sup> The use of tethered PHRs has been seen as beneficial because it allows communication between patients and physicians.<sup>13</sup> PHRs have been advantageous for the correction of errors, such as those in medication lists, which has been seen as useful by physicians.<sup>14</sup>

Providers have been uneasy about the potential for legal liability. They are concerned about information provided by patients being placed in the EHR, which has the potential to happen because of interoperability between systems. Providers have questioned whether patient-entered information should be taken into consideration when making medical decisions.<sup>15</sup> Specific groups of patients are protected by the Health Insurance Portability and Accountability Act (HIPAA). Concerns have been raised regarding the protection of sexual health information of adolescents and the need for a proxy to access PHRs.<sup>16</sup> Patients with HIV have also posed challenges because of the need for special protection of the privacy of medical records.<sup>17</sup> The full potential of PHRs, the challenges of implementation, and the best approaches to these complex issues remain to be determined.<sup>18</sup>

The main objective of this study was to analyze the usefulness of PHRs by exploring and determining the disposition and attitudes of patients and providers regarding the utilization of PHRs.

## **Methodology**

The methodology for this study was a qualitative literature review. The Marshall University library in Huntington, West Virginia, was utilized to obtain full-text articles from PubMed, ProQuest, EBSCOhost, and CINAHL. Google was searched when articles could not be obtained from the databases previously mentioned. Key terms used in the search included “personal health records,” “PHRs,” “cost,” and “utilization.” The search was limited to articles published between 2005 and 2015 to ensure that the data were current. All articles researched were in the English language. Original articles, reviews, and research studies including primary and secondary data were incorporated. Relevant articles were selected after a review of the abstracts was performed. The results were gathered from a diverse population ranging from the young to the elderly. Thirty-four resources were selected for this research. Healthcare providers’ views and opinions were also used to write this research article. This literature search was conducted by S.B. and M.L. and was validated by A.C. and J.S., who acted as second readers and also verified that references met inclusion criteria.

The scheme for this literature review followed the conceptual research framework of Yao et al. (2010).<sup>19</sup> The use of this strategy in the current review is appropriate because the emphasis of both studies is to display how new technologies (PHRs) can be useful in healthcare facilities to improve the care of patients. In addition, this methodology has been replicated in previous studies, including studies of the adoption of PHRs, telemedicine technology, and radio-frequency identification (RFID), thereby supporting its internal validity.<sup>20–22</sup> This framework was applied to document the benefits and the barriers related to the implementation of PHRs for both patients and providers. To research problems involving the current use of PHRs in healthcare, it was first necessary to recognize the existing difficulties and issues that impede adoption of PHRs by providers and patients. Figure 1 shows the progression of the use of PHRs in healthcare facilities and by patients, including the benefits and barriers to adoption.

## Results

PHRs have the potential to improve healthcare because they can engage the patient in healthcare decisions by connecting patients to their medical records and physicians through an electronic portal. Krist et al. (2014) conducted a study of eight medical practices that offered PHRs to patients between the ages of 18 and 75.<sup>23</sup> Of the 112,893 patients offered the PHR, 28,910 patients created an account. It took an average of 59.5 days for patients to create an account. Directly offering the PHR to patients was more effective than mailing invitations. More patients with chronic conditions signed up for a PHR than other patients, which was attributed to these patients' having more visits to the physician's office. One-third of patients aged 60 to 69 years created an account.<sup>24</sup>

Environmental barriers, including capital intensity and market forces also have impacted both EHR and PHR adoption. An associated difficulty is that EHRs must not only exist in individual offices and hospitals facilities but must also be able to communicate with PHRs.<sup>25</sup> In a study from the Library Association/National Library of Medicine, Joint Electronic Personal Health Record Task Force was reported that in only 26 percent of the 91 PHR products analyzed were integrated with EHR, 11 percent were both integrated and standalone and 54 percent were stand-alone only.<sup>26</sup> Wang and Biedermann (2012), identified four groups of barriers that would hinder the implementation of EHRs in provider offices were identified. Table 1 displays that the lack of capital resources has been an obstacle that has inhibited the use of EHRs.<sup>27</sup>

Many authors have agreed that both providers and patients encounter difficulties in the utilization of PHRs. Dontje et al. (2014) conducted a study with six adult focus groups who had visited a healthcare clinic within the last three months.<sup>28</sup> The study included 21 participants with an average age of 64 years. Four-fifths of the participants had an undergraduate or graduate degree. The patients had concerns about their ability to access their information, the value and usefulness of access, and security. Patients found value in viewing medical records, updating medical data, contacting providers, and sharing records with other providers. Several of the participants accessed the PHR only once because of difficulty using the system and challenges understanding information.<sup>29</sup>

Hilton et al. (2012) conducted a study of 338 mental health clinic patients on the use of PHRs.<sup>30</sup> This study compared patients who had mental health and substance use issues and patients without these issues. Training was provided regarding PHR use, and patients with mental health or substance use problems benefited from the training, whereas those without the conditions did not. The study found that patients who had some experience using computers had a more beneficial experience than those who did not).<sup>31</sup>

In a report by Nazi (2013), physicians acknowledged that secure messaging was the one omitted piece in the execution of information technology.<sup>32</sup> Secure messaging was an integral part of entry, transmission, patient self-reporting, and patient/provider rapport. A large disparity was found in the use of electronics, practices, generation of instruction, and the impact of productivity. For the PHR system to succeed, proper training and reinforcement for healthcare providers and patients are needed to encourage information distribution and interaction.<sup>33</sup>

A review by Kim and Nahm (2012) established that 75 percent of adults who did not use PHRs were concerned about the confidentiality of their healthcare data in the PHR system.<sup>34</sup> One study noted in the review found insufficient clarity in the privacy policy and consent form sent to breast cancer patients. Security of patient information was a main concern of several focus groups conducted in numerous cities.<sup>35</sup> A concern about low use of new technology among older patients was reported by Lober et al. (2006).<sup>36</sup>

Limitations of health literacy and competency have been a paramount concern affecting the use of PHRs.<sup>37</sup> Weitzman et al. (2009) described a shortcoming of knowledge of health literacy resources on the current opportunities provided by PHRs among urban residents.<sup>38</sup> A cross-sectional study by Yamin et al. (2011) showed that Hispanics and non-Hispanic blacks were less inclined to embrace PHRs than non-Hispanic whites were.<sup>39</sup> Kim et al. (2007) found that the digital divide was related to racial and socioeconomic status (SES) characteristics and that correlations between SES and lower healthcare literacy rates were evident in several areas of discussion.<sup>40</sup>

Kutner et al. (2006) demonstrated that approximately 97 percent of individuals over the age of 65 years had low healthcare literacy, which was correlated with limited insight on diseases.<sup>41</sup> Patients with low health literacy were found to be less informed about medical conditions, exhibited little preventative care, and did not make productive use of the healthcare system.<sup>42</sup> PHR systems are constructed to enlist patients in managing their healthcare plans, but if a system is too complicated for the user to administer, then it will not result in the advancement of healthcare outcomes.<sup>43</sup>

A concern intertwined with patient literacy issues was accuracy of information. Interviews conducted by Witry et al. (2010) found that healthcare providers were apprehensive about the effectiveness of data, interpretation, and understanding of treatment.<sup>44</sup> Providers had concerns regarding whether correct details would be translated into PHRs and were fearful that patients would eliminate information from the PHR to conceal their illnesses.<sup>45</sup> Providers have expressed concerns that without certain restrictions on patient controls, incorrect diagnosis or treatment would occur.<sup>46</sup>

Ancker et al. (2014) conducted a study in New York regarding PHRs and their effectiveness.<sup>47</sup> Surveys were given to 800 adult residents of New York. From 2012 to 2013, PHR use rose from 11 percent to 17 percent, and the percentage of providers who offered PHRs rose from 50 percent to 73 percent. This study found compelling outcomes in the form of patient communication with physicians regarding records of surgeries, medications, immunizations, and allergies. However, health outcomes were not shown to benefit from access to this information.<sup>48</sup>

Table 2 summarizes the pros and cons of the utilization of PHRs by patients and providers.

## Discussion

The study of the benefits and burdens of PHRs for patients and providers exhibited mixed results. The research articles reviewed suggested that the benefits of PHRs were better health outcomes and correction of errors in medical records, such as errors in medications and allergies. Conversely, some articles noted concerns regarding patients' understanding of PHRs and physicians' concerns regarding cost and time constraints associated with responding to e-mails.

As noted above, in one study of 112,893 patients who were offered PHRs, 28,910 accepted and signed up. Limitations included a participation rate of only 25.6 percent and the fact that patients took an average of 59.5 days to access their PHR. One-third of patients aged 60 to 69 years registered for access to their PHR.<sup>49</sup> This finding suggests a combination of discrimination and reluctance on the part of elderly patients to learn to use the technology. Programs have not been established to help patients understand and be able to successfully navigate through the systems. Also, new technology will always be met with backlash from certain individuals regardless of age group.

Dontje et al. (2014) identified that patients preferred to communicate with the physician's office via phone because the PHR was too cumbersome to utilize and because of concerns related to the protection of health information.<sup>50</sup> Finding methods to educate patients on the use of PHRs, while making the PHR easy to operate and ensuring protection of health information, is very important to engage patients in the utilization of these systems and thereby encourage compliance with treatments and medications and educate patients on healthier lifestyles. Educational programs on the use of PHRs should be offered in healthcare settings for PHRs to be broadly adopted by the population.

Another study found that access to PHRs made no difference in health outcomes, although patients' communication with physicians improved in areas regarding medications, immunizations, surgeries, and allergies.<sup>51</sup> This study was limited in that it was conducted with New York residents only and therefore may not accurately depict the entire nation.

Kim and Nahm (2012) identified challenges that impeded patients who wished to access their PHRs from doing so.<sup>52</sup> Lower SES is a barrier that has been pinpointed as an obstacle to accessing PHRs. Elderly or disabled patients also face barriers in the access to PHRs. The study found that the security of information was a concern for many patients.

In the survey conducted by Wang and Biedermann (2012), three capital factors that slowed or prevented EHR implementation included the lack of capital resources to invest, noted by 46 percent of respondents; lack of proven benefit, noted by 15.3 percent of respondents; and the lack of technical infrastructure, noted by 35 percent of respondents. These findings suggested that the same financial and market forces that are impacting EHR also impact in PHR adoption. A meaningful PHR should be integrated with EHRs for HIE however only 26 percent of PHR were found to be integrated only while 54 percent were stand alone.<sup>53</sup>

The findings reported by Kutner et al. (2006) exemplified the fear of many healthcare administrators about older patients' lack of skills to read and understand the information provided.<sup>54</sup> Their low healthcare literacy rate makes it difficult for healthcare providers to promote healthy lifestyles and for patients to understand details of their health. If patients do not understand how to utilize PHRs, healthcare providers would not be utilizing their time efficiently by providing this information.

Witry et al. (2010) provided information on patients' misuse of PHRs.<sup>55</sup> The belief that patients would insert and delete certain information is a concern for healthcare providers. Trust between patients and physicians would be tested through the use of PHRs. Patients must trust that their physicians will provide the best, most cost-efficient advice. Likewise, providers must trust patients to enter appropriate changes in the PHR. The use of technology to allow or restrict patients' editing of information entered by medical professionals is critical. While patients should be allowed to communicate changes in regard to over-the-counter and prescription medications, the removal and addition of codified medical diagnostic information needs to remain in the hands of medical professionals. Should a patient identify potentially incorrect diagnostic data within a PHR, a secure message to the provider from the patient would be appropriate. Researcher and publisher bias might have affected the results of the study by Witry et al. (2010) because these scholars demonstrated the apprehensiveness of healthcare providers toward PHRs.<sup>56</sup>

Providers have a certain amount of concern about patients' being able to alter their own PHR information, as one of the authors of this article (J.S.) has found on the basis of personal experience in nursing and health informatics. Nonetheless, it is critical to engage patients in the management of their healthcare information. When patients keep paper records, they can write down whatever they want, thus "altering" their personal health information. What is important is that information entered by a healthcare provider and information entered by the patient or the patient's family is clearly indicated as such. Providers and healthcare workers need to remain aware that the information in the PHR belongs to the patient; however, it is not the official medical record of the patient.

Hospitals and physicians are under increased pressure to provide PHRs to their patients. Utilization of PHRs can be beneficial because it allows for the correction of errors in medical records and gives patients access to the information to share with other providers. Conversely, each provider may have a different system, thereby making patient utilization difficult. Trying to maintain data integrity in multiple PHRs provided by retail pharmacies, insurance companies, hospitals, physician offices, and patient-generated systems manually would be nearly impossible for the average healthcare consumer. Patients could potentially end up with as many as ten or more disparate PHRs depending on what facilities, providers, employers, and insurance companies are involved. Interoperability is a substantial issue that needs to be addressed for seamless use of PHRs among providers and patients.

Standards that support interoperability have started to take hold in the realm of PHRs. Blue Button and direct secure messaging are two such examples that have been incorporated into many PHR systems.

This literature review was limited because of constraints in the search strategy utilized, particularly the number of databases searched, and because publication bias could have altered the availability and caliber of research available during the search. Furthermore, although a vast amount of research about PHRs was available, research regarding outcomes of utilization was limited because 2015 was the first year in which availability of PHRs to patients was mandated. Other study limitations included small sample sizes and studies that were specific to geographic regions and may not depict the population across the United States.

Further research should include survey research as well as longitudinal studies regarding patient engagement in utilization of PHRs by their providers and the amount of education provided to encourage the use of these systems. Examination of health outcomes would determine if the investment in PHRs is advantageous. Other research could examine the interoperability of EHRs and PHRs and determine if the information is accessible and useful to providers.

## **Conclusion**

The success or failure of PHRs in the US healthcare system depends on the advancement and use of the technology. Questions have been raised about patient literacy rates, patient information security, HIPAA violations, and disruption of patient and physician relationships. Patient education and active engagement in the use of PHRs is essential for success.

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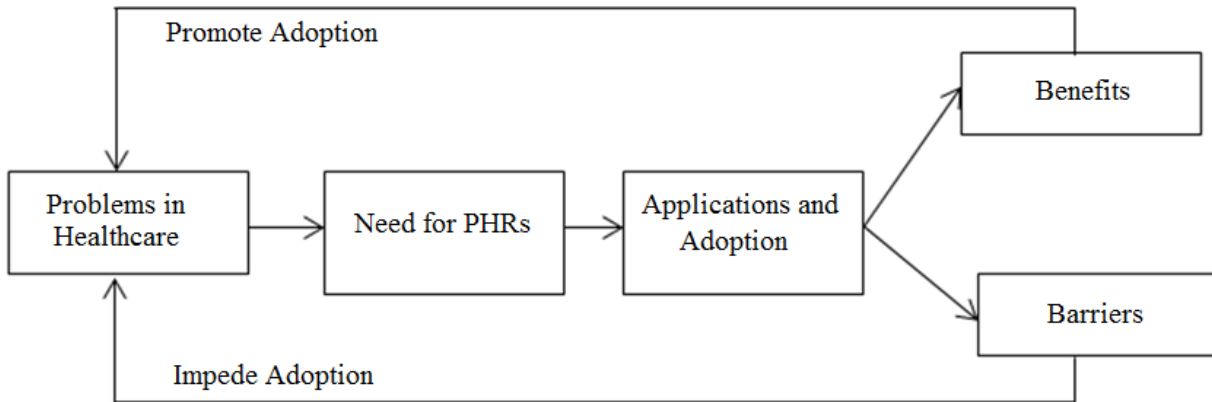


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**Figure 1**

Conceptual Research Framework: Use of Personal Health Records (PHRs)



Source: Adapted from Yao, W., C. H. Chu, and Z. Li. "The Use of RFID in Healthcare: Benefits and Barriers." *Proceedings of the 2010 IEEE International Conference on RFID-Technology and Applications (RFID-TA)* (2010): 128–34.

**Table 1**

Barriers Slowing or Preventing EHR Implementation

<b>EHR product factors</b>		
Difficulty finding HIT products that meet needs		
Too complex		
User interfaces are not user friendly		
Inability to easily input historic medical record data into software/technology system		
<b>Management factors</b>		
Risk of new state/federal requirements		
Not part of the strategic planning		
Unclear benefits of EHR in improving quality		
Unclear needs for change management		
<b>Capital factors</b>		
Lack of capital resources to invest		
Lack of proven benefit		
Lack of technical infrastructure (servers, etc.)		
<b>Human resource factors</b>		
Insufficient time to select, contract, install software/technology		
Lack of HIT knowledge		
Fear of technology		
Lack of technical support staff		

*Abbreviations:* EHR, electronic health record; HIT, health information technology.

*Source:* Adapted from Wang, T., and S. Biedermann. "Adoption and Utilization of Electronic Health Record Systems by Long-Term Care Facilities in Texas." *Perspectives in Health Information Management* 9 (Spring 2012).

**Table 2**

## Pros and Cons of Utilization of Personal Health Records (PHRs) by Patients and Providers

Pros	Cons
<ul style="list-style-type: none"> <li>• Correction of medical errors within the medical record was possible<sup>a</sup></li> <li>• Patients had a broader knowledge base of their health concerns and decreased utilization of healthcare services<sup>b</sup></li> <li>• Opportunities were provided for increased effective communication between patients and physicians<sup>c</sup></li> <li>• Patients initiated health improvement<sup>d</sup></li> <li>• Patients were engaged in their healthcare decisions<sup>e</sup></li> <li>• Records could be shared with other providers<sup>f</sup></li> <li>• Communication with physicians regarding surgeries, medications, immunizations, and allergies had compelling outcomes<sup>d</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Patients had difficulty accessing the PHR and saw a lack in value of accessing PHRs<sup>f</sup></li> <li>• Limited health literacy resources contributed to a lack of understanding of records<sup>g</sup></li> <li>• Challenges were identified regarding the proper information being transmitted to the PHR by the healthcare institution<sup>h</sup></li> <li>• Physicians were concerned with legal liability<sup>i</sup></li> <li>• Providers had concerns regarding incorrect information being placed in the PHR by patients<sup>h</sup></li> <li>• Health Insurance Portability and Accountability Act (HIPAA) regulations were related to concerns with specific diseases (e.g., AIDS)<sup>f</sup></li> <li>• Concerns were expressed regarding security of information and insufficient provision of information<sup>f</sup> regarding privacy policies related to the PHR<sup>j</sup></li> <li>• Health outcomes did not improve as a result of access to the PHR<sup>d</sup></li> <li>• Patients found communicating through the PHR too cumbersome and preferred contacting the provider's office<sup>f</sup></li> <li>• Older patients had limitations related to healthcare literacy and technology use<sup>k</sup></li> </ul>

**Sources:**

<sup>a</sup> Cahill, J., M. Gilbert, and T. Armstrong. "Personal Health Records as Portal to the Electronic Medical Record." *Journal of Neuro-oncology* 117, no. 1 (2014): 1–6.

<sup>b</sup> Taha, J., S. Czaja, J. Sharit, and D. Morrow. "Factors Affecting Usage of a Personal Health Record (PHR) to Manage Health." *Psychology and Aging* 28, no. 4 (2013): 1124–39.

<sup>c</sup> Detmer, D., M. Bloomrosen, B. Raymond, and P. Tang. "Integrated Personal Health Records: Transformative Tools for Consumer-centric Care." *BMC Medical Informatics and Decision Making* 8, no. 1 (2008): 45–59.

<sup>d</sup> Ancker, C., and P. Dykes. "Electronic Health Records and Personal Health Records." *Seminars in Oncology Nursing* 27, no. 3 (2011): 218–28.

<sup>e</sup> Krist, A., S. Woolf, G. Bello, R. Sabo, D. Longo, P. Kashiri, et al. "Engaging Primary Care Patients to Use a Patient-centered Personal Health Record." *Annals of Family Medicine* 12, no. 5 (2014): 418–26.

<sup>f</sup> Dontje, K., W. Corser, and G. Holzman. "Understanding Patient Perceptions of the Electronic Personal Health Record." *The Journal for Nurse Practitioners* 10, no. 10 (2014): 824–28.

<sup>g</sup> Weitzman, E. R., L. Kaci, and K. D. Mandl. "Acceptability of a Personally Controlled Health Record in a Community-based Setting: Implications for Policy and Design." *Journal of Medical Internet Research* 11, no. 2 (2009): e14.

<sup>h</sup> Witry, M., W. Doucette, J. Daly, B. Levy, and E. Chrischilles. "Family Physician Perceptions of Personal Health Records." *Perspectives in Health Information Management* 7 (Winter 2010).

<sup>i</sup> Studeny, J., and A. Coustasse. "Personal Health Records: Is Rapid Adoption Hindering Interoperability?" *Perspectives in Health Information Management* 11 (Summer 2014).

<sup>j</sup> Kim, K., and E. Nahm. "Benefits of and Barriers to the Use of Personal Health Records (PHR) for Health Management among Adults." *Online Journal of Nursing Informatics (OJNI)* 16, no. 3 (2012).

<sup>k</sup> Lober, W. B., B. Zierler, A. Herbaugh, S. E. Shinstrom, A. Stolyar, E. Kim, and Y. Kim. "Barriers to the Use of a Personal Health Record by an Elderly Population." *AMIA Annual Symposium Proceedings* (2006): 514–18.