

# The Consumer View of PHRs: Observational Study Finds Most Value PHRs, but Issues Remain

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By Loya Kelso, MS, and Ruth Walker, MIS, RHIA, CPHQ

Much has been written on the importance of personal health records (PHRs), and many organizations offer them. But what do consumers think of the PHR concept? More importantly, what is the likelihood of them starting a PHR?

In 2008 an observational study attempted to determine the likelihood that people would complete a PHR. It also sought to find the level of effort people believe they would make to create an accurate PHR and determine how people thought they would use one.

## Valuable but Difficult

A convenience sample of 124 participants was gleaned from the general public within Indiana. Participants were given a sample PHR and completed a written 21-question survey about the likelihood that they would complete a PHR such as the one provided.

The PHR used as the sample was a paper form created by AHIMA. It was selected because the form is in the public domain and offers versions for both adults and minors in English and Spanish. The form is comprehensive and includes sections beyond standard medical information, such as legal directives, physical therapy, vision, and dental information.

The survey included a combination of open-ended and Likert questions.

The participants were primarily Caucasian, married, female, insured, college educated, and employed. The modal age range was 40–49, followed closely by age ranges of 20–29 and 50–59. More than 75 percent of the participants selected a score above the midpoint to describe their personal health. Twenty-two percent reported that they already had a PHR, 61 percent of which were in electronic format.

Nearly all respondents saw the value in a PHR. More than 90 percent thought that a PHR was a good idea, and 85 percent thought it could help their doctor or themselves improve their health. The top three reasons noted include “diagnosing and decision making,” “comprehensive,” and “improves patient involvement.”

Unfortunately, more than 66 percent thought it would be difficult to complete a PHR. The leading reason at nearly 23 percent was “difficulty remembering” necessary information. The result indicates that participants are unaware that they must research their medical information they do not know. Additional reasons were listed, but most relate to the time required or the participants’ inability to find the needed information.

## Likelihood to Complete a PHR

Fifty percent of participants reported that they were “somewhat likely” or “very likely” to complete a PHR for themselves or someone else. The remaining were “unsure” (23 percent), “somewhat unlikely” (12 percent), and “very unlikely” (15 percent).

Eighty-five percent of the likely group thought it would be easy to keep the PHR up-to-date, a sharp contrast to the 66 percent who thought it would be difficult to complete a PHR. This likely indicates that participants have concerns about the initial completion of a PHR, but are not concerned about upkeep.

## Expected Accuracy

To determine if the information in the PHR would be accurate, participants were asked, “How do you think you will find the information that you do not already know, such as immunizations or stop and start dates of medications?” Nearly 90 percent of respondents included resources that should lead to accurate information, such as healthcare professionals and personal, family, pharmacy, or other medical records.

Healthcare professionals may be more inclined to trust information contained in a PHR knowing that more than 90 percent of the participants said they would take measures to complete it accurately. However, healthcare professionals might be concerned about their ability to handle requests for information, because more than 40 percent of respondents said they would contact their healthcare professional for information that they did not know or have readily available.

The remaining responses were each less than 3 percent and included “memory,” “no idea,” and “blank or guess.”

## How Consumers Might Use PHRs

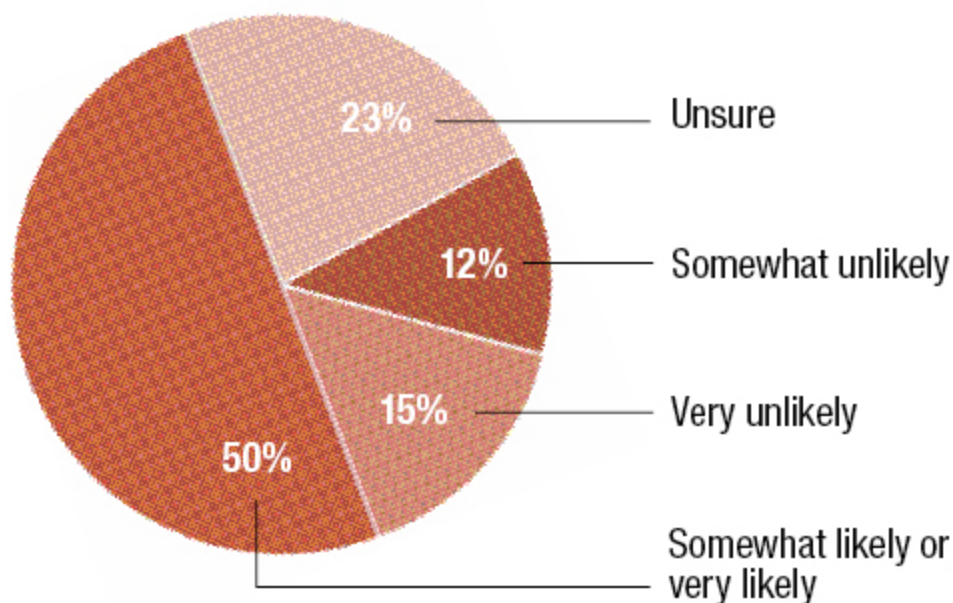
Of those who plan to complete a PHR, 84 percent said they planned to complete the PHR for themselves. Other family members—such as husband, wife, mother, and father—were also selected or noted.

When asked, “What do you plan to do with the PHR after you complete it?” half included “store it,” with another 5 percent stating that they would store it digitally. Responses in the “store it” category did not specify digital and most cited a physical location, such as a safe or with other important papers. More than 20 percent said they would share it with their healthcare professionals.

The majority of responses imply that participants see value in the PHR by storing it with other important papers, yet they are not really sure how to use it.

### Likelihood of Completing a PHR

When asked whether they would complete a PHR for themselves or someone else, a majority of participants said they were somewhat to very likely to do so.



## Favoring Paper

Nearly 51 percent reported that they would prefer a paper version of the PHR, while 33 percent preferred electronic. An additional 10 percent said they preferred both paper and electronic formats. The results are in line with a Harris Interactive survey, which found that of those without a PHR, 40 percent were likely to start an electronic version.<sup>1</sup>

The results of this study might be skewed toward a paper version because that is the format the participants received as a sample. They also may have felt that their healthcare professional would not use an electronic version, and that if they had an electronic version, they would have to print it for their healthcare professional.

More might prefer an electronic version if participants could get a prepopulated PHR in electronic format.

## Participant Comments

Overall, participants provided positive comments about the PHR to open-ended questions. Examples of repeated positive comments included the phrases “diagnosing and decision making,” “comprehensive,” and “improves patient involvement.”

Common concerns were related to finding necessary information and included “unknown difficult to obtain,” “difficulty remembering,” and “complex.” “Time consuming” was also a repeated concern.

Two-thirds of participants in the Harris Interactive survey had concerns about privacy and security. Privacy and security were not reported themes from this sample. There are several potential reasons for this difference in results.

This survey did not specifically ask about concerns, which instead were gleaned by the coders from the comments. The Harris Interactive survey asked specifically about concerns and gave the participants a list of choices that included privacy and security.

The Harris Interactive survey was online, where privacy and security might be at the forefront of the participants’ minds.

This survey’s participants received a paper copy and might not have been considering an online version of the PHR when considering an electronic version option.

The results of this pilot study suggest that it is realistic to expect individuals to complete accurate PHRs. Slightly more than half of the participants stated that they are “likely” to complete a PHR, and more than 90 percent plan to take measures to do so accurately.

Nearly 66 percent thought it would be difficult to complete the PHR, but fewer had concerns about keeping it current. Half of the sample said they prefer a paper version of the PHR, and another 10 percent said they want both electronic and paper.

Mitigating strategies, such as providing prepopulated, editable PHRs might help to overcome the barrier of initial completion and may persuade the preference from paper to electronic.

## Note

1. Harris Interactive. “Two in Five Adults Keep Personal or Family Health Records and Almost Everybody Thinks This Is a Good Idea.” *Health Care News* 4, no. 13 (August 10, 2004). Available online at [www.harrisinteractive.com/news/newsletters/healthnews/HI\\_HealthCareNews2004Vol4\\_Iss13.pdf](http://www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews2004Vol4_Iss13.pdf).

Loya Kelso ([loyakelso@hotmail.com](mailto:loyakelso@hotmail.com)) is an independent consultant. Ruth Walker ([ruawalke@iupui.edu](mailto:ruawalke@iupui.edu)) is a professional practice coordinator for the health information administration program at the Indiana University School of Informatics.

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