

Consumer Survey: June 3, 2013 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 0955-0005. 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

TIME: __ __: __ __ AM/PM Hour Min

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 40 minutes. 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.

TIME: __ __: __ __ AM/PM
Hour Min

First, let's talk about your visits to health care providers. By health care providers, we mean primary care physicians, specialists, mental health professionals, physician assistants, nurses, clinics, and hospitals.

A. Topic: Experience with Health Care System

i. Health Seeking Behavior – Health Care Usage

1. First, how many different health care providers have you visited in the last 12 months?

- 1 to 2
- 3 to 5
- 6 to 9
- 10 or more
- None [SKIP TO Q3]

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

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

B. Topic: Health Status

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

3. In general, how would you rate your overall health now?

- Excellent
- Very good
- Good
- Fair
- Poor

4. Are you being treated for any chronic disease or medical condition such as high blood pressure, diabetes, heart or lung disease, or arthritis?

- YES

- NO

ii. Gaps in Information/Coordination

[SKIP TO Q6 IF Q1=NONE]

Now let's talk about the coordination of your medical care and sharing of your medical record with health care providers. A medical record is information that your health care provider keeps about your health care, such as notes from your visits, a list of drugs that you take or lab test results.

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

a. Had to bring an X-ray, MRI, or other type of test result with you to the appointment?

YES NO

b. Had to wait for test results longer than you thought reasonable?

YES NO

c. Had to redo a test or procedure because the earlier test results were not available?

YES NO

d. Had to provide your medical history again because your chart could not be found?

YES NO

e. Had to tell a health care provider about your medical history because they had not gotten your records from another health care provider?

YES NO

f. Received a paper or electronic copy of your medical record from any of your health care providers?

YES NO

g. Were given online access to any part of your medical record by any of your health care providers?

YES NO

6. How comfortable would you feel asking for a copy of your medical record from your health care provider?

- Very comfortable
- Somewhat comfortable
- Not very comfortable

- Not comfortable at all
7. Within the past 12 months, have you asked for copies of your medical record from any of your health care providers?
- YES
 - NO [SKIP TO Q10]
8. How difficult was it to receive the medical record you requested?
- Very difficult
 - Somewhat difficult
 - Not very difficult
 - Not difficult at all
 - Or did you not get the medical record you requested [SKIP TO Q10]
9. What was the format of the copy of the medical record you received, paper or electronic?
- RECEIVED AN ELECTRONIC COPY
 - RECEIVED A PAPER COPY
 - RECEIVED BOTH
10. Overall, how satisfied are you with the quality of the health care you have received from any of your health care providers?
- Very satisfied
 - Somewhat Satisfied
 - Not very satisfied
 - Not satisfied at all
11. During the past 12 months, has a clinical laboratory given you direct access to any test results, such as blood test results, in either paper or electronic format?
- YES
 - NO

iii. Caregiving

12. Are you currently caring for or making health care decisions for a child, a spouse, a parent, or other family member?
- YES
 - NO

TIME: __ __: __ __ AM/PM Hour Min

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 records. Electronic medical records are created, stored and viewed on computers.

13. How often do you access the Internet?

- Every day
- Most days
- Some days
- Rarely
- Never

14. **[ASK ONLY IF Q13 = NEVER]** Is that because you do not want to use the internet or because it is difficult for you to access it?

- DO NOT WANT TO USE THE INTERNET
- DIFFICULT TO ACCESS THE INTERNET

15. Have you ever...?

- a. Searched online for information about a disease or medical problem
YES NO
- b. Looked at any of your medical test results online
YES NO
- c. Sent or received an e-mail message from your health care provider
YES NO
- d. Sent or received a text message from your health care provider
YES NO
- e. Used a smart phone health application
YES NO

TIME: __ __ : __ __ AM/PM Hour Min
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D. Topic: Perceived Benefits of Health IT/Health Information Exchange

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

16. As far as you know, do any of your health care providers maintain your medical record in an electronic system?

- YES
- NO [SKIP TO Q18]

17. Would you say electronic medical records have an overall positive impact, negative impact, or no impact on the care you receive from your health care providers?

- POSITIVE IMPACT
- NEGATIVE IMPACT
- NO IMPACT

18. To the best of your knowledge, does your health care provider:

a. Electronically send prescriptions or refill requests directly to your pharmacy?

YES NO

b. IF NO: Should they be able to do this?

YES NO

c. Electronically send your medical record to other health care providers that are caring for you?

YES NO

d. IF NO: Should they be able to do this?

YES NO

19. How important is it to you that health care providers be able to share your medical record with each other electronically.

- Very important
- Somewhat important
- Not very important
- Not important at all

E. Topic: Perceived Risks

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

20. CORE QUESTION: Privacy means you have a say in who can collect, use and share your medical record. How concerned are you about the privacy of your medical record?

- Very concerned
- Somewhat concerned
- Not very concerned
- Not concerned at all

21. CORE QUESTION: Security means having safeguards to keep your medical record from being seen by people who aren't permitted to see them. Safeguards may include technology. How concerned are you about the security of your medical record?

- Very concerned
- Somewhat concerned
- Not very concerned
- Not concerned at all

22. **[ASK ONLY IF Q15B (LOOKED AT MEDICAL TEST RESULTS ONLINE)=YES]** How confident do you feel that your online medical record, such as notes from your visits, a list of drugs that you take or lab test results, is kept private and secure?

- Very confident
- Somewhat confident
- Not very confident
- Not at all confident

23. CORE QUESTION: Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record?

- YES
- NO

24. Confidentiality means that information in your medical record will not be disclosed to others in a way that would be inappropriate. How concerned are you about the confidentiality of your medical record?

- Very concerned
- Somewhat concerned
- Not very concerned
- Not concerned at all

25. CORE QUESTION: If your medical record 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 very concerned
- Not concerned at all

26. CORE QUESTION: If your medical record 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 very concerned
- Not concerned at all

Probe 1 (Q20, 21, 24, 25, 26): I asked you some questions on how concerned you were about the privacy and security of your medical record. Can you tell me about how you decided on your answer for these questions? [REVIEW SEVERAL QUESTIONS, FOCUSING ON RESPONSES OF “VERY/SOMEWHAT” CONCERNED.]

Probe 2 (Q20, 21, 24, 25, 26): I am going to repeat some of the questions from the survey, but this time I will give you a slightly different set of answer choices. These choices are the same except in between “very” and “somewhat” the option “fairly concerned” has been added. [PRESENT PRIVACY AND SECURITY QUESTIONS ON PAPER WITH RESPONDENT’S ORIGINAL ANSWERS AND NEW 5-POINT SCALE (VERY-FAIRLY-SOMEWHAT-NOT

VERY-NOT AT ALL CONCERNED). HAVE RESPONDENT REVIEW QUESTIONS AND DETERMINE WHETHER HE/SHE WOULD HAVE CHANGED RESPONSE BASED ON NEW SCALE.]

[REVIEW QUESTIONS IN WHICH RESPONDENT CHANGED ANSWERS AND CHOOSE NEW ANSWER CATEGORY “FAIRLY.”] When I changed the answer choices you said you were “fairly” concerned instead of “very/somewhat” concerned. Can you tell me about how you decided on that answer?

TIME: __ __: __ __ AM/PM
Hour Min

F: Topic: Control Over Data Sharing

27. Should patients be able to decide what specific information should be included when their records are shared between health care providers? Examples of information that could be shared are medications they are prescribed, results of genetic, sexually transmitted disease and other tests, and mental health diagnoses.
- YES
 - NO

Probe 3 (Q27): How did you decide on your answer? Are there any types of medical information you think would be OK to include in the shared medical record without directly asking for permission?

G. Topic: Awareness of Privacy Regulations/Laws

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

28. Existing laws provide a reasonable level of protection for electronic medical records today.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

29. Health care providers have measures in place that provide a reasonable level of protection for electronic medical records today.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

30. Existing laws require that health care providers give me a copy of my medical record in the way I want—either an electronic or paper copy.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

H. Topic: Overall Support in Spite of Concerns

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

31. CORE QUESTION: I want my health care providers to use an electronic 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

32. CORE QUESTION: I want my health care providers to use a computer to share my medical record with other providers treating me despite any concerns I might have about privacy and security.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Probe 4:

Ask prior to presenting Section I: In this survey I talked about “electronic medical records.” Can you tell me what you think of when you hear the term “electronic medical records?” I also referred to “online” information, such as looking at medical test results online. What do you think of when you hear the term “online?” Are electronic and online medical records different kinds of records or do you see them as the same kind of record?

TIME: ___ __: ___ __ AM/PM
Hour Min

I. Topic: Online Medical Records

Some patients can access their medical records online, through websites set up for this purpose. By going to the website, patients can view their own medical records, download the information, or send it somewhere else.

33. Have you ever been given online access to your medical record?
- YES [SKIP TO Q35]
 - NO

Probe 5: [IF R INDICATES IN Q7 TO Q9 THAT HE/SHE HAD GOTTEN AN ELECTRONIC COPY OF THE MEDICAL RECORD IN THE LAST 12 MONTHS]

You said earlier that you had received an electronic copy of your medical record in the last year. How was that electronic file delivered to you?

34. Have you heard of online medical records before?

- YES
- NO

[SKIP TO Q38]

35. Who provided you with access to your online medical record?

a. Your health care provider?

- YES
- NO

b. Your health insurer?

- YES
- NO

c. A clinical laboratory?

- YES
- NO

***Probe 6 (Q35a-c): [IF RESPONDENT ANSWERS “NO” TO Q35A THROUGH C]
Can you remember who provided you with access to your online medical record?***

36. How many times did you access your medical record online over the last 12 months?

- 1 to 2 times
- 3 to 5 times
- 6 to 9 times
- 10 or more times
- None [GO TO Q38]

Probe 7 (Q36): *How difficult was it to remember how often you accessed your online medical record over the past year? You said you accessed the record [NUMBER] times. How did you figure that out?*

[IF Q36 =NONE (R DID NOT ACCESS ONLINE RECORDS), GO TO Q37. ELSE SKIP TO Q38]

37. I would like to learn more about why you have not accessed your medical records online. Was it because...

- a. You do not have a way to access your online record?
- YES
 - NO

Probe 8 (Q37a): *Please tell me more about the difficulties you have with access to online records.*

- b. You did not see value in using the online medical record?
- YES
 - NO

Probe 9 (Q37b): *Can you tell me more about why online medical records are not of*

value to you?

- c. The online medical record was difficult to use?
- YES
 - NO

Probe 10 (Q37c): Can you tell me more about the difficulties you had using the online medical record?

- d. You were concerned about privacy or security of online records?
- YES
 - NO

38. How important is it to you to have online access to your medical record?
- Very important
 - Somewhat important
 - Not very important
 - Not important at all

[IF Q33=NO OR Q36 =NONE (R DID NOT ACCESS ONLINE RECORDS), GO TO Q41. ELSE GO TO Q39a]

39. a. Were you able to do anything with your record other than viewing it? For example, were you able to download it or save a copy to your own computer, or send it to a third party?
- YES
 - NO [SKIP TO Q40c]
- b. Did you download the information?
- YES
 - NO
- c. Did you send it somewhere else, such as to a mobile phone application or a personal health record? A personal health record, or PHR, is an

electronic application that allows you to access, enter, and manage some of your health information.

- YES
- NO [SKIP TO Q40c]

Probe 11 (Q39c): IF YES TO Q39C: Where did you send your electronic record?

40. How did you use your medical record? Did you...

- a. Send it to another health care provider treating you?
- YES
 - NO

Probe 13 (Q40a): IF YES TO Q40A: How did you send the record? [FOR EXAMPLE, DID RESPONDENT PRINT AND SEND A HARD COPY, DID RESPONDENT E-MAIL THE RECORD, DID RESPONDENT UPLOAD TO ANOTHER WEBSITE, ETC.]

- b. Send it to a family member or someone else involved with your health care?
- YES
 - NO

Probe 14 (Q40b): IF YES TO Q40B: How did you send the record? [FOR EXAMPLE, DID RESPONDENT PRINT AND SEND A HARD COPY, DID RESPONDENT E-MAIL THE RECORD, DID RESPONDENT UPLOAD TO ANOTHER WEBSITE, ETC.]

- c. Ask your health care provider to correct any errors you found in your record?
 - YES
 - NO

- d. Use it to monitor your health?
 - YES
 - NO

Probe 15 (Q40d): When I refer to using the online medical record to monitor your health, what comes to mind? How might someone use the online record to monitor their health? What do you think this question is asking?

- e. Use it to help make decisions regarding your health care?
 - YES
 - NO

Probe 16 (Q40e): When I refer to using online medical records to help make decisions regarding your health care, what comes to mind? How might someone use the online record to make decisions regarding their health care?

Questions on Caregivers

- 41. Were you given online access to a family member's medical record?
 - YES
 - NO (SKIP TO Q43)

- 42. How many times did you access your family member's medical record online over the last 12 months?
 - 1 to 2 times
 - 3 to 5 times

- 6 to 9 times
- 10 or more times
- You did not access the records

Probe 17: I would like to ask you about the terms “electronic medical record” and “online medical record.” Based on what you heard in the survey, do you think “electronic” and “online” medical records are the same thing or are they different? Please remember there is no right or wrong answer. We are interested in learning how people understand these terms and making sure the survey questions are as clear as possible.

43. Would you want to be able to update or add health-related information about yourself electronically - to include in your medical record?

- YES
- NO

TIME: __ __: __ __ AM/PM
Hour Min

J. Topic: Demographics

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

44. What is your zip code?

- _____ (ZIP CODE)

45. In what year were you born?

- _____ (YEAR)

46. What is your sex?

- MALE
- FEMALE

47. Are you of Hispanic, Latino/a, or Spanish origin?

- No, not of Hispanic, Latino/a or Spanish origin
- Yes, Mexican, Mexican American, Chicano/a
- Yes, Puerto Rican
- Yes, Cuban
- Yes, Another Hispanic, Latino/a, or Spanish origin

48. What is your race? (One or more responses can be selected)

- White
- Black or African-American
- American Indian or Alaska Native
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander

49. How well do you speak English?

- Very well
- Well
- Not well
- Not at all

50. Are you deaf or do you have serious difficulty hearing?

- YES
- NO

51. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

- YES
- NO

52. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

- YES
- NO

53. Do you have serious difficulty walking or climbing stairs?

- YES
- NO

54. Do you have difficulty dressing or bathing?

- YES
- NO

55. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

- YES
- NO

56. 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

57. Which category comes closest to your total household income before taxes in 2012?

- Less than \$25,000
- Between \$25,000 and \$49,999
- Between \$50,000 and \$99,999
- \$100,000 or greater

58. To the best of your knowledge have you ever been the victim of identity theft or fraud?

- YES
- NO

59. [FOR CELL SAMPLE ONLY]: How many different *cell*-phone numbers, if any, could I have reached you for this call?

[FOR LANDLINE SAMPLE ONLY]: How many different landline telephone numbers, if any, are there in your home that I could have reached you on for this call? This includes listed or unlisted numbers. Please don't count telephone numbers used *only* for faxes or modems.

ENTER NUMBER: _____

TIME: __ __ : __ __ AM/PM Hour Min
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