

Consumer Survey: July 19, 2011 version Cognitive Interview Protocol Draft

Overview of the Cognitive Interviews

The cognitive interview protocol identifies some specific issues to test in the draft instrument. Scripted probes have been included throughout the instrument. In general, the cognitive testing will examine:

- Question comprehension, understanding of terminology, appropriateness of response categories.
- Ability to retrieve the information from memory needed to address the question
- Ability to formulate an accurate answer to the question.
- Issues with question sensitivity.

The cognitive testing will include observation of respondent behavior to identify problems with the questionnaire. Respondent behaviors such as the following will be noted and explored by the interviewer:

- Requests to have a question repeated.
- Requests to have the response scale or response categories repeated.
- Requests for clarification, such as asking the meaning of a term or asking to have a question explained.
- Responses of “don’t know” or responses that are inconsistent with what was expected.

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

Introduction and Consent Script

NORC is working on a survey questionnaire that will be used in a study on electronic health information funded by the U.S. Department of Health and Human Services. To help improve the survey questions, NORC is conducting interviews to find out how clear the questionnaire items are, how long they take to complete and whether we have missed anything in the various topics we are interested in.

If you agree to participate in this interview, we will ask you to complete a questionnaire with an NORC staff member lasting approximately 20 minutes. We will then ask you to participate in a one-on-one interview with the NORC staff member to discuss some of the questionnaire items. The interview will take about one hour. You will receive \$40 for participating even if you skip questions or cannot complete the interview.

Your participation involves answering questions about electronic health information and its related privacy and security aspects. While there is no direct benefit to you for participating in this survey, your feedback may help make critical improvements to the survey questionnaire.

Your participation in this study is entirely voluntary. You can refuse to answer any question and you can stop the interview at any time. If at any point during the interview you wish to withdraw as a participant, please just tell the interviewer that you would like to stop.

You will not be identified in any report of these interviews. Your name will not be associated with any information you provide.

For questions regarding research subjects' rights, please contact the NORC IRB Administrator, toll-free at 866-309-0542.

Do you have any questions? ANSWER ANY RESPONDENT QUESTIONS OR CONCERNS.

Do you agree to participate in this study as I have described it?

INTERVIEWER: INITIAL RESPONDENT CONSENT: _____

IF RESPONDENT DOES NOT CONSENT, THANK THEM FOR THEIR TIME.

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

Probe: Please tell me how you figured out how many different doctors you visited in the last 12 months? How did you figure out how many total visits you made? How hard was it to figure out your answers to these questions?

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

Probe: What kind of medical information did you ask for? In what format was it given to you?

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

Probe: I asked you about receiving a summary after a visit to a provider. Based on your understanding, what kind of information would be in the summary? [Is R thinking of a receipt, lab results, diagnosis, appointment card for next visit, etc.?)

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

Probe: How did you decide on your answer? Were you thinking of a particular doctor or several doctors?

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

Probe: [If R thinks his/her doctor electronically shares information]: What information do you think the providers share?

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

Probe: In this question I mentioned storage of information in a "portable, electronic format." What does that term mean to you? What makes it a "portable" format?

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]

Probe: [If R says yes]: Can you tell me more about that? What do you do with your PHR? How often do you access it? What kind of information is in it? I want to ask you about the term "computerized medical record." What do you think that term means? In

earlier questions I talked about “electronic” medical information and electronic formats. Are computerized medical records and electronic medical records the same thing or do they mean different things to you? Which term do you think makes more sense?

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?

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

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

Probe: When you think about the privacy of your medical record, what comes to mind? What do you think privacy of medical records refers to? How did you decide on your answer to this question?

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

Probe: When you think about the security of your medical record, what comes to mind? What do you think security of medical records refers to?

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

Probe: [If yes]: Can you tell me more about your privacy and security concerns?

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

Probe: How did you decide on that answer? What concerns do you have/why are you not concerned? When I say "unauthorized person" who comes to mind?

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

Probe: How did you decide on that answer? What concerns do you have/why are you not concerned? Are the risks that an unauthorized person will see the medical information greater or lesser depending on how the information is sent?

The question asks about sending information electronically. What does that mean to you? In your definition, does electronically include being sent by: computer, telephone, mail, fax, other means?

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?

For the cognitive interviews, we can ask this question in an open-ended format. This will help to determine what concerns are at the top of people's minds. The concerns mentioned can be compared to what is on the list. Also, discuss with respondent what the top concerns were from the list and why these were concerns.

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.

Probe: What safeguards do you think your doctors and other health care providers take to protect your computerized medical records? How much do you know about your

providers' privacy and security practices? Which of these safeguards are essential for you to feel that your computerized medical record is protected?

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

Probe: What does "only the provider treating you" mean? How about "specific providers of your choice" and "any providers that may need to treat you now or in the future?" How did you decide which medical information should be shared with other providers and which should not be?

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

Probe: How did you decide on that answer? Did you have any specific laws in mind?

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

Probe: Can you tell me about the measures that health care providers have in place (or should have in place) to protect computerized medical records?

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