

Consumer Attitudes Toward Personal Health Records in a Beacon Community

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Objective: To characterize consumers' attitudes about personal health records (PHRs), electronic tools that enable consumers to securely access, manage, and share their health information, in a community participating in health information technology initiatives.

Study Design: Cross-sectional study.

Methods: A random-digit-dial telephone survey about PHRs was conducted among adult residents of New York State's greater Buffalo region. Multivariate regression analyses identified factors associated with potential PHR use.

Results: We obtained a 79% (n = 200) response rate. Many respondents (70%) would potentially use PHRs. Consumers wanted PHRs to incorporate an array of information, including immunization records (89%) and providers visited (88%). They expressed interest in several online activities, including accessing their family members' healthcare information (71%). Potential PHR use was associated with perceptions that PHRs would improve privacy and security of medical information (odds ratio [OR] 4.7; 95% confidence interval [CI] 1.1, 20.1), understanding regarding health (OR 3.7; 95% CI 1.3, 11.1), and overall quality of care (OR 3.6; 95% CI 1.2, 10.6). Potential PHR use was associated with annual household income of more than \$30,000 (OR 3.9; 95% CI 1.3, 11.9) and experience looking up health information online (OR 3.0; 95% CI 1.1, 8.1).

Conclusions: Consumers expressed great interest in using PHRs and wanted comprehensive PHRs. However, the "digital divide" between those with varying levels of Internet experience and concerns about PHRs' effect on privacy and security of medical information may limit use. Designing PHRs that incorporate consumer preferences and developing policies that address these barriers may increase consumers' PHR use.

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For author information and disclosures, see end of text.

Patient-centered care is a key part of a broad framework to improve the US healthcare system.¹ Recommendations for redesigning care so that it is more patient centered include customizing care based on patient needs and values, giving patients greater control over their healthcare decisions, and providing patients with increased transparency and access to their medical information. Personal health records (PHRs) are health information technology (HIT) applications that enable consumers to securely "access, manage and share their health information."²

The definition of PHR is still evolving, and although conceived for consumer use, PHRs are not uniform in nature.³ Personal health records may be tethered to a provider's electronic health record, may include data from multiple providers, or may be stand-alone systems that require patients to directly enter their data.⁴ Thus, PHRs may vary widely in the completeness and the type of information included, the features available, and who controls and manages the information.

Personal health records have been hypothesized to confer a variety of benefits through their ability to provide tools that enable consumers, providers, and caregivers to better communicate and share information with one another. Providing access to more complete and customized data may enable consumers and providers to monitor chronic healthcare conditions collaboratively and enable caregivers to more easily manage care for others.⁴ Personal health records may also allow practices to deal with administrative issues electronically and increase the efficiency of patient-provider communication.⁴ Although empirical evidence regarding the benefits of PHRs is still limited, other disease-specific, consumer-oriented HIT applications that help patients manage their healthcare have been found to increase consumers' engagement with their healthcare and improve the delivery of traditional clinical interventions and health outcomes.^{3,5}

In order to realize the potential benefits of PHRs, the widespread adoption and use of PHRs by consumers is essential. Although PHRs are being sponsored by providers, health plans, and commercial entities, currently a minority of American adults (between 3% and 7%) have access to a PHR.^{6,7} This percentage is likely to increase as a result of federal HIT policies that give providers financial incentives linked in part to demonstrating that they provide patients with electronic access to their health information.^{8,9} However, increasing access to electronic health information may not lead to improved health outcomes unless patients adopt and consistently use

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PHRs. Currently, even among patients who do have access to PHRs, few are using these systems.³ Identifying factors that shape consumers' needs for and potential use of PHRs has been identified as an important next step.^{3,4,10}

Assessing consumers' detailed preferences and identifying potential barriers to use could also inform outreach efforts and the design of PHRs.¹¹ There is evidence to suggest that those hypothesized to benefit most from these technologies—chronically ill, older patients—may experience difficulty using PHRs to better manage their healthcare.¹² Thus, understanding how different types of consumers, including caregivers, may use PHRs is essential to ensuring that PHRs serve as a means to address disparities in healthcare rather than exacerbate them.¹³

A number of community-based health IT initiatives are under way nationwide and in New York State.^{14,15} The Western New York Clinical Information Exchange (also known as HEALTHeLINK) received state funds to develop an operational health information exchange that allows providers to access their patients' clinical information.¹⁵ They also received \$16 million as part of the federal Beacon Community program whose goal is to transform the delivery of care through innovative uses of HIT.^{14,16,17} They are 1 of 17 communities nationwide selected to participate in this program. We conducted a study to characterize consumers' preferences regarding PHRs and to identify factors associated with potential use of PHRs in a community with innovative HIT initiatives under way.

METHODS

Study Design and Context

We conducted a cross-sectional telephone survey of consumer attitudes toward PHRs during the month of February 2009 in the greater Buffalo region of New York State, which is served by HEALTHeLINK. This study was conducted during the early stages of HEALTHeLINK's HIT activities.

Survey Administration and Population

Cornell Survey Research Institute, based in Ithaca, NY, administered a random-digit-dial telephone survey using a computer-assisted telephone system that included landline, unlisted, and cell phone numbers. Each number was called a maximum of 5 times if not answered. The survey took an average of 20 minutes to complete. Participants did not receive incentives. Institutional review board approval was provided by Weill Cornell Medical College.

Take-Away Points

In a community with health information technology initiatives under way, a large proportion of consumers expressed interest in using personal health records (PHRs) to manage their healthcare.

- Consumers preferred comprehensive PHRs that enable them to do a variety of activities and allow them to share their PHR data with their primary care physicians.
- However, the “digital divide” between those with varying levels of Internet access and experience, as well as concerns regarding the potential negative effects of PHRs on privacy and security of medical information, may hinder widespread adoption and use of PHRs.

Individuals eligible to participate included adult, English-speaking residents of the 8 counties comprising the greater Buffalo region of New York State. We excluded individuals responding at a business telephone number, and those who reported being too ill to or incapable of responding ([Appendix A](#)).

Survey Development

A literature review of consumer attitudes toward PHRs helped identify key domains to include in the survey. Wherever possible, previously validated questions from national surveys were incorporated.¹⁸⁻²³ Experts in healthcare quality and medical informatics and a representative from a consumer advocacy organization provided input. After pilot-testing the survey with 25 patients at an adult internal medicine clinic in an academic hospital setting, the survey was administered in 4 communities across New York State that had received state funding to support their HIT initiatives, including the greater Buffalo region (H. O'Donnell, V. Patel, L. M. Kern, et al, unpublished data; V. Patel, et al²⁴).

Survey Domains

The survey domains included attitudes toward and potential use of PHRs, preferences regarding PHRs, Internet experience, healthcare experiences, and demographic and health characteristics ([Appendix B](#)).

The survey described a PHR as “primarily used by you to view your health information and manage your healthcare (for example, to make appointments) on the Internet.” We asked consumers about their preferences, including the types of information they would like included in a PHR, the types of activities they would like to conduct using a PHR, and with whom they would feel comfortable sharing their information. We asked respondents to gauge the potential benefits they expected from their potential use of a PHR and how much they would be willing to pay for a PHR.

To assess Internet experience, we asked about Internet access, frequency of use, and the types of activities done online. We assessed healthcare experience by examining satisfaction with care, problems understanding doctors or written

■ **Table 1.** Select Characteristics of Respondents to Consumer Attitudes Toward Personal Health Records Survey (n = 200)

Characteristic	No. (%) ^a		
	Potential PHR User	Potential Nonuser	Total
Demographic characteristics			
Age, y ^b			
18-34	17 (12)	7 (12)	24 (12)
35-44	32 (23)	8 (13)	40 (20)
45-54	41 (30)	14 (23)	55 (28)
55-64	21 (15)	6 (10)	28 (14)
65+	28 (20)	25 (42)	53 (27)
Female	66 (47)	34 (57)	100 (50)
White	133 (96)	59 (98)	193 (97)
Education			
High school/GED or less	29 (21)	20 (33)	49 (25)
Some college or more	110 (79)	40 (67)	151 (76)
Income ^b			
Under \$30,000	20 (15)	20 (36)	41 (22)
\$30,000-\$60,000	38 (29)	15 (27)	53 (28)
\$61,000-\$100,000	38 (29)	13 (23)	51 (27)
>\$100,000	36 (27)	8 (14)	44 (23)
Employed ^b	94 (68)	29 (48)	123 (62)
Health status			
Self-rated health status			
Excellent or very good	85 (61)	28 (47)	113 (57)
Good or fair	48 (35)	30 (50)	79 (40)
Poor	6 (4)	2 (3)	8 (4)
Visited primary care doctor >3 times in past year	22 (37)	48 (35)	70 (35)
Chronic medical condition	67 (48)	29 (48)	97 (49)
Taking prescribed medication	89 (64)	39 (65)	129 (65)
Healthcare experience			
Caring for someone with chronic illness	30 (22)	7 (12)	37 (19)
Very satisfied or somewhat satisfied with quality of health care received in past 5 years	108 (78)	45 (76)	153 (77)
Collaborative medical decision making ^b			
I leave it to doctor to decide	18 (13)	15 (25)	33 (17)
Doctor and I decide together	91 (65)	28 (47)	119 (60)
Doctor makes recommendations	30 (22)	17 (28)	48 (24)
Internet experience			
Internet access available ^b	127 (91)	40 (67)	168 (84)
Frequency of Internet use ^b			
Rarely or not at all	15 (11)	22 (37)	37 (19)
Weekly or monthly	14 (10)	7 (12)	21 (11)
At least daily	110 (79)	31 (52)	142 (71)
Looked up health information online ^b	116 (83)	28 (47)	145 (73)
Privacy preferences			
Permit primary care physician to view PHR data ^b	134 (96)	53 (88)	188 (94)
Perceived impact of PHR on selected aspects of healthcare			
Improve privacy and security of medical information ^b	44 (32)	3 (5)	47 (24)
Improve understanding of own health ^b	111 (80)	17 (29)	129 (65)
Improve overall quality of healthcare ^b	107 (78)	17 (29)	125 (63)
Improve (reduce) healthcare costs ^b	59 (44)	10 (18)	69 (36)

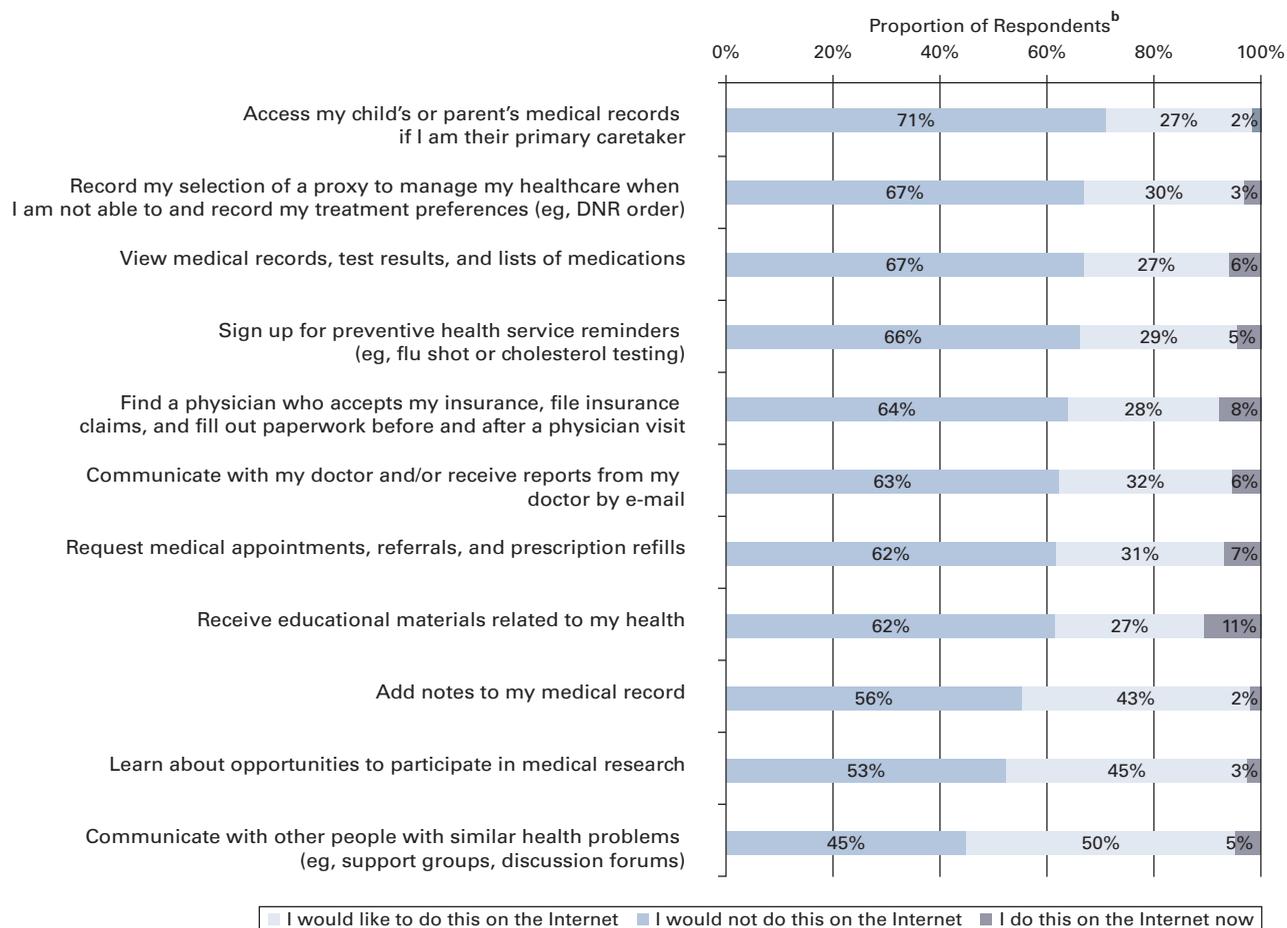
PHR indicates personal health record.

^aPercentages may not sum to 100 due to rounding; numbers may not sum to totals due to missing responses.

^bP ≤ .05.

Consumer Attitudes Toward Health Records

■ **Figure 1.** Consumer Preferences and Experiences With Managing Their Healthcare Online (n = 200)^a



^aResponses for individual items vary.

^bPercentages may not sum to 100 due to rounding.

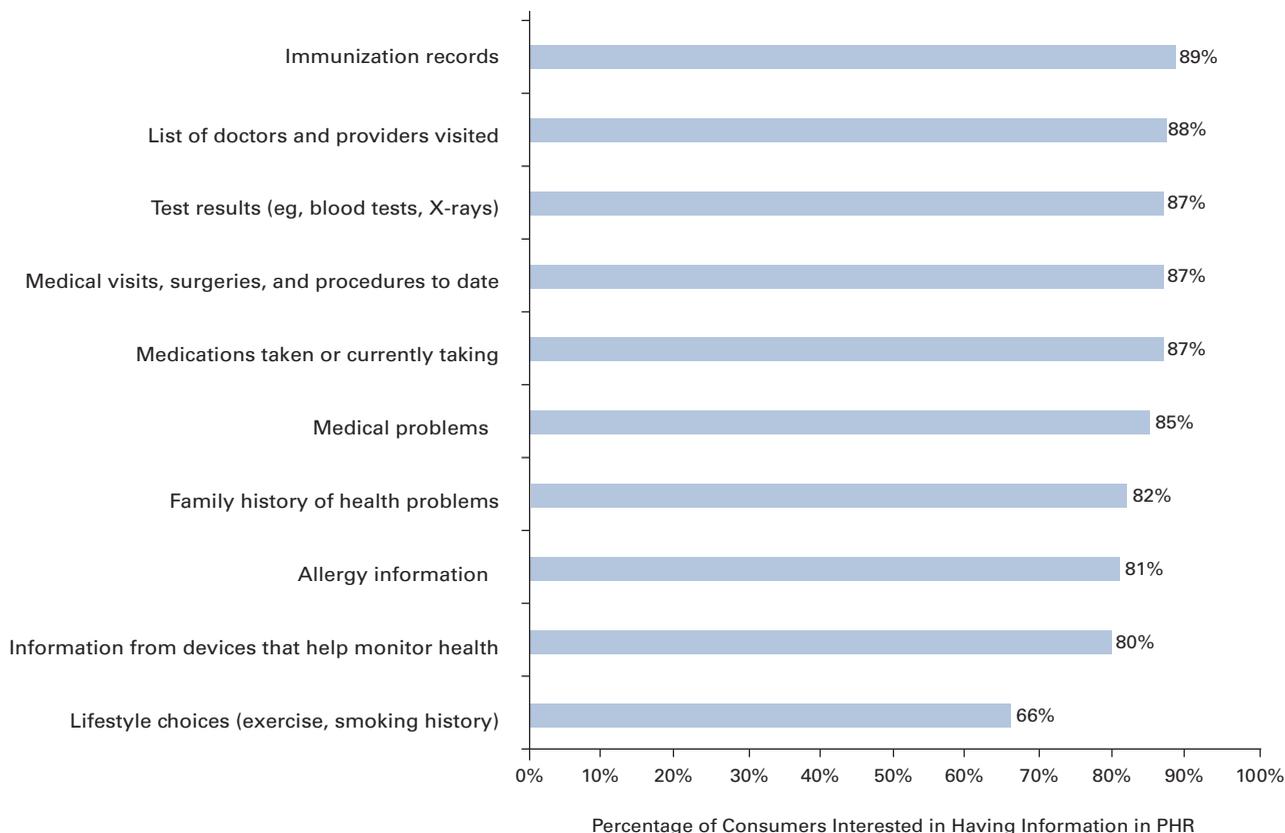
medical information, and interest in collaborative treatment decision making. We also asked about experiences caring for someone with a chronic condition. Health status–related items included questions about overall health status, use of prescribed medications, and treatment for chronic conditions.

Analyses

Our main outcome of interest was consumers' potential PHR use. We assessed this use based on their response to the question: "How often do you think you would use a personal health record to view your health information and manage your healthcare (for example, take care of appointments and insurance issues and communicate with your doctors) on the Internet?" We defined potential PHR users as individuals who indicated they would use PHRs at least every 6 months, and those who would not use PHRs as those who indicated they would use PHRs only "rarely or not at all."

In addition to using descriptive statistics to characterize respondents and examine the distribution of responses, we examined bivariate associations between potential use of PHRs and demographic and health characteristics, health-related experiences, Internet access and use, and attitudes toward PHRs. For categorical and dichotomous variables we assessed these bivariate associations using χ^2 tests or Fisher's exact test where appropriate. Tests were 2 sided. Based on univariable logistic regression models, we selected variables significantly associated with consumers' potential to use PHRs ($P \leq .05$) for inclusion in the multivariable logistic regression model. We examined 2-way associations using Fisher's exact test or χ^2 tests and pairwise concordance between selected independent variables, ultimately reducing the number of related variables represented in the final multivariable model. We used SAS 9.2 (SAS Institute Inc, Cary, NC) for data management and analyses.

■ **Figure 2.** Types of Information Consumers Wish to Include in Personal Health Records (n = 200)^a



^aResponses for individual items vary.

RESULTS

Sample

Of the 1750 phone numbers dialed, 252 individuals were reached and were considered eligible to participate in the survey (Appendix A). Seventy-nine percent (n = 200) of respondents completed the survey. The majority of the respondents were white (97%) and half were female (Table 1). Age varied, with over a quarter (27%) 65 years or older, 42% between 45 and 64 years old, and 32% under 44 years old. Although a majority of respondents had some college education (76%) or were employed (62%), annual household income varied widely (Table 1).

Health Status

Fifty-seven percent (n = 113) of respondents reported they were in excellent or good health, although almost half (49%) reported they had a chronic medical condition and 65% (n = 129) were taking a prescribed medication (Table 1).

Healthcare Experience

More than three-quarters (77%) of respondents reported they were somewhat or very satisfied with the quality of health-

care they received in the past 5 years (Table 1). Sixty percent (n = 119) reported that they collaboratively made decisions about their medical care with their doctor. Yet more than a third of respondents reported they experienced problems understanding their doctors (34%) or written medical information from their doctor or doctor's office (35%) at least occasionally.

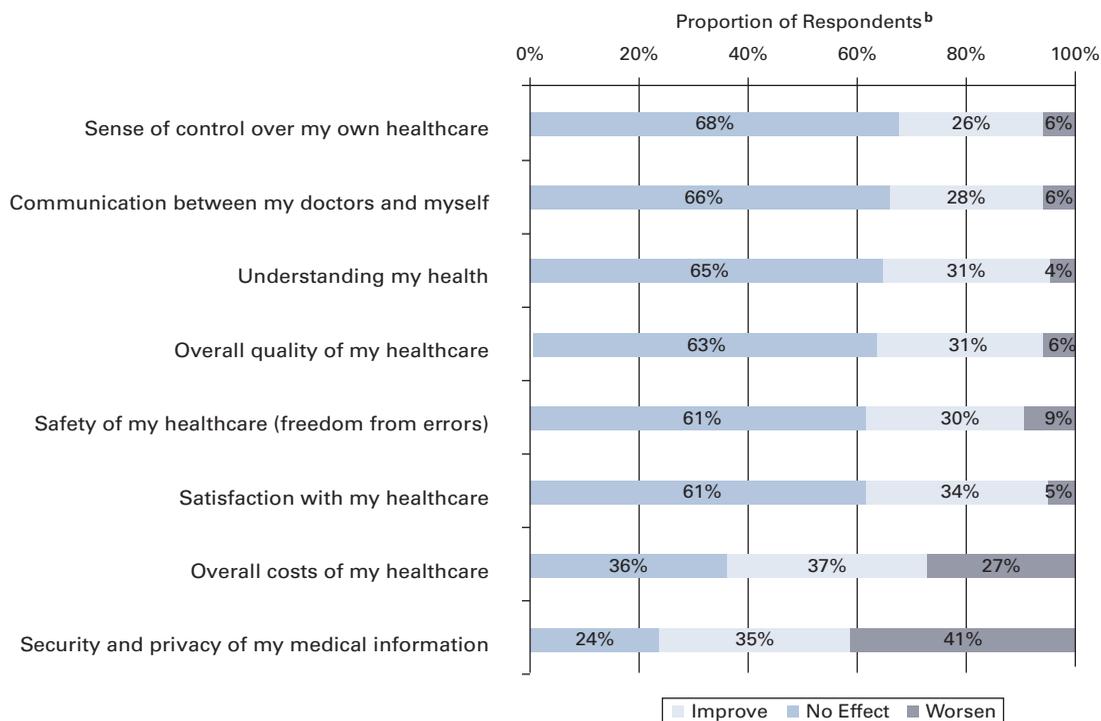
Internet Experience

Eighty-four percent of respondents (n = 168) reported having Internet access, and a majority (71%) reported at least daily Internet use. Respondents reported that they conducted a variety of activities online, including e-mailing (82%), looking up health- and disease-related information (73%), and making purchases (72%). Almost two-thirds (65%) reported that their doctor or healthcare provider currently use a computerized medical record system.

Although a majority of respondents reported experience looking up health information online, very few had experience beyond this activity (Figure 1). A small proportion reported receiving educational materials (11%) and searching for a physician who accepts their insurance and filing insurance claims (8%). Although very few respondents reported prior experi-

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■ **Figure 3.** Consumer Attitudes Regarding Perceived Effects of Personal Health Record Use (n = 200)^a



^aResponses for individual items vary.

^bPercentages may not sum to 100 due to rounding.

ence with managing their healthcare online, 65% (n = 128) of respondents reported they considered it would be easy or very easy for them to use a PHR to view their health information and manage their healthcare.

Current and Potential Use

Although we did not assess current use of a PHR application, few respondents reported using functionality associated with PHRs, such as communicating electronically with their provider (6%) or viewing medical records, test results, and medication lists (6%).

Seventy percent of respondents (n = 139) reported they would use a PHR at least every 6 months. Among potential users, over half (52%) reported they would use it once every 3 to 6 months, and more than one-third (37%) reported they would use it at least monthly. Few would use it weekly (9%) or daily (3%).

Preferences Regarding Personal Health Record Content and Activities

Consumers expressed interest in performing a wide range of activities to manage their healthcare online (Figure 1). Respondents expressed greatest interest in accessing their child or parent's medical record (71%), recording their selection of a healthcare proxy and end-of-life treatment preferences (eg, Do

Not Resuscitate order) (67%), and viewing medical records, test results, and medication lists (67%). A majority also expressed interest in electronically communicating with their physician (64%).

Most consumers indicated they would like their PHR to include a wide variety of information such as immunization records (89%), list of providers visited (88%), lab test results (87%), history of prior medical visits and surgeries (87%), and medication history information (87%; Figure 2). Consumers expressed less interest in including information about lifestyle choices (66%) such as exercise and smoking history.

Privacy Preferences

Consumers reported greater willingness to allow their primary care providers (94%), designated family members or friends (82%), or other healthcare providers treating them (80%) to view information in their PHR as compared with other entities such as health plans (45%), employers (13%), or the government (7%). An additional 4% did not want to share their information with anyone.

Payment Preferences

With regard to payment preferences, 63% (n = 125) reported they would not be willing to pay any monthly fee to

■ **Table 2.** Factors Associated With Consumers' Potential Use of Personal Health Records: Multivariate Analyses

Factor	Unadjusted OR (95% CI)	Adjusted OR (95% CI) (n = 177)	PValue for Adjusted OR
Demographic characteristics			
Annual household income \$30,000 or more ^a	3.1 (1.5, 6.4)	3.9 (1.3, 11.9)	.02
Healthcare experience			
Collaborative medical decision making			
I leave it to doctor to decide	Reference	Reference	
Doctor makes recommendations	1.5 (0.6, 3.6)	1.1 (0.3, 4.2)	
Doctor and I decide together	2.7 (1.2, 6.1)	2.3 (0.7, 7.6)	.23
Internet experience			
Looked up health information online ^b	5.8 (2.9, 11.3)	3.0 (1.1, 8.1)	.03
Privacy preferences			
Permit primary care physician to view PHR data ^b	3.5 (1.1, 11.7)	2.5 (0.4, 15.2)	.32
Perceived impact of PHR on selected aspects of healthcare^c			
Security and privacy of medical information	8.7 (2.6, 29.5)	4.7 (1.1, 20.1)	.04
Understanding of health	9.8 (4.9, 19.7)	3.7 (1.3, 11.1)	.02
Overall quality of healthcare	8.5 (4.3, 17.0)	3.6 (1.2, 10.6)	.02
Healthcare costs	3.5 (1.6, 7.5)	1.0 (0.3, 2.8)	.95
CI indicates confidence interval; OR, odds ratio; PHR, personal health record.			
^a Versus less than \$30,000.			
^b Yes versus no.			
^c Improve versus no effect or worsen.			

use a PHR. More than one-fifth (21%) reported they would be willing to pay \$5 or less per month to use a PHR, 10% would be willing to pay \$10 or less per month, 2% would be willing to pay \$15 or less per month, and 5% would be willing to pay \$20 or more per month to use a PHR.

Perceived Impact of Using PHRs

Perceived benefits of PHRs use varied (Figure 3). About two-thirds believed that PHR use would improve their sense of control over their own health (68%), communication with their doctors (66%), and safety of their care (61%). Few consumers believed that PHR use would improve overall healthcare costs (36%) or privacy and security of their medical information (24%).

Factors Associated With Potential Personal Health Record Use: Bivariate Results

Bivariate results show that potential PHR use is significantly ($P \leq .05$) higher among consumers who (1) perceive greater potential benefits from PHR use; (2) have greater Internet experience; (3) have fewer privacy concerns; (4) have a higher income, are employed, or are younger; and (5) make treatment decisions collaboratively with their provider (Table 1 and Appendix C).

Factors Associated With Potential Personal Health Record Use: Multivariate Results

Multivariate analyses (adjusted results are shown in Table 2) showed that potential PHR use is significantly ($P \leq .05$) higher among consumers who perceived that PHR use would improve the privacy and security of their medical information (odds ratio [OR] 4.7, 95% confidence interval [CI] 1.1, 20.1); had an annual household income of \$30,000 or more (OR 3.9, 95% CI 1.3, 11.9); perceived that PHR use would improve understanding of their health (OR 3.7, 95% CI 1.3, 11.1) or quality of care (OR 3.6, 95% CI 1.2, 10.6); and had experience looking up health- and disease-related information on the Internet (OR 3.0, 95% CI 1.1, 8.1).

DISCUSSION

Our study is among the first to characterize consumers' attitudes and detailed preferences related to PHRs in a community on the forefront of HIT initiatives. Although few consumers (between 6% and 7%) are currently using functionality associated with PHRs, we found that 70% of respondents would potentially use a PHR, a proportion considerably higher than that reported in recently conducted national surveys, which indicated that between 40% and 47% of respondents were in-

terested in PHRs.^{6,7} Most respondents desired a comprehensive PHR that enabled them to engage in a variety of healthcare activities. Individuals more likely to indicate they would potentially use a PHR perceived that PHR use would improve the privacy and security of their medical information, understanding regarding their health, or overall quality of care. Additionally, individuals with prior experience looking up health information online or with an annual household income higher than \$30,000 were more likely to indicate they would potentially use PHRs.

Potential barriers to PHR use may relate to a “digital divide” between those who have access to and experience using the Internet, and computers more broadly, and those who have very limited experience.^{12,25} Our finding that individuals with annual household incomes lower than \$30,000 were significantly less likely to potentially use a PHR also underscores this potential digital divide. Addressing gaps in both Internet accessibility and computer literacy will require outreach efforts to ensure that those individuals who may be more vulnerable are not denied the potential benefits of PHRs.^{12,24,25}

Although consumers desired a comprehensive PHR, a majority were unwilling to pay to use a PHR. Concerns regarding costs have been identified as a possible barrier to PHR use.⁷ Although PHRs are typically offered free of charge to consumers, as the cost model for PHRs continues to evolve, cost sharing in the form of fees might diminish PHR use and potentially exacerbate the digital divide.

Privacy and security concerns may also limit PHR use and affect the types of PHRs supported by consumers. These concerns may also be a barrier to consumer HIT application use generally.^{5-7,26} Consumers’ unwillingness to share their PHR data with health plans and employers may indicate less support for PHRs supported by third parties.^{6,27} However, our findings also suggest that consumers want PHRs with the capability to share information across providers. Thus, PHRs or patient portals that only allow viewing health information from 1 provider may also not be preferred.

Finally, despite high levels of consumer interest, provider resistance may limit widespread use of PHRs. Prior studies examining ambulatory care providers’ perceptions of PHRs suggest that many providers may be unaware of PHRs or have concerns regarding the accuracy of PHR data and the burden associated with the time required to interact with patients electronically.^{28,29} These concerns may be borne out by the broad range of information and functionality desired by patients, including the ability to directly communicate with their providers.

Although a number of potential barriers may limit PHR use, our findings suggest that consumers’ positive perceptions

regarding PHRs may facilitate initial adoption. Potential users who perceive a particular technology as beneficial are more likely to consider using it.^{30,31} However, if perceived benefits are not realized, initial adoption may not lead to consistent use.³²

Thus, addressing the limited functionality of PHRs is critical.³³ Incorporating functionality preferred by consumers—such as permitting access to a child’s or parent’s health-care information online—may improve the utility of PHRs. Consumers appear to value PHRs for their potential to help better manage the health of family members.^{6,7} The advent of the Veterans Administration and the Centers for Medicare & Medicaid Services “Blue Button” initiative, which enables users to view, print, or download their electronic health information, may greatly facilitate the use of PHR applications to manage and share health information with trusted parties.³⁴⁻³⁶ Medicare beneficiaries and veterans may find this tool particularly valuable because they may obtain services from a number of different healthcare providers and may need assistance of caregivers to manage their care. Consumers also want to use PHRs to record treatment preferences and to select a proxy to manage their healthcare decisions. This reflects the value patients place on having advance directives in place before they lack the capacity to make end-of-life care–related decisions.³⁷

Limitations

We examined consumer attitudes about PHRs in a unique region where a number of HIT initiatives are under way. Although this may limit generalizability in the short term, in the long term more communities are likely to resemble this one. Such communities could serve as “living laboratories” to help inform future HIT policy.¹² Although the survey methods we used included unlisted and cell phone numbers and we obtained a high response rate, selection bias may still be a problem as nonrespondents may differ from respondents. Frail, older patients with health problems—who may have the most to gain from PHR use—may be less likely to participate in a telephone survey, although almost a fifth of our sample were caregivers who may be caring for this population.

CONCLUSION

This study provides a baseline portrait of consumer attitudes toward PHRs in a community participating in HIT initiatives. As part of their Beacon Community Program, HEALTHeLINK is selecting a PHR vendor and will be using these analyses to help guide its development and outreach to consumers. Our study, among the first to identify factors associated with potential use of PHRs, found that a large proportion of consumers

want a comprehensive PHR that enables them to do a range of activities to manage their individual and family healthcare needs. However, a number of barriers related to the digital divide, including Internet access and experience, as well as privacy and security concerns, may limit adoption. Some of these barriers may be addressed through greater consumer outreach, through policies that strengthen the privacy and security safeguards, and policies that address providers' concerns. Developing functionality (eg, the Blue Button) that consumers find beneficial and that allows them to control access and sharing of their data may also help facilitate PHR use.

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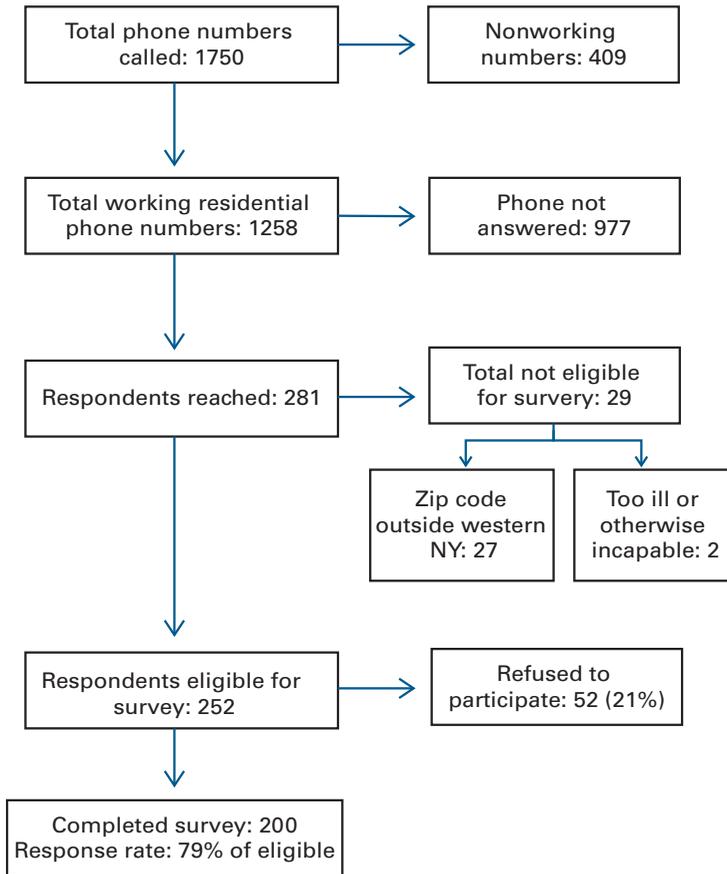
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■ **Appendix A.** Consumer Attitudes Toward Personal Health Record Survey Administration and Response



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■ Appendix B. Health Information Technology Evaluation Collaborative (HITEC) Consumer Health Information Technology Survey

Questions 1-9: These questions ask about your health and use of healthcare services.

1) In general, how would you rate your overall health?

- Excellent Very good Good Fair Poor

2) Are you being treated for any ongoing, persistent, or intermittent disease or medical condition such as high blood pressure, diabetes, heart or lung disease, mental health problem, or arthritis?

- Yes
 No

3) Are you taking any medication(s) prescribed by a doctor?

- Yes
 No

4) How many visits in the **past year** have you had with the following healthcare providers or facilities?

	None	1	2-3	More than 3
a) Primary Care Provider (including doctors and nurse practitioners)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Specialist (gynecologist, heart doctor, skin doctor, lung doctor, allergist, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Emergency Department	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Hospital (stayed at least overnight)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5) Overall, how satisfied are you with the quality of health care service you have received in the past **5 years**?

- Very satisfied Somewhat satisfied Neutral Somewhat dissatisfied Very dissatisfied

6) How often do you have problems understanding your doctors when they are talking to you about your health?

- Always Often Sometimes Occasionally Never

7) How often do you have problems understanding written medical information (such as forms, written instructions, or pamphlets) from your doctor or your doctor's office?

- Always Often Sometimes Occasionally Never

8) Which of the following **best** describes the way you make decisions about your medical care? Please choose one:

- My doctor(s) gives recommendations, but I make my own decisions about my medical care
 My doctor(s) and I make decisions about my medical care together as a team
 I leave it up to my doctor(s) to make the best decisions about my medical care

9) Are you currently caring for or making healthcare decisions for a family member or a close friend with a debilitating or chronic illness?

- Yes
 No

■ **Appendix B.** Health Information Technology Evaluation Collaborative (HITEC) Consumer Health Information Technology Survey (*Continued*)

Questions 10-14: These questions ask about use of computers and the Internet. The **Internet** is a collection of computers that are connected together that provides information and services.

10) Do you have a computer with Internet access available for use, either at home or work?

- Yes
- No

11) How often do you access the Internet?

- Several times a day
- About once a day
- Once weekly
- Once monthly
- Rarely or not at all

12) What is your primary source of information for issues in your community?

- Newspaper
- Television
- Radio
- Internet

13) Which of the following activities have you done on the Internet? Please check all that apply:

- Sent and received e-mails
- Purchased something online with a credit card
- Paid bills and/or managed bank accounts online
- Looked up information on health and diseases

14) Do any of your doctors or healthcare providers currently use a computer to store and access your medical record?

- Yes
- No
- Don't know

Questions 15-22: These questions ask about electronic **personal health records**. Unlike an electronic medical record that is primarily used by your healthcare providers, an electronic **personal health record is primarily used by you to view your health information and manage your healthcare (for example, to make appointments) on the Internet.**

15) Please indicate how strongly you agree or disagree with the following statement: I am interested in using a personal health record on the Internet to view my health information and manage my healthcare.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

16) Which of the following types of health information would you like to have as part of your personal health record? Please check all that apply:

- My allergies
- Test results (examples: blood tests, X-rays)
- Immunization records (a record of vaccines you have received)
- Medications I have taken or am currently taking
- List of doctors and healthcare providers I have seen
- Family history of health problems
- Medical problems
- Medical visits, surgeries, and medical procedures that I have had
- Lifestyle choices (example: exercise, smoking history)
- Information from devices that help me monitor my health (example: glucose from a diabetes meter)

Consumer Attitudes Toward Health Records

■ Appendix B. Health Information Technology Evaluation Collaborative (HITEC) Consumer Health Information Technology Survey (Continued)

17) For each of the activities below, please indicate if this is an activity you already do, you don't currently do but would like to be able to do, or you do not want to do **on the Internet**:

	I do this on the Internet now	I would like to do this on the Internet	I would <u>not</u> do this on the Internet
a) View my medical records, test results, and lists of medications I am taking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Add notes to my medical record	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Request medical appointments, referrals to other doctors, and prescription refills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Communicate with my doctor and/or receive reports from my doctor by e-mail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Find a physician who accepts my insurance, file insurance claims, and fill out paperwork before and after a physician visit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Sign up for reminders for preventative health services (such as the flu shot or cholesterol testing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Learn about opportunities to participate in medical research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Access my child's or parent's medical records if I am their primary caretaker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) Communicate with other people with similar health problems (examples: support groups, discussion forums, etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) Receive educational materials related to my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) Record my selection of a family member or friend to manage my healthcare when I am not able to and record my treatment preferences (example: Do Not Resuscitate order)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18) How often do you think you would use a personal health record to view your health information and manage your health care (for example, take care of appointments and insurance issues and communicate with your doctors) on the Internet?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
About once daily	Once weekly	Once monthly	Once every 3 to 6 months	Rarely or not at all

19) How do you think using a personal health record to view your health information and manage your health care on the Internet will affect the following:

	Greatly improve	Slightly improve	No effect	Slightly worsen	Greatly worsen
a) The security and privacy of my medical information	<input type="radio"/>				
b) Communication between my doctors and myself	<input type="radio"/>				
c) My understanding of my own health	<input type="radio"/>				
d) My sense of control over my own healthcare	<input type="radio"/>				
e) My worries about my own healthcare	<input type="radio"/>				
f) The safety of my care (freedom from errors)	<input type="radio"/>				
g) My satisfaction with my healthcare	<input type="radio"/>				
h) The overall quality of my healthcare	<input type="radio"/>				
i) The overall costs of my healthcare	<input type="radio"/>				

■ **Appendix B.** Health Information Technology Evaluation Collaborative (HITEC) Consumer Health Information Technology Survey (*Continued*)

20) How difficult or easy do you think it would be for you to use a personal health record to view your health information and manage your health care on the Internet?

- Very difficult Difficult Somewhat difficult Easy Very easy

21) What is the **maximum** amount of money you would be willing to pay **per month** to use a personal health record to view your health information and manage your health care on the Internet?

- Nothing-\$0 \$5 per month or less \$10 per month or less \$15 per month or less \$20 per month or more

22) Who would you give permission to view information in your personal health record? Please check all that apply:

- Designated family members or friends
- My primary care doctor
- Other doctors or healthcare providers who care for me (in clinic, the ER, or the hospital)
- My health plan
- My employer
- Government officials
- I would not give anyone permission

Questions 23-34: The following questions are to help us understand who is responding to this survey. This information will be used collectively; it will not be used to identify you individually.

23) How old are you?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75 or older

24) Are you male or female?

- Male
- Female

25) Are you of Hispanic or Latino origin or descent?

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

26) What is your race?

- White
- Black or African American
- Asian
- Native Hawaiian or Pacific Islander
- American Indian or Alaskan Native
- Mixed race/ethnicity
- Other

27) What is the primary language spoken in your home?

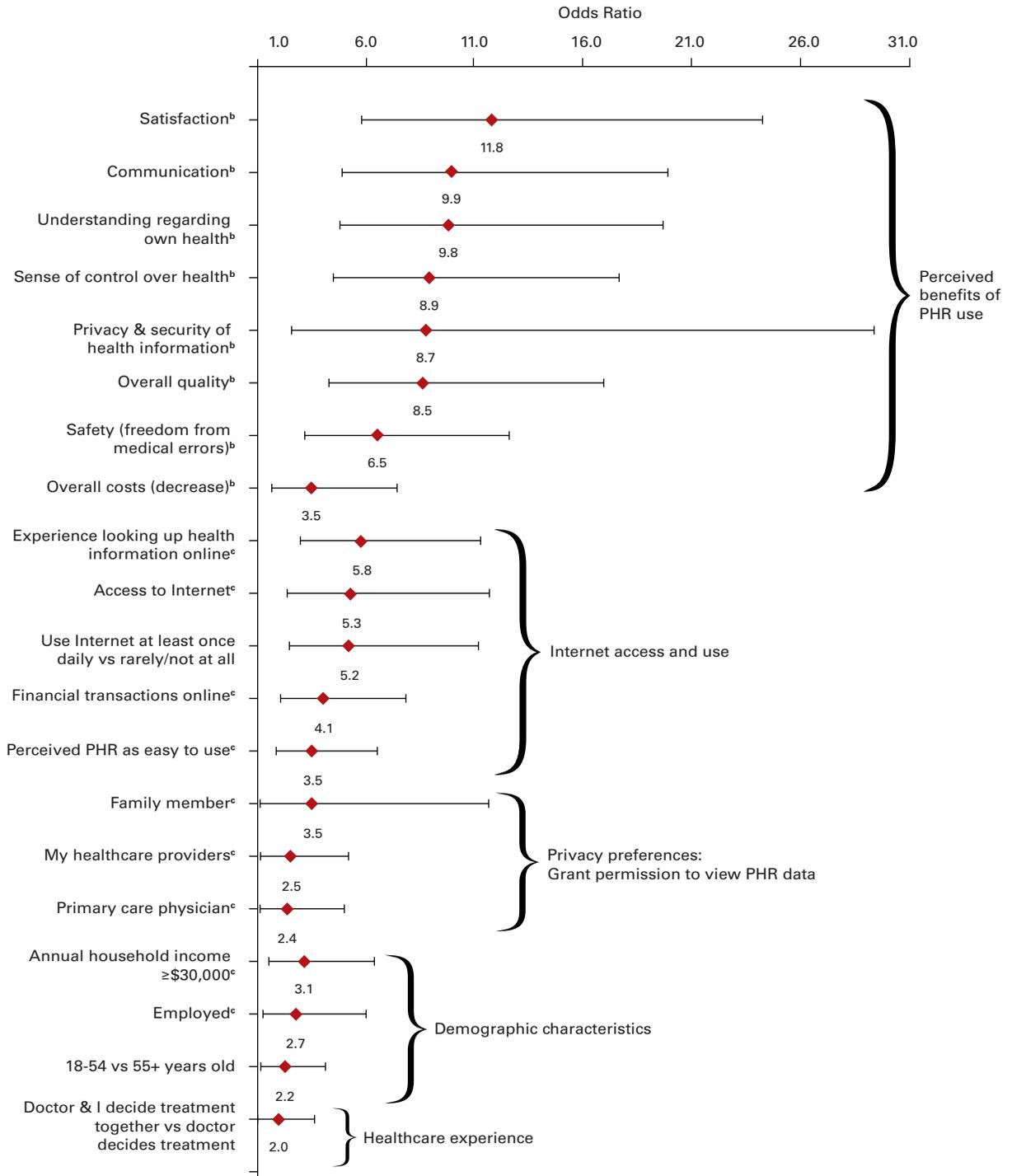
- English
- Spanish
- Chinese
- Other – Please state: _____

Consumer Attitudes Toward Health Records

■ Appendix B. Health Information Technology Evaluation Collaborative (HITEC) Consumer Health Information Technology Survey (*Continued*)

- 28) What is the highest grade or level of school you have completed?
- 8th grade or less
 - Some high school, but did not graduate
 - High school graduate or GED
 - Some college or 2-year degree
 - 4-year college graduate or greater
- 29) Are you covered by private health insurance or a government program, like Medicare?
- Private health insurance
 - Medicare
 - Medicaid
 - Other
 - I do not have health insurance
- 30) What is your employment status?
- Employed full or part time
 - Self-employed
 - Full time student
 - Homemaker
 - Disabled and not working
 - Currently unemployed, not disabled
 - Retired
- 31) Which describes the best estimate of your 2008 household income before taxes?
- Under \$30,000
 - \$30,000-\$60,000
 - \$61,000-\$80,000
 - \$81,000-\$100,000
 - More than \$100,000
- 32) How many people, including yourself, live in your household? _____
- 33) How many children aged 18 or under live with you? _____
- 34) What is your current zip code? _ _ _ _ _

Appendix C. Factors Significantly Associated With Personal Health Record Use^a



PHR indicates personal health record.
^aBased on univariable logistic regression results ($P \leq .05$).
^bImprove versus no effect/worsen.
^cYes versus no.