

# Patient Access to Personal Health Information: An Analysis of the Consumer's Perspective

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## Abstract

The purpose of this exploratory study was to analyze the perceptions of healthcare consumers in accessing their health information via provider portals, when using personal health records, and through the release of information process. Availability of electronic health records and consumers' electronic access to their health information has changed dramatically since the enactment of the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009. Results indicated that only 10 percent of consumers were charged for their health information and 82 percent reported that they took advantage of their provider's portal if it was available. Less than half (49.1 percent) of the consumers surveyed reported that they maintained a personal health record. These findings indicate that healthcare consumers are now requesting access to their health information in electronic form and are accessing their information through patient portals.

**Keywords:** electronic health record (EHR); Health Insurance Portability and Accountability Act (HIPAA); Health Information Technology for Economic and Clinical Health (HITECH) Act; patient portal; personal health record (PHR); release of information

## Introduction

Knowledgeable, engaged healthcare consumers are actively participating in their care and treatment, improving healthcare outcomes.<sup>1-4</sup> Availability of personal health information via provider portals is crucial for consumers desiring access, and yet many healthcare providers fail to provide for such requests via patient portals.<sup>5,6</sup> Health information technology continues to generate more health-related data, spurring interest in the consumerization of healthcare and supporting mandated patient access.<sup>7-9</sup> Because of this changing healthcare environment, researchers continue to evaluate existing health information management (HIM) policies and practices supporting consumer access to personal health information.

In a 2015 study, HIM professionals working in leadership positions in healthcare organizations were surveyed.<sup>10</sup> More than half of the respondents (52.6 percent) reported that they charged consumers for electronic or paper copies of their health information; 87.5 percent of the respondents reported that they had an electronic health record (EHR) and 38.0 percent reported that they had a patient portal. However, portal utilization by consumers was found to be low, with nearly half of the organizations with a portal reporting that less than 5 percent of their patients were using the portal.<sup>11</sup> Because of these deficiencies, this research was undertaken to expand the body of knowledge regarding HIM practices in providing consumers access to their health information.

## Background

The Health Information Technology for Clinical and Economic Health (HITECH) Act was enacted in 2009 to promote the adoption and meaningful use of health information technology.<sup>12</sup> Since that time, there has been a shift from largely paper-based health record systems to EHRs. In 2008, less than 10 percent of hospitals had adopted EHRs. As of September 2016, 96 percent of hospitals and 78 percent of physicians are using EHRs.<sup>13</sup>

Under HITECH, healthcare providers with EHRs must provide patients with digital versions of their medical records upon request.<sup>14</sup> These digital records can be provided in various forms, including a flash drive or DVD when requested. As mandated by the Centers for Medicare and Medicaid Services' Meaningful Use Stage 2 requirements, consumers must be

given the ability to view online, download, and transmit their health information.<sup>15-17</sup> Costs associated with providing EHRs are a concern for health organizations; however, the incremental cost of access to digital records is quite low and offers savings.<sup>18</sup>

Although the Health Insurance Portability and Accountability Act (HIPAA) requires that providers grant patients access to their own records, historically few patients have taken advantage of this benefit, with only 28 percent accessing their records in the last year.<sup>19</sup> Patients continue to be afforded opportunities to take more responsibility for their own personal health information via information technologies, but patient engagement remains low.<sup>20</sup> Only a few studies have examined whether patients avail themselves of this resource.

Satisfaction with portal use by both providers and patients is a needed attribute for portals to succeed.<sup>21</sup> Studies indicate mixed results on patient satisfaction.<sup>22-24</sup> This finding is of concern because satisfaction is an important driver of portal use and acceptance.<sup>25</sup> With the increased availability of EHRs, portal use is of interest to those studying the patient experience.

Some patients choose to maintain their own health record, and these records can take several forms.<sup>26</sup> When personal health records (PHRs) are part of an EHR system, they provide greater benefits.<sup>27</sup> Obviously electronic rather than paper records support integration and sharing, but several barriers exist to using electronic PHRs.<sup>28-30</sup>

## Research Questions

This research sought to determine the perspectives of the healthcare consumer when accessing their health information through the release of information (ROI) process, through the use of a patient portal, and when maintaining a PHR. The authors assessed the following research questions:

1. Are consumers requesting and receiving access to their health records?
2. What costs are associated with health record requests?
3. What is the level of usage and satisfaction with patient portals and PHRs?

## Methods

The purpose of this exploratory study was to analyze the perceptions of healthcare consumers in accessing their health information. Data were collected using a survey developed by the researchers containing 12 open- and closed-ended questions. [Appendix A](#) presents the survey questions. Construct validity was established by conducting a pilot test with a class of HIM students ( $n = 30$ ) and by having the department chair and several other faculty members take the survey. Study participants were campus-based and online students enrolled in a College of Health Professions course, alumni of the HIM program at the researchers' university, members of a local American Health Information Management Association (AHIMA) professional chapter, and friends and family of the researchers.

Demographics were collected on participants' age, gender, ethnicity, and years of healthcare experience. SPSS was used to generate frequencies and percentages to describe the participants. Two chi-square tests were conducted to determine if a significant relationship existed between years of healthcare experience and the levels of portal usage, and between years of healthcare experience and the levels of PHR usage.

## Participants

The participants chosen for this study were campus-based and online students enrolled in a College of Health Professions course, alumni of the bachelor of science in HIM program at the researchers' university, members of a local AHIMA professional chapter, and friends and family of the researchers. Participants were selected using convenience sampling. The goals were to have as many people as possible complete the survey and to include respondents with varying levels of healthcare experience. These participants are currently consumers of healthcare services and are thus qualified to evaluate their usage of and satisfaction with the access to their personal health information.

## Results

## Demographics

One hundred sixty-seven consumers completed the survey. The respondents were predominantly female (83 percent), with ages ranging from 25 years or younger (11.4 percent) to 66 years or older (9 percent). [Table 1](#) presents participant demographic characteristics.

**Table 1: Participants' Demographic Characteristics (n =167)**

Characteristics	<i>N</i>	%
Gender		
Male	29	17
Female	138	83
Age		
25 years or younger	19	11.4
26–30 years	14	8.4
31–35 years	17	10.2
36–40 years	9	5.4
41–45 years	15	9.0
46–50 years	16	9.6
51–55 years	22	13.2
56–60 years	25	15.0
61–65 years	15	9.0
66 years or older	15	9.0
Ethnicity		
American Indian or Alaska Native	0	0.0
Asian	7	4.2
Black or African American	12	7.2
Hispanic	30	18.0
Native Hawaiian or Pacific Islander	2	1.2
White	111	66.5
Other	5	3.0

Respondents' years of healthcare experience were as follows: no healthcare experience (10.8 percent), less than 1 year (4.8 percent), 1 to 5 years (16.8 percent), 6 to 10 years (9.0 percent), 11 to 15 years (14.4 percent), and more than 15 years (44.3 percent). [Table 2](#) presents the years of healthcare experience.

**Table 2: Participants' Years of Healthcare Experience (n = 167)**

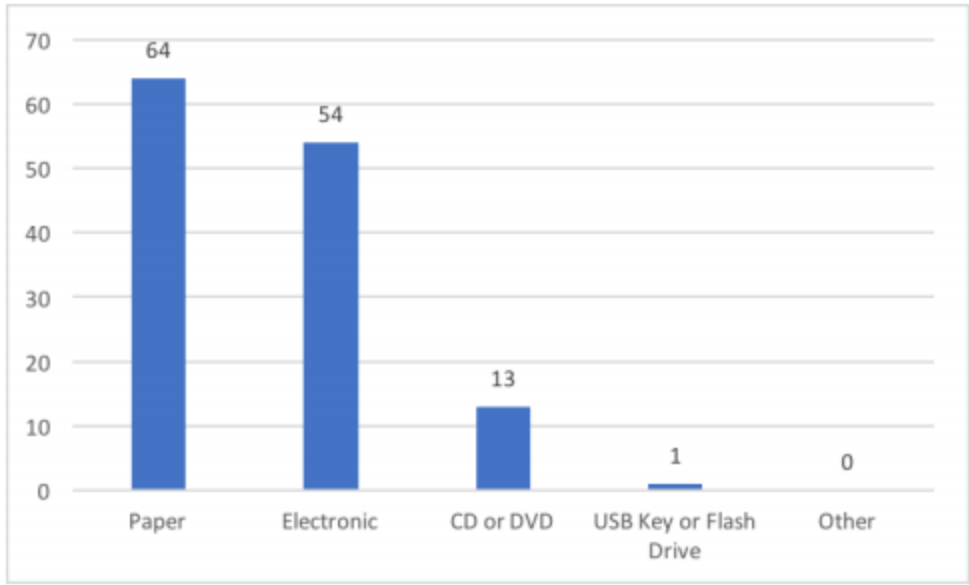
Healthcare Experience	<i>N</i>	%
No healthcare work experience	18	10.8
Less than 1 year	8	4.8
1–5 years	28	16.8
6–10 years	15	9.0

11–15 years	24	14.4
More than 15 years	74	44.3
Totals	167	100.0

Release of Information

Ninety-six consumers (57 percent) requested their records using the ROI process. Records were requested in a variety of formats: 41 percent electronically, 48 percent on paper, 10 percent on CD or DVD, and less than 1 percent on USB key or flash drive. [Figure 1](#) presents the record formats requested.

Figure 1: Record Formats Requested (n=132)



The consumers generally received their records in the requested format (88 percent), and most were not charged (90 percent). Among the 10 percent who were charged, the ranges of charges were less than \$5.00 (10 percent), \$5.00 to \$10.00 (50 percent), and \$10.01 to \$25.00 (40 percent). Most patients received their records within in 1 to 15 days (54 percent), but some waited more than 30 days (5 percent) or never received the records at all (5 percent). [Table 3](#) displays the time to receive records.

Table 3: Time to Receive Records (n=96)

Time to Receive Records	N	%
Less than 1 day	33	34.4
1–15 days	52	54.2
16–30 days	1	1.0
More than 30 days	5	5.2
Never received the records	5	5.2
Totals	96	100.0

Portal Use

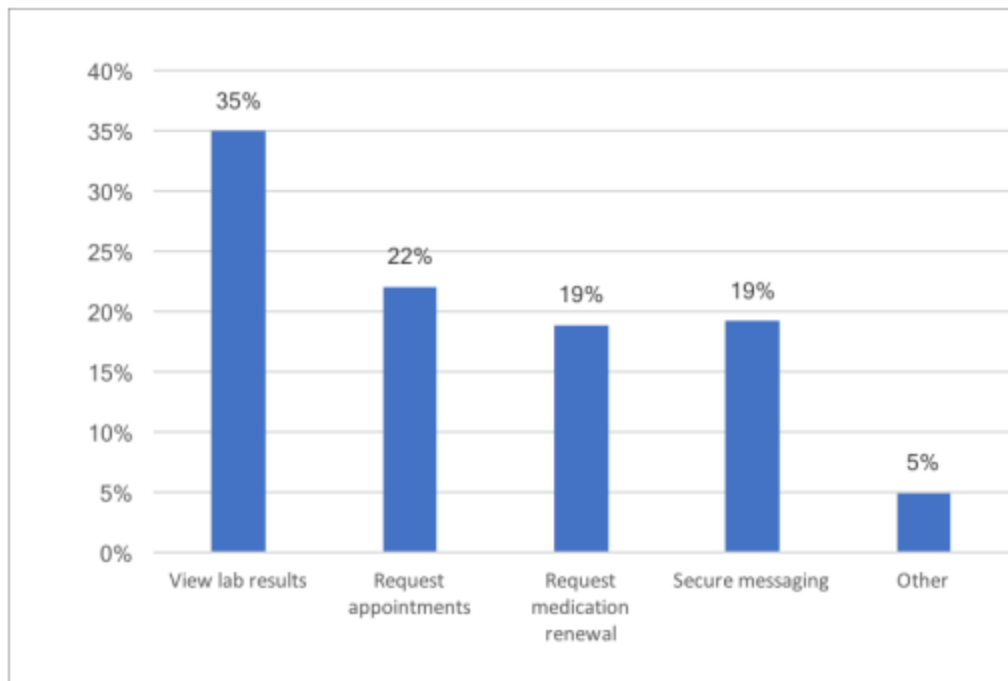
Among those surveyed, 83 percent indicated that their providers had portals, and 82 percent of those who had access to a provider portal indicated that they used the portal. Uses for portals included viewing lab results (35 percent), requesting medication renewal (19 percent), requesting appointments (22 percent), secure messaging (19 percent), and other (5 percent).

Among those using portals, most were satisfied (38 percent) or very satisfied (53 percent). [Table 4](#) depicts the portal satisfaction ratings, and [Figure 2](#) shows portal usage.

**Table 4: Portal Satisfaction Ratings**

Satisfaction Rating	<i>N</i>	%
Dissatisfied	2	1.79
Neither satisfied nor dissatisfied	9	8.04
Satisfied	42	37.50
Very satisfied	59	52.68
Totals	112	100.00

**Figure 2: Portal Uses by Consumers (*n* = 286)**



Reasons for not using the portal were that they were not interested in managing their health record, were not sure how to use the portal, or had other reasons for not using it. Responses in the “other” category included comments related to multiple issues with logging on, a lack of interface usability, not being able to locate the needed information, and the issue of multiple unwanted portal-generated e-mails. [Table 5](#) presents reasons for not using the provider’s portal.

**Table 5: Reasons for Not Using Provider’s Portal**

Reasons for Not Using Portal	<i>N</i>
Not interested in managing health records	4
Not sure how to use portal	5
Other	16
Totals	25

## Personal Health Records

Eighty-two respondents (49 percent) indicated that they maintained PHRs. The most commonly reported record format was the combined category of paper and electronic (46 percent), followed by paper only (35 percent), electronic only (18 percent),

and other (1 percent). [Table 6](#) shows the results for PHR formats.

**Table 6: Personal Health Record Formats**

Format	<i>N</i>	%
Paper	31	35.2
Electronic	16	18.2
Both paper and electronic	40	45.5
Other	1	1.1
Totals	88	100.0

## Relationship of Years of Healthcare Experience to Portal and PHR Usage

Chi-square tests were conducted to examine the relationships between years of healthcare experience and the levels of portal usage, and between years of healthcare experience and the levels of PHR usage. A chi-square test did not confirm a significant relationship (with  $p < .05$  as the threshold for significance) between healthcare experience and portal use,  $\chi^2(12, n = 168), p = .307$ . A second chi-square test confirmed that there was not a significant relationship between years of healthcare experience and the levels of PHR usage  $\chi^2(12, n = 168), p = .221$ .

## Overall Satisfaction with Access to Personal Health Information

Participants provided a variety of comments in response to the question inviting them to discuss their access to health information. Advantages of access to personal health information cited were ease of use for making appointments and easy access to information when seeing multiple providers, when traveling, or just when they wanted to view the information. Examples of the many positive comments are as follows:

- “It seems over the years that getting access to one’s own health information is getting easier to do through technology.”
- “I believe that patients should have access to their health records. I think patient portals will be the preferred method of accessing this information in the near future.”

Conversely, respondents expressed concerns about the security of electronically stored personal health information and the time and difficulty of accessing their records.

- “There is some concern over the security of health information in the government and private sectors.”
- “Some physicians would like to have the opportunity to go over test results with their patients before HIM releases the results. It is not safe for HIM to put the information on [the] patient’s flash drive for virus concerns.”

Some described issues with a lack of interoperability between physicians’ offices and electronic personal health information, and the difficulty of getting data into the portal or updated when it is in the portal.

- “Lack of interoperability between systems and my PCP [primary care provider] still on paper charts creates an inefficient and hard to access system of record.”
- “It seems to be a challenge getting information from other sources added to the patient portal. (i.e., Military, other providers)”

Finally, there were concerns about the lack of centralization of information between healthcare providers.

- “My physician prefers paper records and reluctantly moved to electronic records and a patient portal. For the first year, there was no information available on the portal. Only after I asked did he release information about an office visit.”
- “I think a universal health record, maybe in the form of a scannable card, would provide greater continuity of care. Right now, my family physician has to call my other doctors for information on my medical records, and vice versa.”

Respondents supplied many more comments, much too long to include in this work. In general, feedback fell into seven different themes. The most common were related to accessibility, closely followed by ease of use. The next most common theme was security. Record quality, system integration, and time issues were also mentioned often in respondent-supplied comments.

## Discussion

These survey results demonstrated a significant reduction in charging consumers for access to their medical records, a significant increase in portal availability, and a moderate rate of usage of PHRs. Only 10 percent of respondents were charged for paper or electronic records.<sup>31</sup> Patient portals were available to 83 percent of the respondents, and 90 percent of the portal users were satisfied or very satisfied. Among the portal users, 82 percent used the portal for viewing lab results, requesting medication refills, requesting appointments, and secure messaging.

Increased portal use is to be expected as eligible providers seek to meet the requirements of the Centers for Medicare and Medicaid Services' Meaningful Use Stage 3 incentive program. Stage 1 objectives included providing electronic copies of health information and electronic prescriptions when permissible.<sup>32</sup> Meaningful Use Stage 2 directs providers to use secure messaging; to provide consumers the ability to view, download, and transmit their health information; and to provide clinical reminders for follow-ups. Furthermore, Meaningful Use

Stage 3 objectives include recording electronic notes in patient records and making image results available electronically.<sup>33,34</sup>

Cost reductions are to be expected as more facilities move to EHR systems, whereby the cost of providing consumers with copies of their medical records is reduced. Also, as consumers become more aware of the HITECH requirements, they will scrutinize provisioning charges for record copies.

The results of the questions about PHR format were somewhat surprising, with 35 percent of the respondents reporting use of paper records. Eighteen percent preferred electronic records and 46 percent used both formats. We expect that more consumers will opt to use electronic PHR in the future, because of convenience and ease of use.

## Limitations

The study has several limitations. The sample was a convenience sample of healthcare students, members of a local AHIMA chapter, and friends and family of the researchers. This type of nonrandom sampling limits the generalizability of study conclusions. The sample size was moderate ( $n = 167$ ), and respondents were largely female. Larger studies at multiple locations with more diverse respondent demographics may have different results. Moreover, although respondents were consumers of healthcare who were relaying their personal experiences accessing healthcare, most of the respondents had some previous healthcare experience. The perceptions of consumers with no healthcare background may yield different results.

## Conclusion

The availability of EHRs and patient portals has significantly increased since the HITECH Act was enacted in 2009. Consumers are now requesting access to their health information in electronic form and are accessing their information through patient portals. Although the majority of respondents used patient portals and reported that they were satisfied, opportunities exist for HIM professionals to continue to assist patients in accessing and understanding their health information and developing their own PHRs.

Looking forward, a recent Federal Trade Commission report urges healthcare organizations to develop best practices related to "Internet of things" devices. For many in HIM, the recommendations will sound familiar—train employees in security, make sure external service providers focus on security, and employ controls that prevent unauthorized users from accessing consumer information on devices and networks.<sup>35</sup> As more consumers access their personal health information electronically, privacy and security concerns will become paramount for HIM professionals.

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## Appendix A: Survey Instrument

1. In the past year, have you tried to obtain copies of your health records from a doctor, clinic, hospital or other healthcare provider?
  - a. Yes
  - b. No
2. Indicate the access format(s) that you requested for your health records. Mark all that apply.
  - a. Paper
  - b. Electronic
  - c. CD or DVD
  - d. USB Key or Flash Drive
  - e. Other
3. Did you receive your records in the form(s) requested?
  - a. Yes
  - b. No
4. How much were you charged for accessing your records?
  - a. Less than \$5.00
  - b. \$5.00–\$10.00
  - c. \$10.01–\$25.00
  - d. Over \$25.00
5. How long did it take for you to get the records you requested?
  - a. Less than one day
  - b. 1–15 days
  - c. 16–30 days
  - d. Over 30 days
  - e. Never received the records
6. Does your healthcare provider have a patient portal?
  - a. Yes
  - b. No
  - c. Don't know
7. Do you use the patient portal?
  - a. Yes
  - b. No
  - c. Don't know
8. What have you used to portal for? Check all that apply.

- a. View lab results
- b. Request medication renewal
- c. Request appointments
- d. Secure messaging
- e. Other, please describe

9. How satisfied are you with the portal?

- a. Very satisfied
- b. Satisfied
- c. Neither satisfied nor dissatisfied
- d. Dissatisfied
- e. Very dissatisfied

### Patient Does Not Use Portal

10. Indicate why you do not use the patient portal.

- a. Not interested in managing health records
- b. Not comfortable with computer
- c. Not sure how to use the Internet
- d. Not sure how to use the portal
- e. No Internet access
- f. No computer
- g. Other (please specify)

### Personal Health Record

11. Do you keep a personal health record?

- a. Yes
- b. No

12. What format(s) do you use for your personal health record?

- a. Paper
- b. Electronic
- c. Both paper and electronic
- d. Other (please specify)

13. Is there anything else you would like to share about your experience regarding access to your medical information?

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