

Public Attitudes Toward Health Information Exchange: Perceived Benefits and Concerns

Linda Dimitropoulos, PhD; Vaishali Patel, PhD, MPH;
Scott A. Scheffler, MAppSt; and Steve Posnack, MHS, MS

Electronic health information exchange (HIE), the electronic sharing of health information among healthcare providers, patients, and other entities, promises an array of potential benefits for healthcare consumers through improved quality, safety, and efficiency.¹ Health information exchange may also provide consumers with new, more effective, methods for engaging with their healthcare providers to view and manage their health information. In February 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act was passed, which included substantial funding to support the nationwide adoption of health information technology (health IT) and HIE.

With the benefits of HIE come challenges and opportunities for keeping health information private and secure. To better understand these challenges and opportunities the Office of the National Coordinator for Health Information Technology (ONC) and the Agency for Healthcare Research and Quality supported the Health Information Security and Privacy Collaboration (HISPC) between 2006 and 2009. The HISPC was the first coordinated nationwide effort established to assess and address the effect of variations in organization-level business practices, policies, and state laws governing the privacy and security of electronic health information on nationwide electronic HIE.²

High levels of consumer concern about privacy and security may be a barrier to widespread participation in HIE.³⁻⁵ Yet, emerging studies also indicate that consumers recognize that there are benefits to the electronic collection, storage, and sharing of their health information, such as better coordination of care.^{3,4,6-9} What remains unclear is how consumer engagement and participation in HIE is affected by consumers' perceptions of the risks and benefits of HIE.

Understanding the specific privacy and security concerns of consumers, and assessing their preferences for specific safeguards, could help inform the further development of privacy and security policies and other measures that will be critical to the overall implementation of the HITECH Act. This study sought to examine the reasons underlying consumer concerns and how the perceived risks and benefits impact decisions about sharing

their health information. In addition, we examined the types of safeguards that could help address these concerns. We also sought to characterize consumers who expressed greater concerns and, therefore, may be less likely to participate in HIE.

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Objectives: To characterize consumers' attitudes regarding the perceived benefits of electronic health information exchange (HIE), potential HIE privacy and security concerns, and to analyze the intersection of these concerns with perceived benefits.

Study Design: A cross-sectional study.

Methods: A random-digit-dial telephone survey of English-speaking adults was conducted in 2010. Multivariate logistic regression models examined the association between consumer characteristics and concerns related to the security of electronic health records (EHRs) and HIE.

Results: A majority of the 1847 respondents reported they were either "very" or "somewhat" concerned about privacy of HIE (70%), security of HIE (75%), or security of EHRs (82%). Concerns were significantly higher ($P < .05$) among employed individuals 40 to 64 years old and minorities. Many believed that HIE would confer benefits such as improved coordination of care (89%). Overall, 75% agreed that the benefits of EHRs outweighed risks to privacy and security, and 60% would permit HIE for treatment purposes even if the physician might not be able to protect their privacy all of the time. Over half (52%) wanted to choose which providers access and share their data.

Conclusions: Greater participation by consumers in determining how HIE takes place could engender a higher degree of trust among all demographic groups, regardless of their varying levels of privacy and security concerns. Addressing the specific privacy and security concerns of minorities, individuals 40 to 64 years old, and employed individuals will be critical to ensuring widespread consumer participation in HIE.

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**For author information and disclosures,
see end of text.**

Take-Away Points

A national survey of adults regarding electronic health information exchange (HIE) found that greater participation by consumers in determining how HIE takes place could engender a higher degree of trust among all demographic groups, regardless of their varying levels of privacy and security concerns.

- Statistically significant variations in concerns about the security of electronic health records and HIE were found among employed individuals 40 to 64 years old, and minorities, indicating that HIE policies need to account for demographic and social factors in order to encourage widespread participation.

- Consumers desire greater transparency and control over who accesses their personal information.

METHODS

A random-digit-dial (RDD) telephone survey was conducted, in English, among adults 18 years or older residing in the United States between August and November of 2010. The sample consisted of 12,795 cell phone–only households and 15,036 landline households. This was intended to be an exploratory study, and we did not oversample for minority subgroups or conduct the survey in Spanish.

The methods for weighting cell phone and landline RDD studies are still in their infancy. We followed a methodology proposed by Brick¹⁰ and the guidelines in a report from the American Association for Public Opinion Research (AAPOR) Cell Phone Task Force to weigh the data.¹¹ We created base weights using the initial probabilities of selection and adjusted to account for nonresponse using a weight-class approach based on region. We then used a composite estimator to adjust the weights to account for dual, overlapping sample frames and compared weight sums to control totals from the 2009 National Health Interview Survey for post-stratification.

The survey methodology was approved by an Institutional Review Board at RTI International.

Survey Development

The survey (see [eAppendix](#)) sought to examine consumers' detailed preferences and attitudes related to privacy and security of HIE. The survey domains included: 1) demographic information; 2) current computer and Internet usage; 3) experience with the healthcare system and general knowledge about health information; 4) general attitudes toward HIE; 5) specific questions about the privacy and security of HIE, and awareness of regulations governing privacy and security; and 6) safeguards that might address these concerns. The questionnaire items underwent multiple rounds of cognitive testing for concept clarity to ensure a general audience could understand them. The survey was then programmed as a computer-assisted telephone interview instrument.

Analysis

We used descriptive statistics to characterize respondents and attitudes. We also examined bivariate associations between consumer characteristics and attitudes toward privacy and security of HIE and electronic health records (EHRs). For categorical and dichotomous variables we assessed these bivariate associations using χ^2 test, or Fisher exact test where appropriate. Tests were 2-sided and Bonferroni corrections applied to multiple comparisons.

We ran logistic regression models using an iterative, backward, stepwise selection procedure to examine the association between levels of concern about the security of EHR and security of HIE with the following variables: age (18-39, 40-64, 65+); race (white, black, Hispanic, other); gender; education (>high school vs <high school); employment (full time vs part time); health insurance (private, public vs none); Internet usage (most or every day vs infrequent use); Internet banking or purchasing experience (yes/no); and annual number of doctor visits (≥ 3 visits or ≤ 2). We used SAS version 9.2 (SAS Institute Inc, Cary, North Carolina) and SUDAAN version 10.0.1 (RTI International, Research Triangle Park, North Carolina) for analyses.

RESULTS

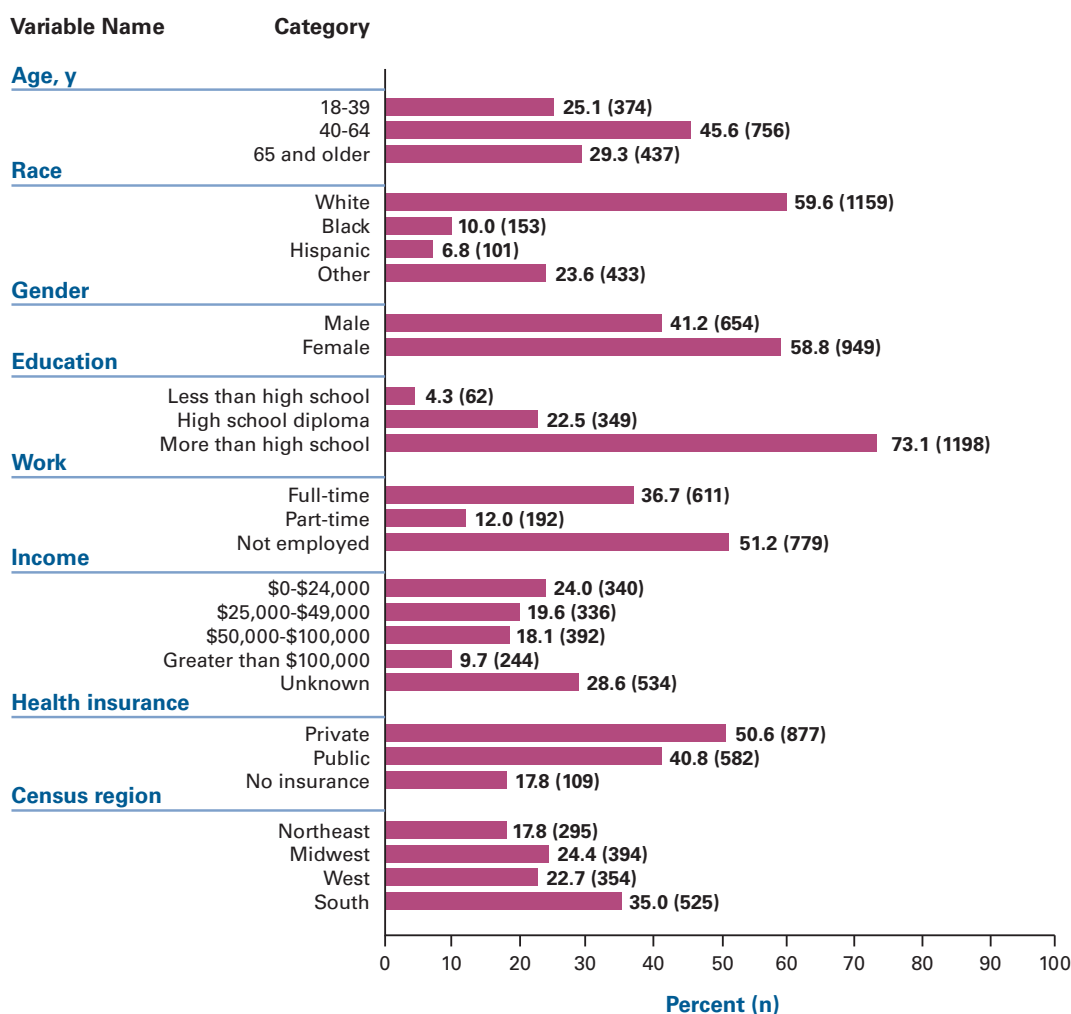
Of the 1847 respondents, 68% (n = 1261) were from the landline phone household sample. Approximately 40% (n = 8297) of the sample was ineligible; most were nonworking numbers, businesses, or fax/modems. Among those that were eligible, 6607 (55%) refused to participate. Additionally, some households (n = 3463) did not answer the phone despite 15 callbacks, while others had language barriers or other impairments (n = 472) that prevented them from completing the survey.

Twenty-five percent of the respondents were between 18 and 39 years old, 46% were between 40 and 64 years old, and 29% were 65 years or older (**Figure 1**). According to 2009 US Census data, these age groups are 41%, 43%, and 16%, respectively. A majority of respondents were white (60% vs 72% US) or female (59%). Almost three-quarters (73% vs 84.6% US) of respondents attended high school or beyond.¹² Half reported they were either unemployed, retired, or a student.

Concerns About the Security of EHR and HIE

Of all respondents, 82% reported that they were “very” (59%) or “somewhat” concerned (23%) about the security of EHR. Additionally, 75% of respondents reported being “very” (45%) or “somewhat” concerned (30%) about the

■ **Figure 1. Respondent Characteristics**



security of HIE. Security was described as “the protections (policies and technologies) used to keep unauthorized individuals from being able to access and view your electronic health information.” Most of the reasons underlying consumers’ concerns about the security of HIE related to the potential misuse of their personal health information for fraud or identity theft (93%), posting of personal data on the Internet (90%), the receipt of unsolicited advertising and junk mail (88%), or discrimination (77%). Another reason for consumers’ concern regarding the security of HIE was the potential loss of their personal health information (82%).

Consumers With Greater Concern Regarding the Security of EHR

Multivariate analyses regarding concerns about the security of EHR are significantly higher ($P < .05$) among respondents between the ages of 40 and 64 years (odds ratio [OR]

2.1, 95% confidence interval [CI] 1.5-2.9), 65 years and older (OR 1.6, CI 1.1-2.3), and full-time employed individuals (OR 1.5, CI 1.1-2.0). Race ($P = .0684$) and frequency of physician visits ($P = .1092$) approached significance.

Consumers With Greater Concerns Regarding the Security of HIE

Multivariate analyses show that concerns regarding the security of HIE are significantly higher ($P < .01$) among respondents between the ages of 40 and 64 years (OR 1.6, 95% CI 1.1-2.1), full-time employees (OR 1.7, 95% CI 1.3-2.4), and minorities including black (OR 1.6, 95% CI 1.0-2.3), Hispanic (OR 1.7, 95% CI 1.0-2.7), and other minorities (OR 1.7, 95% CI 1.1-2.6).

Concerns About the Privacy of HIE

Nearly 70% of respondents were either “very” (35%) or “somewhat” (35%) concerned about the privacy of HIE.

■ **Table.** Willingness to Share Information and Benefits of EHR Versus Risks Among Individuals Either “Very” or “Somewhat” Concerned About Privacy and/or Security of EHR and HIE

	Would Permit the Physician to Share Their Information for Treatment Even If They May Not Be Able to Protect Privacy All of the Time				The Benefits of EHR Outweigh Any Potential Risk to Privacy or the Security of Patient Information			
	n	Yes, %	No, %	P	n	Yes, %	No, %	P
Very concerned about privacy of HIE	538	51.3	48.7	.5392	578	58.0	42.0	<.0001
Somewhat concerned about privacy of HIE	559	59.1	40.9	<.0001	595	79.2	20.8	<.0001
Very concerned about security of EHR	939	50.2	49.8	.9071	976	65.5	34.5	<.0001
Somewhat concerned about security of EHR	372	66.2	33.8	<.0001	385	85.6	14.4	<.0001
Very concerned about security of HIE	711	47.9	52.1	.2588	737	64.6	35.4	<.0001
Somewhat concerned about security of HIE	477	60.6	39.4	<.0001	491	80.3	19.7	<.0001

EHR indicates electronic health record; HIE, health information exchange.

Concern about privacy was described as the concern that an unauthorized individual would gain access to or view their personal health information without their permission. The most frequent reasons underlying consumer privacy concerns were being denied credit (58%) or employment (54%). When asked about how *likely* certain events would occur if their health information was accessed by someone that did not have permission, the majority reported that it was “very” or “somewhat” likely that identity theft (74%) or fraud (65%) would occur, and about half of the respondents reported it was at least “somewhat” likely that they would be discriminated against (49%).

Benefits and Risks Associated With HIE

Consumers reported potential risks and benefits associated with HIE more generally. In addition to concerns regarding access by unauthorized individuals, a majority of respondents (75%) reported concerns that it was at least “somewhat likely” that their information would be accidentally linked to the wrong person or accidentally released to the wrong physician (65%).

Yet, respondents also indicated that HIE would have benefits. They thought HIE was “very likely” or “somewhat likely” to help doctors better coordinate care (89%), reduce the number of medical tests needed (81%), improve medical care (78%), and improve quality of care (76%).

When asked which of these potential risks or benefits was the most important, consumers reported that benefits were most important. These included the ability of HIE to better coordinate care (23%), improve quality of care for the country (16%), and for themselves personally (15%).

We also asked about the tradeoffs associated with privacy and security. Nearly 75% of respondents agreed that an EHR has benefits that outweigh any risk to privacy and security.

Even among respondents who reported being “somewhat” or “very” concerned, a significant majority agreed that the benefits of HIE outweigh the risks (Table).

Sixty percent of respondents reported they would be willing to allow physicians to share their information electronically for treatment, even if they may not be able to protect their privacy all of the time. Approximately half of those who reported they were “very” concerned about privacy or security of EHR and HIE would permit their physician to share their information for treatment even if they may not be able to protect privacy all of the time (Table). A significantly higher proportion of individuals who reported they were “somewhat” concerned would allow their physician to do so ($P < .0001$).

Consumer Preferences Regarding Who Should Be Involved in Determining Privacy Settings for HIE

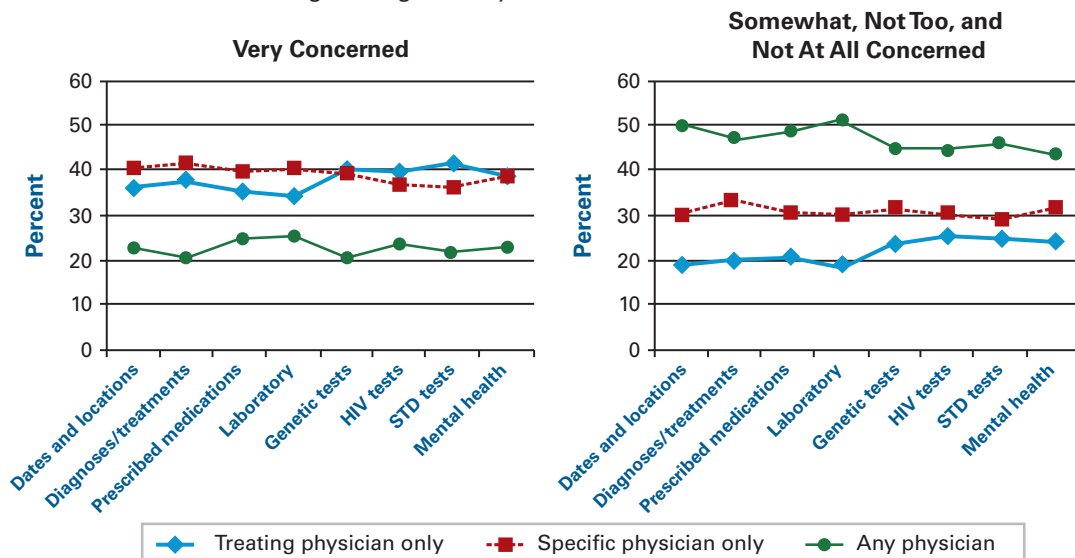
Most individuals desired to have their physicians involved in determining their privacy settings. Over a third (39%) preferred that they, their physicians, and their family determine their privacy setting. A little over a quarter (26%) indicated that they and their physician could determine this. Few individuals wanted to have the sole responsibility (18.5%) or have their physician (4.8%) have the sole responsibility in determining their privacy settings.

Over three-quarters (79%) indicated they would want a physician to override their privacy settings in a medical emergency in order to treat them.

Consumer Preferences Regarding Setting Limits on Who May Access Their Health Information

Only about a third of respondents indicated that it was important to limit access to their health information by family (39%) or physicians (32.9%) involved in their healthcare.

■ **Figure 2.** Preferences for Sharing Among the Very Concerned Versus All Others



HIV indicates human immunodeficiency virus; STD, sexually transmitted disease.

However, most indicated that it was “somewhat” or “very” important to be able to limit access among physicians not involved in their care (69.1%), friends (68.7%), employers (67.6%), and payers (67.1%).

Permission would be granted by 90% of respondents to electronically share their health information with at least some healthcare providers. Over half (52%) reported they preferred limiting access specifically to chosen providers, whereas 38% indicated they would permit access to any provider.

Most respondents (71%) reported they would be “somewhat” or “very” likely to request a list of disclosures their physician made through an EHR about treatment, payment, and other healthcare purposes. Among those requesting disclosure, nearly all responders wanted to know what was disclosed (95%), who disclosed it (95%), to whom it was disclosed (97%), and why it was disclosed (97%).

Data Segmentation

About half (49%) of respondents reported that they would be willing to share all of their health information with their healthcare provider, less than a third (32%) would share some of it, and about 12% would refuse to share any information. Respondents who were very concerned about privacy of HIE or security of EHR or HIE were significantly more likely to prefer limiting data sharing to either physicians of their choosing or the treating physician, and not sharing data with any physician, in comparison to those who expressed fewer concerns (Figure 2).

DISCUSSION

Overall, we found that consumers remain concerned about privacy and security, and these concerns are greater among those aged 40 to 64 years, employed individuals, and minorities. Overall consumer concerns related to HIE focused on unauthorized access, and the potential misuse of their information for fraud and by other parties for denying credit or employment. Despite these concerns, most consumers recognize the benefits of HIE and many believe that the benefits outweigh privacy and security concerns. Although most consumers would permit HIE among at least some of their healthcare providers, about half wanted to choose which providers could access and share their data, and a majority wanted to limit access among those not directly involved with their treatment.

The reasons underlying consumer concerns suggest the need to improve individuals’ engagement in decisions about who determines access to their health information and the need to continue to improve consumer trust in the technology and the healthcare system. Education about data security, consumer rights, and recourse in cases of unauthorized disclosures and misuse of data may help address the reasons underlying consumer concerns and build trust in the use of electronic information.

Providing consumers with greater access to and control over their electronic health information may also help increase consumer confidence in electronic HIE. The ability to readily obtain a list of disclosures may help build a better

sense of trust between individuals and the healthcare system by making it easier for them to monitor data accuracy and to better understand who has accessed their information and why.

Limitations and Future Research

Care should be taken in generalizing these results. Although the study is cross-sectional, the total number of respondents is only 1847 and many important demographic subgroups are not heavily represented. Although we did not oversample racial and ethnic subgroups or conduct the interview in Spanish, participation by minority and racial and ethnic subgroups was higher than in the overall US population. The findings indicate that the concerns held by the general population may be more strongly held among these groups consistent with Patel et al.¹³ Given the modest scale of the study, the results should be interpreted as exploratory for future research.

Policy Implications of Findings

These findings suggest that as policymakers establish privacy and security policies for HIE, consideration should be given to variations in concerns expressed by specific demographic groups. Moreover, policymakers should recognize that they have a shared responsibility to assure public trust in HIE. Ultimately, reaching the intended goals of HIE will require greater effort to educate consumers about HIE and make HIE data practices more transparent.

Author Affiliations: From Center for the Advancement of Health IT (LD), RTI International, Chicago, IL; Statistics and Epidemiology (SAS), RTI International, Research Triangle Park, NC; Office of the National Coordinator (VP, SP), Washington, DC.

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Address correspondence to: Linda Dimitropoulos, PhD, Director, Center for the Advancement of Health IT, RTI International, 230 W Monroe St, Suite 2100, Chicago, IL 60606. E-mail: lld@rti.org.

REFERENCES

- 1. President's Council on Advisors on Science and Technology.** Report to the President realizing the full potential of health information technology to improve health care for Americans: the path forward. <http://www.whitehouse.gov/sites/default/files/microsites/ostp/pcast-health-it-report.pdf>. Published December 2010. Accessed December 10, 2010.
- 2. Office of the National Coordinator for Health Information Technology.** Health Information Security and Privacy Collaboration (HISPC). http://healthit.hhs.gov/portal/server.pt?open=512&objID=1240&parentname=CommunityPage&parentid=8&mode=2&in_hi_userid=10882&cached=true. Published January 2010. Updated April 9, 2010. Accessed August 17, 2011.
- 3. O'Donnell HC, Patel V, Kern LM, et al.** Healthcare consumers' attitudes towards physician and personal use of health information exchange. *J Gen Intern Med.* 2011;26(9):1019-1026.
- 4. Patel VN, Dhopeswarkar RV, Edwards A, Barrón Y, Sparenborg J, Kaushal R.** Consumer support for health information exchange and personal health records: a regional health information organization survey. [published online ahead of print July 29, 2010] *J Med Syst.*
- 5. Wen KY, Kreps G, Zhu F, Miller S.** Consumers' perceptions about and use of the Internet for personal health records and health information exchange: analysis of the 2007 Health Information National Trends Survey. *J Med Internet Res.* 2010;12(4):e73.
- 6. California HealthCare Foundation.** Consumers and Health Information Technology: A National Survey. April 2010. <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/C/PDF%20ConsumersHealthInfoTechnologyNationalSurvey.pdf>. Accessed April 13, 2010.
- 7. NPR/Kaiser Family Foundation/Harvard School of Public Health.** The Public and the Health Care Delivery System. <http://www.kff.org/kaiserpolls/upload/7888.pdf> (top line report) and <http://www.kff.org/kaiserpolls/upload/7887.pdf> (summary and charts). Published April 2009. Accessed August 9, 2011.
- 8. Simon SR, Evans JS, Benjamin A, Delano D, Bates DW.** Patients' attitudes toward electronic health information exchange: qualitative study. *J Med Internet Res.* 2009;11(3):e30.
- 9. Kaiser Permanente.** Health care information technology summit survey results revealed. <http://xnet.kp.org/newscenter/ehr/2007/050207/healthcareitsummit.html>. Published May 2007. Accessed August 9, 2011.
- 10. Brick M, Dipko S, Presser S, Tucker C, Yuan Y.** Nonresponse bias in a dual frame sample of cell and landline numbers. *Public Opin Q.* 2006;70(5):780-793.
- 11. AAPOR Cell Phone Task Force.** New Considerations for Survey Researchers When Planning and Conducting RDD Telephone Surveys in the U.S. With Respondents Reached via Cell Phone Numbers. http://aapor.org/AM/Template.cfm?Section=Cell_Phone_Task_Force&Template=/CM/ContentDisplay.cfm&ContentID=2818. Published 2010. Accessed May 22, 2008.
- 12. U.S. Census Bureau.** Population estimates; national characteristics, national sex and age. <http://www.census.gov/popest/national/asrh/NC-EST2009-sa.html>. Accessed August 14, 2011.
- 13. Patel VN, Dhopeswarkar RV, Edwards A, et al.** Low-income, ethnically diverse consumers' perspective on health information exchange and personal health records. *Inform Health Soc Care.* 2011;36(4):233-252. ■

■ **eAppendix.** Attitudes Toward Electronic Health Information Exchange and Associated Privacy and Security Aspects

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0990-0359. The time required to complete this information collection is estimated to average (18 minutes) per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, OS/OCIO/PRA, 200 Independence Ave., S.W., Suite 537-H, Washington, D.C. 20201, Attention: PRA Reports Clearance Officer.

Section 1. Internet usage.

We would like to start by asking you about your use of the Internet.

1. Do you use a computer or handheld device to access the Internet?
 - a. Yes
 - b. No

If no, skip to section 2.
2. How often do you access the Internet?
 - c. Every day (7 days per week, typically)
 - d. Most days (4-6 days per week, typically)
 - e. Some days (1-3 times per week, typically)
 - f. Rarely (less than 3 times per month)
 - g. Never (ie, person has access but doesn't use it) **Skip to section 2**
3. I'm going to read a list of reasons people access the Internet. For each reason, please say yes or no to indicate whether you have accessed the Internet for this activity **in the past 30 days:**
 - a. Do any banking online
 - b. Buy a product
 - c. Use a social networking site (such as Facebook, MySpace, LinkedIn)
 - d. Look for health/medical information
 - e. Use a search engine, check the weather, look for information on a hobby or interest, or get news
 - f. Watch a video, download music or download a podcast
 - g. Buy or make travel reservations
4. How many hours do you spend on the Internet in a typical week?
_____ hours per week

Section 2. Current relationship with healthcare providers and general knowledge about health information/medical records.

Before I read the next set of questions, I want to define what we mean by primary care doctor. When we say primary care doctor or healthcare provider we mean the medical professional you would see if you need a check-up, want advice about a health problem, or get sick or hurt.

Now I have a few general questions about your healthcare providers and the kinds of information most healthcare providers keep.

5. Are you the primary person responsible for keeping track of your health information? By health information we mean immunization records, medical test results, current medications you may be taking, family history, and allergies.
 - a. Yes
 - b. No
6. Are you the primary person responsible for keeping track of the health information for 1 or more family members?
 - a. Yes
 - b. No
7. Please tell me how many different doctors and other healthcare providers, including dentists, you have visited in the past 3 years. (We are not asking about the number of visits, just the number of doctors you have seen for your own care.)
 - a. 1 to 2
 - b. 3 to 5
 - c. 6 to 9
 - d. 10 or more
 - e. None

8. Please think about your primary care doctor and indicate how much you agree or disagree with the following statement:

I believe that my doctor needs to know everything about my medical history to take good care of me. (By medical history we are referring to the questions you are usually asked at the start of a medical visit. For example, family history, allergies, immunization records, etc.) Do you...

- a. Strongly agree?
- b. Somewhat agree?
- c. Neither agree nor disagree?
- d. Somewhat disagree?
- e. Strongly disagree?

9. Now, please think about how you make healthcare decisions and tell me which of the following statements best represents your preferences:

- a. I would rather have my doctor make decisions about what's best for my health than to be given a whole lot of choices, or
- b. I would rather work together with my doctor to make decisions about what's best for my health

10. When you visit your primary care doctor, does he or she use a computer in the examination room to enter information about your visit?

- a. Yes
- b. No

11. As far as you know, if you request a copy of your medical record is your doctor required by law to give it to you?

- a. Yes
- b. No

12. How often do you think you would access your medical record information if it was available electronically through a secure Web site? By secure Web site, we mean something similar to the sites currently available for Internet banking. Would you say...

- a. Very often
- b. Sometimes
- c. Never

13. When you visit your primary care doctor do you feel confident that you can provide a complete and accurate medical history? By medical history we mean the questions you are usually asked at the start of a

medical visit. For example, family history, allergies, immunization records, etc.

- a. Yes
- b. No

14. Should patients be able to control whether or not a doctor can access medical record information collected by another doctor?

- a. Yes
- b. No **Skip to 15**

- 14a. Should patients be able to control access to medical record information collected by another doctor if it means that treatment could be delayed or that doctors could have to make treatment decisions without complete information?

- a. Yes
- b. No

15. Does a patient have a responsibility to provide a doctor with complete information about their medical history?

- a. Yes
- b. No

16. Have you ever purposely kept any part of your medical history from your doctor?

- a. Yes
- b. No

17. Have you ever asked a doctor not to write down your health problem in your medical records, or asked the doctor to put a less serious or less embarrassing diagnosis into the record than was actually the condition?

- a. Yes
- b. No

Section 3. General attitudes toward the use of electronic health information exchange.

Electronic health records allow your doctor to record and store health information on a computer. This may make it easier and faster for doctors to share your health information with your other doctors. The sharing of electronic health information is known as electronic health information exchange.

Using electronic health records may also provide you with new ways to review and manage your health information. It may also provide new ways for you to interact with your healthcare providers.

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18. Now I am going to read a list of some of the ways that electronic health records may change the way you review and manage your health information. I'd like you to tell me how useful each of these activities may be to you.

If you could <insert a, b, c...> through a secure Internet connection, would that be very useful, somewhat useful, not very useful, or not at all useful to you?

- a. access the dates and locations of your doctor and hospital visits
 - b. access the dates and types of immunizations you have had
 - c. access your medication history and information about your allergies
 - d. access your medical tests including the date, the doctor who ordered them, and the test results (for example, cholesterol values)
 - e. receive reminders, request lab results, request a referral, and schedule or cancel appointments electronically
 - f. request prescriptions or prescription refills
 - g. review summaries after office visits, and review your medical history online to make sure the information is complete and accurate
 - h. track certain medical information over time such as weight, blood pressure readings, cholesterol levels, or other important information
 - i. participate in e-visits such as consulting with your doctor through secure email, online chat, or videoconferencing
19. Do you currently have electronic access to your medical information? (This includes clinical and laboratory results.)
- a. Yes
 - b. No
20. Do you currently have an electronic personal health record, or PHR? By PHR, we mean an electronic application that allows you to access, enter, and manage some of your health information.
- a. Yes
 - b. No **Skip to 21**
- 20a. When was the last time you used your PHR? Would you say within the past 3 months, the past 6 months, the past 12 months, or more than a year ago?
- a. Within the past 3 months
 - b. Within the past 6 months

- c. Within the past 12 months
- d. More than a year ago

Section 4. Associated privacy and security aspects of electronic health information exchange.

21. I'm going to read you a statement and please tell me if you agree or disagree with it: "The benefits of electronic medical records, such as better care in an emergency and a reduction in medical errors, outweigh any potential risk to patient privacy or the security of patient information."
- a. Strongly agree
 - b. Somewhat agree
 - c. Somewhat disagree
 - d. Strongly disagree
 - e. Don't know/unsure
22. Some people are concerned that electronic health information exchange will make it easier for unauthorized individuals to access or view their personal health information.
- How likely do you think it is that unauthorized individuals will access your personal health information if it is collected and shared electronically without your permission?
- a. Very likely
 - b. Somewhat likely
 - c. Not very likely
 - d. Not at all likely
23. I am going to read a list of reasons some people are concerned about the privacy of electronic health information exchange. For each of the following, please tell me whether you are very concerned, somewhat concerned, not too concerned, or not at all concerned.

How concerned are you that <insert a-e>? Would you say that you are very concerned, somewhat concerned, not too concerned, or not at all concerned?

- a. Potential employers will access your records and deny you employment
- b. Insurance companies will access your records and deny you coverage
- c. Credit card and finance companies will access your records and deny you credit
- d. Your doctor will see information that you do not want him or her to see
- e. Someone else may see your personal health information

■ POLICY ■

24. If your health information were accessed by someone who did not have permission, how likely do you think it is that any of the following would happen? Respond with very likely, somewhat likely, not very likely, or not at all likely
- a. You would be discriminated against
 - b. You would experience personal embarrassment
 - c. You would experience professional embarrassment
 - d. The information would be used to commit fraud
 - e. The information would be used to steal your identity

- 24a. Is there anything else you think might happen if your electronic health information were accessed by someone who did not have permission?
[Fill response]

25. How important is it to you to limit <insert a-f> from accessing or viewing your health information – very important, somewhat important, not too important, or not at all important?
- a. Family
 - b. Friends
 - c. Your employer
 - d. Your health insurance company or health plan
 - e. Doctors and healthcare professionals involved in your care
 - f. Doctors and other healthcare professionals NOT involved in your healthcare

26. How concerned are you about the security of electronic health records? By security, we mean the protections (policies and technologies) used to keep unauthorized individuals from being able to access and view your electronic health information (to keep your information private).
- a. Very concerned
 - b. Somewhat concerned
 - c. Not too concerned
 - d. Not at all concerned

27. How concerned are you about the security of electronic health information exchange? Again, the sharing of electronic health information is known as electronic health information exchange.
- a. Very concerned

- b. Somewhat concerned
- c. Not too concerned **Skip to 28**
- d. Not at all concerned **Skip to 28**

- 27a. I am going to read a list of reasons some people are concerned about the security of electronic health information exchange. Please tell me how concerned you are with each of the following.

Would you say you are very concerned, somewhat concerned, not too concerned, or not at all concerned that <insert 1-5>?

- 1. Your personal health information could be lost
- 2. Your personal health information could be posted on the Internet
- 3. Your personal health information could be used to commit fraud (for example, identity theft)
- 4. Your personal health information could be used to send you unwanted junk email, spam, or other unsolicited advertising
- 5. Your personal health information could be used to discriminate against you

28. If you were allowed to control how your doctors share your information electronically, would you permit them to share your health information in order to treat you, even if they may not be able to fully protect your privacy all of the time?
- a. Yes **Go to 29**
 - b. No **Go to 28a**

- 28a. Which of the following reasons best represents the primary reason you would NOT permit your information to be shared with other doctors for purposes of your care and treatment? (Please select only 1)

Would you say that you...

- 1. Don't believe it will improve care
- 2. Don't want your doctors to see all of your information
- 3. Don't trust computers or the Internet
- 4. Don't trust hospitals or doctors to adequately protect the information
- 5. None of the above

29. Electronic health information exchange presents some potential risks and benefits. I am going to read you a list of some of these potential risks and benefits. I want you to tell me how likely you think each is to occur if doctors exchanged health information electronically.

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<insert a-g> would you say that is very likely, somewhat likely, not very likely, or not at all likely?

- a. The overall quality of medical care in the country would be improved
 - b. The quality of the care that you receive would be improved
 - c. You would have fewer repeated tests because doctors and hospitals could access your recent test results
 - d. Your information could be accidentally linked to the wrong person
 - e. An unauthorized person would access or view your medical records
 - f. Your doctors would do a better job coordinating your care with other doctors
 - g. Your information would be accidentally released to the wrong doctor
30. Thinking now about the list of potential risks and benefits I just read, which of these issues would you say is most important to you?
- a. The overall quality of medical care in the country would be improved
 - b. The quality of the care that you receive would be improved
 - c. You would have fewer repeated tests because doctors and hospitals could access your recent test results
 - d. Your information could be accidentally linked to the wrong person
 - e. An unauthorized person would access or view your medical records
 - f. Your doctors would do a better job coordinating your care with other doctors
 - g. Your information would be accidentally released to the wrong doctor

Section 5. Addressing privacy/security concerns related to electronic health information exchange.

31. Now, I'm going to read a list of some of the types of information that may be in your health record. For each type of information, I'd like you to tell me whether you would prefer that this information be shared only with the doctor treating you at the time, with specific doctors of your choice, or with any doctors that may need to treat you both now and in the future.

Would you prefer that <insert 1-8> be shared with
a) only the doctor treating you at the time, b) specific doctors of your choice, or c) any doctors?

1. The dates and locations of doctor and hospital visits
2. Diagnosis and treatment information
3. The medications you've been prescribed
4. Lab, x-ray, MRI, or other test results
5. Results of genetic tests
6. Results of HIV tests
7. Results of test for sexually transmitted diseases
8. Mental health diagnoses and treatment

32. Do you know if there are any federal health privacy laws that require doctors and health plans to protect the information in your health record during electronic health information exchange?
- a. Yes
 - b. No **Skip to 33**

- 32a. Can you name any of these federal health privacy laws?

- a. Yes – **[Fill response]**

- b. No

33. If your health information could be made available for electronic health information exchange, who do you think should have the ability to determine what the privacy settings related to your health information should be, beyond the requirements imposed by applicable law? By determining privacy settings, we mean allowing permission for some portions of your health information to be shareable and other portions to be blocked from access.

- a. Just you
- b. You or a family member
- c. You and your primary doctor
- d. You, a family member, and your primary doctor
- e. Just your primary doctor
- f. Other (specify)

34. If you could choose the healthcare providers that could electronically access and share your health information, would you...? *(Please select only 1)*

- a. Grant permission to all of your healthcare providers
- b. Grant permission to specific healthcare providers
- c. Not grant permission to any of your healthcare providers

■ POLICY ■

35. If you could choose the amount of information that healthcare providers could access and share electronically, would you choose to share...?
(Please select only 1)
- a. All of your information
 - b. Some of your information
 - c. None of your information
36. If you had a medical emergency would you want a doctor to override your privacy settings in order to treat you?
- a. Yes
 - b. No
37. If doctors could access information about patients through an electronic health information exchange, should they be held responsible for making a mistake in diagnosis and treatment if the patient has withheld health information?
- a. Yes
 - b. No
38. The law allows your health information to be used and shared for specific reasons, like making sure doctors give good care, making sure nursing homes are clean and safe, or reporting when the flu is in your area.

If you were able to obtain a list of the disclosures that your doctors make about your health information for treatment, payment, and other healthcare purposes through an electronic health record—for example which doctors had accessed your health information and to whom they sent your health information—how likely is it that you would ask for such a list? Would you say...?

- a. Very likely
- b. Somewhat likely
- c. Not very likely
- d. Not at all likely

Skip to section 6

- 38a. I am going to read you some of the types of information that could be included in a list of disclosures. I'd like you to tell me which types of information you would be most interested in knowing about. For each, please answer yes or no. Would you be interested in knowing about...?
- a. The kinds of health information that were disclosed
 - b. The person or organization that disclosed the information
 - c. The person or organization that received the information
 - d. The reason the information was disclosed
 - e. What other types of information, if any, would you be most interested in knowing about?)
-
- 38b. Now, I am going to read some potential reasons for obtaining a list of disclosures. Please tell me which of the following is your primary reason for asking for this information? Would you say it would be ...?
- a. to confirm that your healthcare providers and/or their business partners are protecting your information
 - b. to know who has had access to your information
 - c. to ensure that the information being shared is accurate
 - d. to ensure that the information is not being disclosed to an unauthorized individual or organization, or
 - e. some other reason? (Please specify)
-

Section 6. Demographics

39. How old are you?
Years
40. Are you male or female?
- a. Male
 - b. Female
 - c. Other
41. What is your zip code?

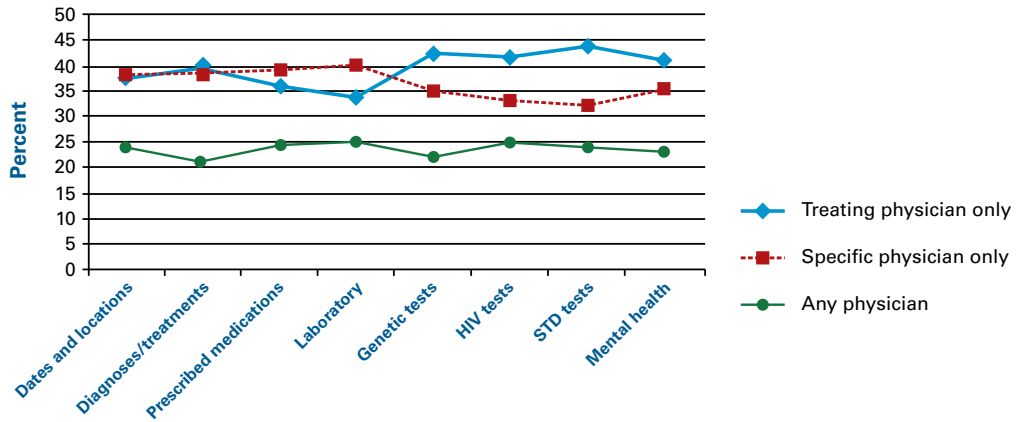
42. What is the highest level of education that you have completed?
- a. Completed grade school
 - b. Completed high school/GED
 - c. Some college
 - d. Completed college
 - e. Completed graduate school
43. Are you currently...
- a. Employed full-time (40 hours per week)
 - b. Employed part-time
 - c. Not employed

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- d. A student
 - e. Retired
44. Which category best describes how much total money your household earned in 2009, before taxes?
- a. Under \$25,000
 - b. \$25,000-\$49,999
 - c. \$50,000-\$100,000
 - d. Over \$100,000
45. Are you of Hispanic, Latino, or Spanish origin or descent?
- a. Yes
 - b. No
46. Which of these groups describes you? *Select 1 or more of the following categories.*
Respondents who report their race as Native American should be included in response category 3.
- a. White
 - b. Black/African American
 - c. American Indian or Alaska Native (American Indian includes North American, Central American, and South American Indians)
 - d. Native Hawaiian
 - e. Other Pacific Islander
 - f. Asian (For example: Asian Indian, Chinese, Filipino, Japanese, Korean, and Vietnamese)
 - g. Other (Specify)
47. How does your family usually pay for healthcare? *(Select all that apply)*
- a. Insurance or HMO
 - b. Out of pocket
 - c. Medicare
 - d. Free clinic
 - e. Medicaid
 - f. Other

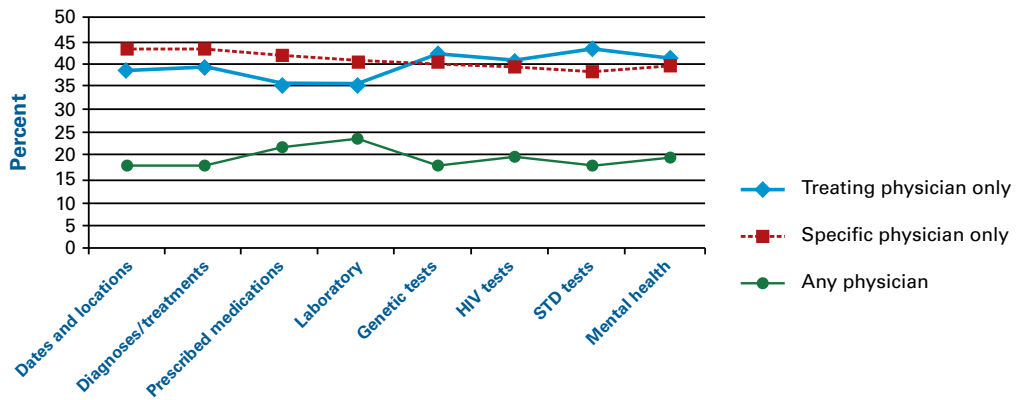
(eAppendix Figures follow)

■ **eAppendix Figure A.** Preferences Regarding Sharing Various Types of Data With Physicians Among Those That Are “Very Concerned” About the Privacy of Health Information Exchange



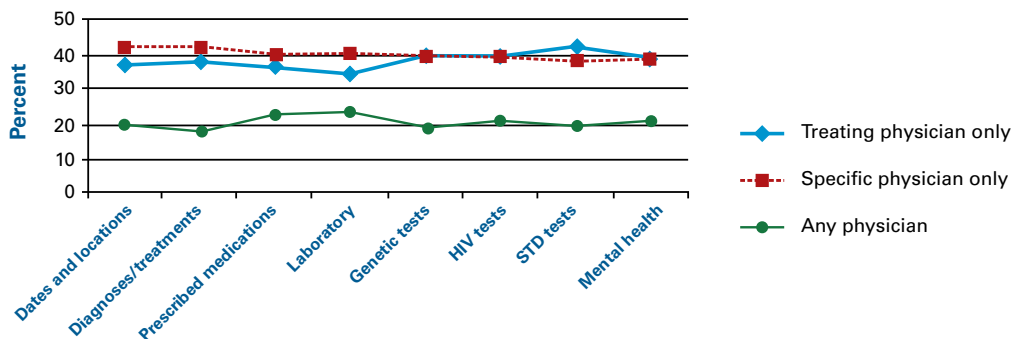
HIV indicates human immunodeficiency virus; STD, sexually transmitted diseases.

■ **eAppendix Figure B.** Preferences Regarding Sharing Various Types of Data With Physicians Among Those That Are “Very Concerned” About the Security of Health Information Exchange



HIV indicates human immunodeficiency virus; STD, sexually transmitted diseases.

■ **eAppendix Figure C.** Preferences Regarding Sharing Various Types of Data With Physicians Among Those That Are “Very Concerned” About the Security of Electronic Health Records



HIV indicates human immunodeficiency virus; STD, sexually transmitted diseases.