Consumer Survey: August 1, 2012 final main study version

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 <u>clinical laboratory</u> given you <u>direct</u> access to any test results, such as blood test results, in either paper or electronic format?
 - YES
 - NO
- iii. <u>Caregiving</u>
 - 12. Are you currently caring for or making health care decisions for a child, a spouse, a parent, or other family member?
 - YES
 - NO
- <u>C.</u> <u>Topic: Prior Experience and Exposure to IT and Health IT Computer/Internet Access and Use</u>

The next questions are about your use of the internet and familiarity with <u>electronic</u> 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 $\ensuremath{\mathsf{YES}}\ \ \ \ensuremath{\mathsf{NO}}\ \ \ensuremath{\mathsf{NO}}\ \ensuremath{\mathsf{E}}$
 - 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. Renewed a prescription online

YES NO

f. Used a smart phone health application YES NO

- 16. A personal health record (or PHR) is an electronic application that allows you to access, enter, and manage some of your health information. Have you ever heard of a PHR?
 - YES
 - NO [SKIP TO Q19]
- 17. Do you currently have a personal health record, or PHR?
 - YES
 - NO
- 18. Do you currently have a personal health record, or PHR that you keep for a family member?
 - YES
 - NO

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.

- 19. As far as you know, do any of your health care providers maintain your medical record in an electronic system?
 - YES
 - NO [SKIP TO Q21]
- 20. 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
- 21. 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

- 22. Please tell me how important each of the following is to you.
 - a. Health care providers should be able to share your medical record with each other electronically.
 - Very important
 - Somewhat important
 - Not very important
 - Not important at all
 - b. Health care providers should make your medical record available to you 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.

- 23. 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
- 24. 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

25. [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
- 26. 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
- 27. 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
- 28. CORE QUESTION: If your medical record is sent by <u>fax</u> 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
- 29. CORE QUESTION: If your medical record is sent <u>electronically</u> 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

F: Topic: Control Over Data Sharing

- 30. When medical records are shared between health care providers, should patients be able to decide whether the following information is included in the shared record?
 - a. Should patients be able to decide whether the medications they have been prescribed are included in the shared record?

YES NO

b. Should patients be able to decide whether results of genetic tests are included in the shared record?

YES NO

c. Should patients be able to decide whether results of HIV tests are included in the shared record?

YES NO

d. Should patients be able to decide whether results of test for sexually transmitted diseases are included in the shared record?

YES NO

e. Should patients be able to decide whether mental health diagnoses and treatment are included in the shared record?

YES NO

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?

- 31. Existing laws provide a reasonable level of protection for electronic medical records today.
 - Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- 32. 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

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?

- 33. CORE QUESTION: I want my health care providers to <u>use</u> an electronic medical record to <u>store and manage</u> my health information despite any concerns I might have about privacy and security.
 - Strongly agree
 - Agree
 - Disagree
 - Strongly disagree
- 34. CORE QUESTION: I want my health care providers to use a computer to <u>share</u> my medical record with other providers treating me despite any concerns I might have about privacy and security.
 - Strongly agree
 - Agree
 - Disagree
 - Strongly disagree

I. Topic: Demographics

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

- 35. What is your zip code?
 - _____(ZIP CODE)
- 36. In what year were you born?
 - _____(YEAR)
- 37. What is your sex?
 - MALE
 - FEMALE
- 38. 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
- 39. 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
- 40. How well do you speak English?
 - Very well
 - Well
 - Not well
 - Not at all
- 41. Are you deaf or do you have serious difficulty hearing?
 - YES
 - NO
- 42. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
 - YES
 - NO
- 43. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
 - YES

- NO
- 44. Do you have serious difficulty walking or climbing stairs?
 - YES
 - NO
- 45. Do you have difficulty dressing or bathing?
 - YES
 - NO
- 46. 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
- 47. 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
- 48. Which category comes closest to your total household income before taxes in 2011?
 - Less than \$25,000
 - Between \$25,000 and \$49,999
 - Between \$50,000 and \$99,999
 - \$100,000 or greater
- 49. To the best of your knowledge have you ever been the victim of identity theft or fraud?
 - YES
 - NO