

Consumer Survey:

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

A. Experience with Healthcare System - 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

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

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-xxxx . The time required to complete this information collection is estimated to average 25 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

4. 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

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.

5. 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?
YES NO
 - Had to wait for test results longer than you thought reasonable?
YES NO
 - Had to redo a test or procedure because the earlier test results were not available?
YES NO
 - Had to provide your medical history again because your chart could not be found?
YES NO
 - Had to tell another doctor or health care provider about your medical history because they had not gotten your records from another doctor.
YES NO
6. How often do you receive a paper or electronic summary of your visit with a doctor or other health care provider?
- Never
 - Rarely
 - Sometimes
 - Most times
 - Every time

7. How comfortable would you feel asking for a copy of your medical information from your doctor or other health care provider?
- Very comfortable
 - Somewhat comfortable
 - Slightly comfortable
 - Slightly uncomfortable
 - Uncomfortable
 - Very uncomfortable
8. Within the past 12 months, have you asked for copies of your medical information from your doctor or other healthcare provider(s)?
- YES
 - NO [skip to #11]
9. How difficult was it to receive the medical information you requested? If you did not receive the information, please let us know.
- Not difficult at all
 - A little difficult
 - Somewhat difficult
 - Very difficult
 - I was not able to get the information I requested [skip to #11]
10. What was the format of the copy of the medical information you received, paper or electronic?
- RECEIVED AN ELECTRONIC COPY
 - RECEIVED A PAPER COPY
 - RECEIVED BOTH
11. 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
 - Somewhat Satisfied
 - Dissatisfied
 - Very dissatisfied

iii. Caregiving

12. Are you currently caring for or making health care decisions for a family member?
- YES
 - NO [skip to # 18]

13. Overall, how satisfied are you with the quality of the health care *they* have received from their doctor and other health care provider(s)?
- Very satisfied
 - Somewhat Satisfied
 - Dissatisfied
 - Very dissatisfied
14. Within the past 12 months have you asked for copies of their medical information from their doctor or other health care provider?
- YES
 - NO [skip to #17]
15. How difficult was it to receive the medical information you requested for your family member? If you didn't receive the information, please let us know.
- Not difficult at all
 - A little difficult
 - Somewhat difficult
 - Very difficult
 - I was not able to get the information I requested [skip to #17]
16. What was the format of the copy of the medical information you received (paper or electronic)?
- RECEIVED AN ELECTRONIC COPY
 - RECEIVED A PAPER COPY
 - RECEIVED BOTH
17. Have you accessed or used an electronic personal health record (PHR) on behalf of your family member? A PHR is an electronic application that allows you to access, enter, and manage medical information.
- 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. Electronic medical information is medical information that is created, stored and viewed on computers.

18. How often do you access the Internet?
- Every day
 - Most days
 - Some days

- Rarely
- Never

19. **[ASK ONLY IF Q18 = NEVER]** Could you access the internet easily if you needed to? (for example, at work, school, someone else's house, a community center or library, etc.)

- YES
- NO

20. Have you ever...?

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

21. Have you ever kept an electronic personal health record, or PHR, for yourself? A PHR is an electronic application that allows you to access, enter, and manage some of your medical information.

- YES
- NO

D. Topic: Perceived Benefits of Health IT/HIE

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

22. As far as you know, do any of your doctors or other health care providers maintain your medical information in a computerized system?

- YES
- NO [SKIP TO #24]

23. Would you say computerized medical records have an overall 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

24. 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
 - Very important
 - Somewhat important
 - Not important at all
- You should be able to get to your own medical information electronically
 - Very important
 - Somewhat important
 - Not important at all

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

- Electronically send prescriptions or refill requests directly to your pharmacy?

YES	NO
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 - IF NO: Should they be able to do this?

YES	NO
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- Electronically send your medical records to other providers that are caring for you?

YES	NO
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 - IF NO: Should they be able to do this?

YES NO

- Electronically obtain your medical records from other providers?

YES NO

- o IF NO: Should they be able to do this?

YES NO

26. 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?

	Very likely	Somewhat likely	Not very likely	Not at all likely
a. The quality of the care that you receive would be improved.				
b. The safety 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.

27. **CORE QUESTION:** How confident are you that you have some say in who is allowed to collect, use and share your medical information?

Having a say in who can collect, use and share your medical information has to do with the privacy of your records.

- Very confident
- Somewhat confident
- Not confident

28. **CORE QUESTION:** How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't permitted to see them?

Having safeguards (including the use of technology) in place has to do with the security of your medical records.

- Very confident
- Somewhat confident
- Not confident

29. If you have looked online at your medical information, like lab tests, how confident do you feel that your medical information was kept safe and private?

- Very confident
- Somewhat confident
- Not very confident
- Not at all confident
- Not applicable/I have never looked online at my medical information

30. **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

31. **CORE QUESTION:** 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

32. **CORE QUESTION:** 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

33. 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.

	Very likely	Somewhat likely	Not very likely	Not at all likely
a. You would be discriminated against				
b. You would experience personal or professional embarrassment				
c. The information would be used to steal your identity				
d. The information would be used to commit fraud				

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

34. 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, on a scale of 1 to 5, how much safer do you think your medical information would be? With 5 being much safer, and 1 being not any safer.

	1 Not any safer	2	3	4	5 Much safer
a. Train employees on privacy and security					
b. Notify you if your medical information falls into unauthorized hands					
c. Allow you to review who has accessed your medical information					
d. Allow you to make informed choices about how your medical information is collected and used					
e. Prosecute and penalize those who violate privacy and security laws					

G. Topic: Control over Data Sharing

35. 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 kept separate from the rest of your medical record when it is being shared.

- The medications you've been prescribed
YES NO
- Results of genetic tests
YES NO
- Results of HIV tests
YES NO

- Results of test for sexually transmitted diseases
YES NO
- Mental health diagnoses and treatment
YES NO

36. For each of the following types of information, please indicate whether you would want to limit sharing to: a) only the provider treating you for that condition, b) specific providers of your choice, or c) all providers treating you?

	Only the provider treating you	Specific providers of your choice	All providers treating you
a. The medications you've been prescribed			
b. Results of genetic tests			
c. Results of HIV tests			
d. Results of test for sexually transmitted diseases			
e. 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?

37. 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

38. 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

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?

39. **CORE QUESTION:** 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

40. **CORE QUESTION:** 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

J. Topic: Demographics

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

41. What is your zip code?

42. Do you live in an urban, rural or suburban area?

- URBAN
- RURAL
- SUBURBAN

43. In what year were you born?

- _____ (YEAR)

44. What is your gender?

- MALE
- FEMALE

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

- YES
- NO

46. 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): _____

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 2010?

- Less than \$25,000
- Between \$25,000 and \$49,000
- 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