

**Attitudes toward Electronic Health Information Exchange and Associated Privacy and Security Aspects**

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FINAL INSTRUMENT  
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**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?
  - a. Every day (7 days a week, typically)
  - b. Most days (4-6 days a week, typically)
  - c. Some days (1-3 times/week typically)
  - d. Rarely (less than 3 times per month)
  - e. Never (i.e., 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 Health Care 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 health care 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 health care providers and the kinds of information most health care 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.
- YES
  - NO
6. Are you the primary person responsible for keeping track of the health information for one or more family members?
- YES
  - NO
7. Please tell me how many different doctors and other health care 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.)
- 1 to 2
  - 3 to 5
  - 6 to 9
  - 10 or more
  - 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...
- Strongly Agree?
  - Somewhat Agree?
  - Neither agree nor disagree?
  - Somewhat Disagree?
  - Strongly Disagree?
9. Now, please think about how you make healthcare decisions and tell me which of the following statements best represents your preferences:
- 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
  - 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?
- YES
  - 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 website? By secure website, 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 health care providers.

- 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

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? [insert open ended text]
25. How important is it to you to limit **<INSERT>** 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 health care professionals involved in your care
  - f. Doctors and other health care professionals NOT involved in your health care
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 ONE)

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.  
<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 a-h>** be shared with a) only the doctor treating you at the time, b) specific doctors of your choice, or c) any doctors?

- a. The dates and locations of doctor and hospital visits
- b. Diagnosis and treatment information
- c. The medications you've been prescribed
- d. Lab, x-ray, MRI, or other test results
- e. Results of genetic tests
  
- f. Results of HIV tests
- g. Results of test for sexually transmitted diseases
- h. 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 health care providers that could electronically access and share your health information, would you...? [Please choose one]

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

**35.** If you could choose the amount of information that health care providers could access and share electronically, would you choose to share...? [Please choose one]

- 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 health care 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...?

[IF NECESSARY:

- 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
  - 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 one 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 health care? **(SELECT ALL THAT APPLY)**

- a. Insurance or HMO
- b. Out of pocket
- c. Medicare
- d. Free Clinic
- e. Medicaid
- f. Other

Those are all of the questions I have for you. Thank you for your time.