CONSUMER HEALTH INFORMATICS SURVEY

Instructions appear in [UPPERCASE LETTERS ENCLOSED IN BRACKETS].

Text to be read aloud to participants appears in bold, lowercase letters

Text that is underlined should be emphasized.

[THE FOLLOWING INTRODUCTORY INFORMATION WILL BE READ ALOUD TO INDIVIDUAL RESPONDENTS].

Hello, my name is _____ calling on behalf of the University of Connecticut Health Center. We are doing a survey and are asking questions about how health information technology (such as electronic medical records) affects health care consumers. The information provided will be used to better understand how individuals feel about health information technology tools and to allow for consumers to give input about the benefits and challenges associated with health IT. The purpose of this survey is not to try to sell you anything. Your phone number has been chosen at random to be included in the study.

I will not ask for your name, address, or other personal information that can identify you. However, we will ask you for your zip code during the survey to correlate geographic information with your responses. Please note that you are not required to share this information; you may refuse to answer this question.

With your permission, I will record your phone number with your responses to the survey. This will be for the purpose of contacting you in the future for a follow-up survey. If you indicate that you would not like to participate in a follow-up survey, we will not record your phone number and your responses will remain anonymous.

This survey is voluntary and will take about twenty minutes to complete. You can refuse to participate in the survey or withdraw from the survey at any time. Also, you can refuse to answer any question for any reason. The results of the survey will be publicly available upon completion of the study; however, data will be reported in an aggregate (collective) form only. Your personal responses to questions will not be shared.

[IF THE RESPONDENT ASKS ANY OF THE FOLLOWING FREQUENTLY ASKED QUESTIONS, PLEASE PROVIDE THEM WITH THE APPROPRIATE RESPONSES:]
1. Why are you doing this study?

This study is part of a larger effort to assess awareness of and readiness for health information technology. Other individuals and groups that will be surveyed as part of this study include physicians, laboratories, and pharmacies. The information that is collected will give investigators a better understanding of how tools such as the electronic health record (EHR), the personal health record (PHR), and health information exchange (HIE) can serve as both a benefit and challenge within the current health care arena.

2. Who is funding this?

This project is currently being funded by the Connecticut Department of Public Health. This particular project, though funded by the CT Department of Public Health, is being carried out by the University of Connecticut Health Center.

3. How are the results going to be used?

The results will be used in reports that are published by the University of Connecticut Health Center and given to the Connecticut Department of Public Health. Some results may be used in subsequent publications that are submitted to academic journals; however, all information provided will remain confidential. Results of the survey will be aggregated so that at no point will individual data be published or distributed.

4. How was I selected?

This study relied upon random-digit-dialing, a telephone survey strategy that gives all households with a telephone an equal chance of being selected to participate. As an individual with telephone access, you and your household became eligible to be in the sample. The selection of your phone number was completely random.

5. Where can I obtain more information?

We do have a 1-800 number that you can call to ask any additional questions you may have or to speak with someone further about the study. The 1-800 number is: 1-800-xxx-xxxx.

We hope you will take this chance to talk to us about your opinions regarding health information technology.

How many individuals in this household are 18 years or older?  
[IF NONE, DISCONTINUE THE SURVEY].
[IF MORE THAN ONE INDIVIDUAL IS OLDER THAN 18 YEARS OF AGE IN THE HOUSEHOLD, ASK THE FOLLOWING QUESTION]:

Of the individuals who are 18 years or older, may we continue the survey with the person who had the most recent birthday?

[IF THAT PERSON IS UNAVAILABLE, ATTEMPT TO RESCHEDULE THE SURVEY. IF THE PERSON WITH THE MOST RECENT BIRTHDAY IS EXPECTED TO BE UNAVAILABLE FOR A LONG PERIOD OF TIME (LONGER THAN ONE MONTH), ATTEMPT TO COMPLETE THE SURVEY WITH THE INDIVIDUAL WITH THE NEXT MOST RECENT BIRTHDAY. IF THE PERSON WITH MOST RECENT BIRTHDAY IS EITHER THE CURRENT SPEAKER OR IS WILLING TO COME TO THE PHONE, CONTINUE WITH THE FOLLOWING QUESTION].

Are you willing to participate in this survey?  
[IF RESPONDENT CHOOSES NOT TO PARTICIPATE, END THE SURVEY HERE].

Thank you very much for your time.

[IF RESPONDENT AGREES TO PARTICIPATE IN THE SURVEY, CONTINUE WITH THE FOLLOWING SECTIONS.]

[EVERY QUESTION SHOULD BE READ IN ITS ENTIRETY TO THE PARTICIPANT AND THE RESPONSE SHOULD BE RECORDED ACCORDING TO THE RESPONDENTS ANSWER.]

Qpre-a. What are the number of landlines which ring in your household and you might pick up? ______

Qpre-b. What are the number of cell phones used by the household? ______

Qpre-c. Is this a landline or a cell phone number? ______

[IF RESPONDENT ANSWERS CELL PHONE, PLEASE CONTINUE WITH THE FOLLOWING QUESTIONS. IF RESPONDENT ANSWERS THAT IT IS A LANDLINE, CONTINUE WITH QUESTION 1 OF THE SURVEY].

Qpre-D. Would you like to continue the survey on a cell phone or would you prefer to continue the call at a later date using a landline? _____

[IF RESPONDENT WOULD NOT LIKE TO COMPLETE THE SURVEY USING A CELL PHONE, ATTEMPT TO RESCHEDULE THE CALL AT A LATER TIME OR USING A DIFFERENT NUMBER. IF RESPONDENT PREFERS TO USE THE CELL PHONE, PROCEED TO QUESTION 1].
---BEGIN SURVEY---

Q1. What is the ID Number?

[ENTER ID NUMBER].

Q1a. Currently, if you regularly visit a primary care physician, how satisfied are you with the care you receive: very satisfied, mostly satisfied, neither satisfied nor unsatisfied, slightly satisfied, not at all satisfied?

1. Very satisfied
2. Mostly satisfied
3. Neither satisfied nor unsatisfied
4. Slightly satisfied
5. Not at all satisfied
6. Do not regularly visit (N/A)

Q2. Approximately how many doctors, including any individual with a medical degree, do you visit in one calendar year? [THIS IS AN OPEN-ENDED QUESTION; CODE THE RESPONSE ACCORDING TO THE FOLLOWING CATEGORIES.]

<table>
<thead>
<tr>
<th>Category Number</th>
<th>Category Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Visits</td>
<td></td>
</tr>
<tr>
<td>01.</td>
<td>0</td>
</tr>
<tr>
<td>02.</td>
<td>1-2</td>
</tr>
<tr>
<td>03.</td>
<td>2-4</td>
</tr>
<tr>
<td>04.</td>
<td>5-7</td>
</tr>
<tr>
<td>05.</td>
<td>8-10</td>
</tr>
<tr>
<td>06.</td>
<td>11+</td>
</tr>
</tbody>
</table>

Q3. Have you heard a lot, some, or not at all about each of these new technologies in health care:

Q3a. Electronic health information exchange, where health information is shared electronically across organizations (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure
Q3b. Electronic medical records, where physicians store patient health information (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure

Q3c. Web sites or personal health records where people can get, keep, and update health information (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure

Q3d. The Connecticut Health Information Technology and Exchange (a lot, some, not at all, or unsure)?

1. A lot
2. Some
3. Not at all
4. Unsure

Q4. Some health care institutions invite individuals to join services that provide free online electronic personal health record access. Through such a service, you could view and update your health information on a secure web site. How interested would you be in using this type of website: very interested, somewhat interested, not very interested, or not at all interested?

1. Very interested
2. Somewhat interested
3. Not very interested
4. Not at all interested

[IF RESPONDENT SELECTS NOT VERY INTERESTED OR NOT AT ALL INTERESTED, CONTINUE TO QUESTION 4A. IF RESPONDENT SELECTS VERY INTERESTED OR SOMewhat INTERESTED, CONTINUE TO QUESTION 5.]
Q4a. What is the main reason you are uninterested in using a personal health record?[CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS].

1. Concerned about privacy
2. Unfamiliar with technology
3. No internet access
4. Don’t feel it’s necessary
5. Too much responsibility
6. Might cost too much
7. Don’t know
8. Other [SEE 4B]

Q4b. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE]:

________________________________________________________________________
________________________________________________________________________

Q4c. Of the answers you provided, which do you feel is most important? [THIS QUESTION SHOULD ONLY BE ASKED IF RESPONDENT PROVIDED MORE THAN ONE ANSWER TO QUESTION 4A].

________________________________________________________________________

Q5. If your doctor had an EHR, or an electronic health record system, your information might be shared with health insurance plans, researchers and other companies. This information would be about your health but would not contain private information like your name or date of birth. How interested would you be in allowing your health information to be shared: very interested, somewhat interested, not very interested, or not at all interested?

1. Very interested
2. Somewhat interested
3. Not very interested
4. Not at all interested

[IF RESPONDENT SELECTS NOT VERY INTERESTED OR NOT AT ALL INTERESTED, CONTINUE TO QUESTION 5A. IF RESPONDENT SELECTS VERY INTERESTED OR SOMewhat INTERESTED, CONTINUE TO QUESTION 6.]
Q5a. What is the main reason you are uninterested in sharing data in an electronic medical record? [CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS].

1. Concerned about privacy
2. Unfamiliar with technology
3. Don’t feel it’s necessary
4. Too much responsibility
5. Might cost too much
6. Don’t know
7. Other [SEE 5B]

Q5b. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

Q5c. Of the answers you provided, which do you feel is most important? [THIS QUESTION SHOULD ONLY BE ASKED IF RESPONDENT PROVIDED MORE THAN ONE ANSWER TO QUESTION 5A; OTHERWISE, LEAVE BLANK].

Q6. Would you ever purposely withhold information from your doctor: yes, no, or not sure?

1. Yes
2. No
3. Not sure
4. No answer given

Q7. If your doctor had an EHR that would allow them to share your health information (but not your name, date of birth, address, or Social Security number), would there be anything that you would not tell your doctor: yes, no, or not sure?

1. Yes
2. No
3. Not sure
4. No answer given

[IF RESPONDENT SELECTS YES, CONTINUE TO QUESTION 7A. IF RESPONDENT SELECTS NO OR NOT SURE, CONTINUE TO QUESTION 8.]

**Q7a.** Why would you not tell your doctor information if you knew it would be shared?

[CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS].

1. Privacy reasons
2. Emotional reasons
3. Don’t know
4. Other reason [SEE 7B]

**Q7b.** [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

---

**Q8.** Imagine a nationwide health information exchange that both doctors and patients can access. Information in the network can be controlled, and in an emergency, a patient’s information could only be seen by an authorized family member or representative. Would you strongly oppose, oppose, favor, or strongly favor the creation of this type of network?

1. Strongly oppose
2. Oppose
3. Favor
4. Strongly favor

**Q9.** Which of the following do you consider to be the main barrier to achieving a nationwide health information exchange: privacy concerns, ensuring compatibility of multiple networks, cost, liability, limited public support, none of the above, or don’t know?

1. Privacy concerns
2. Compatibility of multiple networks
3. Cost
4. Liability
5. Limited public support
6. None of the above
7. Don’t know

Q10. Within a health information exchange, there are two ways that doctors could obtain your consent to participate. One way is for you to have to tell the doctor that you would allow your information to be shared before any of your information would enter the network – this is called opt-in. The other way would be that your information would enter the network unless you asked that it not be exchanged electronically – this is called opt-out. Which of these two methods would you prefer to use: opt-in, opt-out, or don’t know?

1. Opt-in
2. Opt-out
3. Don’t know

Q11. On a scale from 1 to 7, with 1 being the least and 7 being the greatest, please rate your level of agreement with the following:

11a. Health IT could improve quality of care?

11b. Health IT could improve doctor-patient interaction?

11c. Health IT could lead to a reduction in medical errors?

11d. Health IT could reduce the amount of unnecessary tests?
Q12. If you were offered the opportunity to sign up for a PHR, what is the primary factor that would most encourage you to join? [CHECK ALL ANSWERS AS THEY APPLY TO RESPONDENT OPINIONS].

1. Trust in organization or physician
2. Safeguards (privacy policies)
3. Popularity with friends and family
4. Don't know
5. Other [SEE 12A]

Q12a. [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

Q13. Does your doctor currently have an electronic medical record: yes, no, or not sure?

1. Yes
2. No
3. Not sure

Q14. Have you ever been diagnosed with any type of chronic health condition (such as asthma or diabetes): yes, no, or unsure?

1. Yes
2. No
3. Unsure

Q15. Have you ever looked for information about health or medical topics: yes, no, don’t know?

1. Yes
2. No
3. Don’t know
[IF RESPONDENT SELCTS YES, CONTINUE TO QUESTION 15A. IF RESPONDENT SELCTS NO OR DON'T KNOW, CONTINUE TO QUESTION 16.]

**Q15a.** Think back to the most recent time you looked for this information. Did you look for this health information from: your physician, another doctor, the internet, a magazine, a book, a journal, or another source?

1. Physician
2. Another doctor
3. The internet
4. Magazine
5. Book
6. Journal
7. Other [SEE 15B]

**Q15b.** [IF RESPONDENT PROVIDES RESPONSES NOT SIMILAR TO ABOVE, PLEASE DESCRIBE THEM HERE; OTHERWISE, LEAVE BLANK]:

**Q16.** For health-related concerns, how many times over the past 30 days would you say that you used the Internet to get health information?

**Q17.** How many times in the past 7 days did you access banking information online?

**Q18.** Think back to the last time you received printed information from your doctor's office. This information could be a brochure, instructions, or a pamphlet. How much of it did you read: a lot, some, none, don't know?

1. A lot
2. Some
3. None
4. Don't remember; don't know

**Q19.** Was any of the information in the material difficult to understand: yes, no, not sure?
1. Yes
2. No
3. Not sure

Q20. Were any of the words in the material unfamiliar to you: yes, no, not sure?

1. Yes
2. No
3. Not sure

[IF RESPONDENT SELECTS YES, CONTINUE TO QUESTION 20A. IF RESPONDENT SELECTS NO OR DON'T KNOW, CONTINUE TO QUESTION 21.]

Q20a. You answered that you had trouble with some of the words in the material. Did you ask someone such as a doctor, nurse, or family member for help understanding the material: yes, no, not sure?

1. Yes
2. No
3. Not sure

Q21. Think back to the last time you visited your doctor. During your appointment, did your doctor use any medical words that you did not understand: yes, no, don’t know?

1. Yes
2. No
3. Don’t know

[IF RESPONDENT SELECTS YES, CONTINUE TO QUESTION 21A. IF RESPONDENT SELECTS NO OR DON'T KNOW, CONTINUE TO QUESTION 22.]

Q21a. Did the doctor explain those words to make them easier to understand: yes, no, not sure?

1. Yes
2. No
3. Not sure
Q22. What is your zip code?

Q23. What is your gender?
   1. Male
   2. Female
   3. Other

Q24. What was your age at your most recent birthday?

Q25. What is your total annual household income? [THIS IS AN OPEN-ENDED QUESTION; CODE THE RESPONSE ACCORDING TO THE FOLLOWING CATEGORIES.]

<table>
<thead>
<tr>
<th>Category Number</th>
<th>Category Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>01.</td>
<td>1. Less than $25,000</td>
</tr>
<tr>
<td>02.</td>
<td>2. $25,000 to $39,999</td>
</tr>
<tr>
<td>03.</td>
<td>3. $40,000 to $49,999</td>
</tr>
<tr>
<td>04.</td>
<td>4. $50,000 to $79,999</td>
</tr>
<tr>
<td>05.</td>
<td>5. $80,000 to $99,999</td>
</tr>
<tr>
<td>06.</td>
<td>6. $100,000 or higher</td>
</tr>
</tbody>
</table>

Q26. What is the highest level of education you have completed: less than high school, some high school, high school diploma, some college, college degree, or graduate school?
   1. Less than high school
   2. Some high school
   3. High school diploma
   4. Some college
   5. College degree
   6. Graduate school

Q27. What is your ethnicity? Hispanic or Latino or not Hispanic or Latino?
   1. Hispanic or Latino
2. Not Hispanic or Latino

**Q28.** Please select one of the following racial categories to describe yourself: American Indian or Alaska Native, Black or African American, Asian, Native Hawaiian or other Pacific Islander, White, or more than one of these categories? [CHECK ALL THAT APPLY].

1. American Indian or Alaska Native
2. Black or African American
3. Asian
4. Native Hawaiian or other Pacific Islander
5. White

**Q29.** Would you say your health in general is excellent, very good, good, fair, poor, or don't know?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
6. Don't know

**Q30.** During the past twelve months, about how many times did you see or talk to a medical doctor or assistant?

[THIS IS AN OPEN-ENDED QUESTION.]

**Q31.** We will be doing a follow-up to this survey in the following year. May we call you to follow-up with you at that time?

1. Yes
2. No

[IF NO, REMOVE TELEPHONE NUMBER FROM MASTER LIST]

That completes our survey. Thank you very much for your time. If you have any questions or concerns, please call the following toll-free number: 1-800-xxx-xxxx.

[DISCONNECT THE CALL. THE FOLLOWING QUESTION SHOULD BE ANSWERED ONCE THE CALL HAS BEEN COMPLETED].
Q32. Please describe any thoughts or opinions regarding the survey or the respondent: