

Consumer Survey: July 20, 2011 version

Introduction and Consent Script

This is _____ calling on behalf of the U.S. Department of Health and Human Services. We are conducting an important research study to learn more about what people think about the privacy and security aspects of electronic health records and electronic health information exchange and the ways that they may affect how you manage your health information. Your telephone number/cell phone number has been selected at random.

[FOR LANDLINE SAMPLE ONLY:] I would like to speak to a member of the household who is age 18 or older who will have the next birthday. Would that be you? [IF YES, CONTINUE; IF NO, ASK TO SPEAK WITH THAT PERSON. ONCE CORRECT PERSON IS ON PHONE, CONTINUE.]

[FOR CELL PHONE SAMPLE ONLY:] Are you at least 18 years of age? [IF YES, CONTINUE.]

The interview will take approximately 25 minutes. Your participation is voluntary, but important. If we come to a question you don't want to answer, we will skip over it. You can end the interview at any time. The information you provide will be kept private to the extent allowed by law. You will not be identified in any report of these interviews. I also want to let you know that this call may be monitored or recorded for quality purposes. Do you have any questions about the study?

INTERVIEWER, READ IF NECESSARY: If you have any questions about your rights as a study participant, you can call the NORC IRB Administrator toll-free at 866-309-0542. NORC is the research organization coordinating this research. You can also call **TBD** of the Office of the National Coordinator for Health Information Technology at 202-**XXX-XXXX**.

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 0990-0376. The time required to complete this information collection is estimated to average one hour and thirty 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 336-E, Washington D.C. 20201, Attention: PRA Reports Clearance Officer

First, let's talk about your visits to a doctor or other health care provider.

A. Experience with Healthcare System

i. Health Seeking Behavior – Healthcare usage

1. I am interested in the visits you made to a doctor or other health care provider within the last 12 months. I want to know both the number of different doctors or other health care providers you visited and then the total number of visits. First, how many different doctors and health care providers have you visited in the last 12 months? Please include primary care physicians, specialists, mental health professionals, physician assistants, nurses, clinics, and hospitals.

- 1 to 2
- 3 to 5
- 6 to 9
- 10 or more
- None

2. Altogether, how many total visits did you make to a doctor or other health care provider in the last 12 months?

- 1 to 2
- 3 to 5
- 6 to 9
- 10 or more
- None

ii. Gaps in information/coordination

Now let's talk about the coordination of your medical care and sharing of information with doctors and other health care providers.

3. In the past 12 months, when getting care for a medical problem, was there ever a time when you:

- Had to bring an X-ray, MRI, or other type of test result with you to the appointment?
- Had to wait for test results longer than you thought reasonable?
- Had to redo a test or procedure because the earlier test results were not available?
- Had to come back for another appointment because medical information was not available?
- Tried to get two of your doctors or other health care providers to talk to each other and failed?

Electronic medical information is medical information that is created, stored and viewed on computers.

4. Within the past 12 months, if you asked for copies of your medical information from your doctor or other health care provider(s), did you receive the information? The copies of your medical information can be in either paper or electronic format.
 - Yes
 - No
 - Not applicable, did not request within the past year
 - Refused

5. How often do you receive a written or electronic summary after a visit with a doctor or other health care provider?
 - Never
 - Rarely
 - Sometimes
 - Most times
 - Every time
 - Refused

iii. Provider satisfaction – Satisfaction with health care received

6. Overall, how satisfied are you with the quality of the health care you have received from your doctor and other health care provider(s)?
 - Very satisfied
 - Satisfied
 - Slightly satisfied
 - Neither satisfied nor dissatisfied
 - Slightly dissatisfied
 - Dissatisfied
 - Very dissatisfied

B. Topic: Health Status

Now I would like to find out more about your health.

7. In general, how would you rate your overall health now?
 - Excellent
 - Very good
 - Good
 - Fair

- Poor
- DON'T KNOW
- REFUSED

8. Are you being treated for any chronic disease or medical condition such as, but not limited to, high blood pressure, diabetes, heart or lung disease, a mental health problem or arthritis?

- Yes
- No

9. Are you currently caring for or making health care decisions for a family member or a close friend with a debilitating or chronic illness?

- Yes
- No

C. Topic: Prior Experience and Exposure to IT and Health IT – Computer/internet access and use

The next questions are about your use of the internet and familiarity with electronic medical information.

10. Have you ever accessed the Internet?

- Yes
- No (skip to Q13)

11. How often do you access the Internet?

- Every day (7 days a week, typically)
- Most days (4-6 days a week, typically)
- Some days (1-3 times/week typically)
- Rarely (less than 3 times per month)
- Never (i.e., person has access but doesn't use it)

12. Have you ever...?

- Searched online for information about a disease or medical problem
- Looked at any of your medical test results online
- Sent or received an e-mail message from your doctor or other health care provider
- Sent or received a text message from your doctor or other health care provider
- Renewed a prescription online
- Used a smart phone application to send or receive health information

13. Are you aware that certain doctors and other health care providers may electronically share and view the medical information of the patients they provide care for? (Electronically means from computer to computer, instead of by telephone, mail, or fax machine.)

- Yes
- No

14. As far as you know, do your doctors or other health care providers maintain your medical information in a portable, electronic format? This would include a computerized medical record.

- Yes
- No

15. Do you currently have an electronic personal health record, or PHR? A PHR is an electronic application that allows you to access, enter, and manage some of your medical information.

- Yes
- No [SKIP TO Q17]

IF Q15=NO (R DOES NOT HAVE A PHR) THEN SKIP TO Q17.

16. Think back to when you were first able to look online at your medical information, like lab tests. How confident were you that your medical information would be kept safe and private?

- Very confident
- Somewhat confident
- Not very confident
- Not at all confident
- Not applicable (not able to view medical information online using PHR)

D. Topic: Support for and Perceived Benefits of Health IT/HIE

The next questions are about your views on computerized medical records and electronic sharing of medical information.

17. Would you say computerized medical records have a positive impact, negative impact, or no impact on the care you receive from your doctor and other health care providers?

- Positive impact
- Negative impact

- No impact
- Don't know
- Refused

18. Please indicate how important each of the following is to you.

- Doctors and other health care providers should be able to share your medical information with each other electronically
- You should be able to get to your own medical information electronically
 - Very important
 - Somewhat important
 - Not important at all

19. To the best of your knowledge, does your doctor or other health care provider:

- Electronically check your medical test results from other providers?
 - IF NO: Should they be able to do this?
- Electronically view your medical records from other providers?
 - IF NO: Should they be able to do this?
- Electronically send your medical records to other providers that are caring for you?
 - IF NO: Should they be able to do this?
- Electronically send prescriptions or refill requests directly to your pharmacy?
 - IF NO: Should they be able to do this?

20. Some doctors and other health care providers send medical information about their patients to each other electronically. If your providers were able to share your medical information electronically, do you think it is very likely, somewhat likely, not very likely or not at all likely that each of the following is to occur??

- Doctors or other health care providers would have quicker, easier access to your medical information
- The quality of the care that you receive would be improved.
- You would have fewer repeated tests because doctors and other health care providers and hospitals could access your recent test results.
- Your doctors and other health care providers would do a better job coordinating your care with other doctors and health care providers.

E. Topic: Perceived Risks

Now I would like to ask you about the privacy and security of your medical information.

21. How concerned are you with the privacy of your medical records? “Privacy” means you have some say in who is allowed to collect, use and share your medical information.

- Very concerned
- Somewhat concerned
- Not concerned

22. How concerned are you with the security of your medical records?

By 'secure' we mean that safeguards are in place to protect your medical records from being seen by people who aren't permitted to see them.

- Very concerned
- Somewhat concerned
- Not concerned

23. In the past year, have you kept information from your health care provider because you were concerned about the privacy or security of your medical record?

- Yes
- No

24. If your medical information is sent by fax from one health care provider to another, how concerned are you that an unauthorized person would see it?

- Very concerned
- Somewhat concerned
- Not concerned

25. If your medical information is sent electronically from one health care provider to another, how concerned are you that an unauthorized person would see it?

(Electronically means from computer to computer, instead of by telephone, mail, or fax machine.)

- Very concerned
- Somewhat concerned
- Not concerned

26. To the best of your knowledge, in the past 12 months, have you been the victim of identity theft or fraud?

- Yes
- No

27. I am going to read a list of possible concerns regarding computerized medical records and the electronic sharing of medical information. On a scale from 1 to 5, where 1 is not at all concerned and 5 is extremely concerned, how concerned are you about the following:

- your doctor or other health care providers cannot adequately protect your medical information?
- you could not control who could access or who could use your medical information?
- you could not control how or for what purposes your medical information could be used?

- your medical information could be lost
- your medical information could be posted on the Internet
- your medical information could be used to commit fraud (for example, identity theft)
- your medical information could be used for purposes other than to provide care or handle billing, such as to send you unwanted junk email, spam or other advertising
- your medical information could be used to discriminate against you
- your medical information could be accidentally linked to the wrong person
- your medical information may be misused by employers to limit your job opportunities?
- your medical information may be misused by insurance carriers to deny you coverage?
- your medical information may be misused by credit card and finance companies to deny you credit or a loan?
- using computerized medical records may increase your out of pocket and/or healthcare insurance costs?
- you will not have access to your medical information because you do not have access to the Internet or a computer?
- you generally do not trust technology such as computers and the Internet?

I. Topic: Overall Support in spite of concerns

Now how much do you agree with these statements about support for the use of computerized medical records?

28. I want my doctors or other health care providers to use a computerized medical record to store and manage my health information despite any concerns I might have about privacy and security.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

29. I want my doctors or other health care providers to use a computer to share my health information with other providers treating me despite any concerns I might have about privacy and security.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

F. Topic: Safeguards that would help address privacy and security concerns

30. I am going to read to you some safeguards that could be taken to protect your computerized medical record. If doctors and other health care providers followed these safeguards, would you feel that your medical information is safe? Please answer with one of the following: Yes/No/Don't Know

- Protect your medical information with technology solutions
- Keep your records in a secure facility
- Do background checks on employees before hiring them
- Train employees on privacy and security
- Notify you if your medical information falls into unauthorized hands
- Allow you to review your medical information
- Provide a process to request corrections or dispute how your information is handled
- Allow you to review who has access to your medical information
- Allow you to control what medical information can be shared with others
- Allow you to make informed choices about how your medical information is collected and used.

G. Topic: Control over Data Sharing

31. I'm going to read a list of some of the types of information that may be in your medical record. I'd like you to tell me if you prefer this information be shared: (a) only with the doctor or health care provider treating you at the time, (b) specific

providers of your choice, or (c) any providers that may need to treat you now or in the future.

Would you prefer that <insert a-h> be shared with a) only the provider treating you at the time, b) specific providers of your choice, or c) any providers that are involved with your care?

- a. The dates and locations of doctor or other health care provider 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

H. Topic: Awareness of privacy regulations/laws

I am going to read some statements about protection of computerized medical records. How much do you agree with each of the following statements?

32. Existing laws provide a reasonable level of protection for computerized medical records and medical information today

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don't know

33. Doctors and other health care providers have measures in place that provide a reasonable level of protection for computerized medical records and medical information today

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don't know

J. Topic: Demographics

We are nearly finished. I would like to get a little information about your background.

34. What is your zip code?

35. In what year were you born?

- _____ (Year)
- Don't know
- Refused

36. ASK ONLY IF NOT SURE: What is your gender?

- Male
- Female

37. Are you of Hispanic or Latino origin or descent?

- Yes
- No
- Don't know
- Refused

38. Which of the following best describes your race?

- White or Caucasian
- Black or African-American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or other Pacific Islander
- More than one race
- Other (please specify): _____
- Don't know
- Refused

39. What is the highest grade or level of school that you have completed?

- Not a high school graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree
- Don't know
- Refused

40. Which category comes closest to your total household income before taxes in 2010?

- Less than \$25,000
- Between \$25,000 and \$49,000
- Between \$50,000 and \$99,999
- \$100,000 or greater
- Don't know
- Refused