

CHCF: Survey 070805

Introduction: Hello, my name is _____ and I am conducting a survey about some health and privacy issues that affect people’s everyday lives. It is important to know that this is a confidential survey, all of your responses will be aggregated so that no one will be able to identify your individual responses to these questions.

1. Here is my first question, when you think of your personal medical information that is kept in your medical records, what type of information comes to mind? Does your personal medical information include ... (INSERT - READ AND ROTATE)?

- Your Social Security Number
- Your current medical conditions
- Previous medical conditions you have had
- Your health insurance information
- Information about where you work
- Family health history
- Your doctor’s personal notes or observations
- Procedures that have been done
- Medications you currently take
- Medications you have taken in the past
- Past health expense and payment information
- Your risk of developing certain conditions in the future
- Other (Please specify)

2. How concerned are you with the privacy of your personal medical records?

- Very concerned
- Somewhat concerned
- Not very concerned
- Not at all concerned
- Don’t know/Refused (DO NOT READ)

3. Which of the following statements describe how you view your personal medical records. Are they...

- Information I own and control
- Information I own and have a duty to share to advance health care
- Information I can choose to share in exchange for some benefits (ie. Access to care, discounts, research studies)
- Information I can sell if I choose
- Information that my doctors have a right to use
- Information researchers have a right to use
- Information that the broader medical community has a right to use
- Information that anyone has the right to use

4. Please tell me how much access you think each of the following now has to your own personal medical records – access to everything in your medical records, only limited access, or no access at all. If you do not have a relationship with the person or company in this question, please assume you do have a relationship with that person or company. (First,) how much access do/does (INSERT, READ ITEMS IN ORDER) have?

You, yourself	Access to everything
Your husband/wife/partner	Limited Access
Close relatives like your parents or children	No Access
Your employer	Don’t know/Refused (DO NOT READ)
Your health insurance company or health plan	
The doctor you use most often	
Other doctors and health care professionals involved with your own health care	
Doctors and other health care professionals not involved with your own health care	

Government agencies	
Pharmacies	
Drug companies	

5. How important is it to you to control the amount of access each of the following has to your personal medical records? (First,) how important is it to you to control the access that (INSERT - READ AND ROTATE) has to your records?

Your husband/wife/partner	Very important
Close relatives like your parents or children	Somewhat important
Your employer	Not very important
Your health insurance company or health plan	Not at all important
The doctor you use most often	Don't know/refused (DO NOT READ)
Other doctors and health care professionals involved with your own health care	
Doctors and other health care professionals not involved with your own health care	
Government agencies	
Pharmacies	
Drug companies	

6. Are you, yourself, now covered by any form of health insurance or health plan, including any private insurance plan as well as government programs like Medicare or (Medicaid)? (VARIANT WORDING FOR CA RESPONDENTS: MEDI-CAL)

Yes
No
Don't know/refused (DO NOT READ)

7. As far as you know, do individuals have the right to see their own personal medical records?

Yes
No
Don't know/Refused (DO NOT READ)

8. Have you ever tried to see or get a copy of your own medical records?

Yes
No
Don't know/Refused (DO NOT READ)

[ASK ONLY IF Q8=YES]

9. Thinking about the most recent time you tried to see or get a copy of your own medical records, what was the main reason you wanted access to your medical records?

Moved/Transferred doctors
Personal interest/concern
Need to submit medical records to school, government agency, or another organization
Personal record/copy
Verification of test results/Monitor care
Some other reason
No specific reason
Don't know/Refused (DO NOT READ)

[ASK ONLY IF Q8=YES]

10. Still thinking about the most recent time you tried to see or get a copy of your own medical records, which of the following best describes how you requested access to your records?

In person
Over the telephone
Through postal mail

Through the Internet (i.e. via email or requesting from a Website)

[ASK ONLY IF Q8=YES]

11. Were you successful in getting access to your medical records during your most recent attempt to access your own medical records?

Yes

No

Partial success

Don't know/Refused (DO NOT READ)

12. As far as you know, do you have the right to ... (INSERT - READ AND ROTATE)?

Have corrections made to your own health information

Be notified if your health information has been accessed or shared

Prevent certain parties from accessing or sharing your health information

Give your permission before your health information can be accessed or shared for certain purposes

Get a report on when and why your health information was shared for certain purposes

13. How willing are you to share your personal medical records with (INSERT - READ AND ROTATE)? Are you...

Your husband/wife/partner	Very willing
Close relatives like your parents or children	Somewhat willing
Your employer	Not very willing
Your health insurance company or health plan	Not at all willing
The doctor you use most often	Don't know/refused (DO NOT READ)
Other doctors and health care professionals involved with your own health care	
Doctors and other health care professionals not involved with your own health care	
Pharmacies	
Drug companies	
Government agencies	

14. If sharing your personal medical records with (INSERT ANSWERS FROM Q13 WHERE ANSWER IS 3 OR 4) gave you (INSERT - READ AND ROTATE), how likely would you be to share them with this party? Are you ...

Better coordination of medical care or treatment	Very likely
Current information on medical news or developments	Somewhat likely
Enhanced medical coverage or benefits	Not very likely
Financial incentives	Not at all likely
Access to experimental treatment	Don't know/refused (DO NOT READ)
Access to personalized treatment	
Lower insurance premiums	
Access to preventative health programs	

15. As far as you know, can healthcare organizations or insurance companies access your personal health information without your express knowledge or permission to... (INSERT -- READ AND ROTATE)?

Coordinate your treatment and care across multiple doctors or facilities

Pay doctors and hospitals for your treatment

Determine how much to charge you for insurance

Help run their own business more effectively

Provide information to your family, relatives, friends, or others who are involved with your health care

Provide information to your family, relatives, friends, or others who are involved with paying your health expenses

Make sure doctors or hospitals are giving good care

Protect the public's health, such as by reporting when the flu is in your area

Make required reports to police

Give your information to your employer

Use or share your information for marketing or advertising purposes

Share notes with other health professionals

16. Are you now enrolled in any health insurance plan through a current employer?

Yes

No

Don't know/Refused (DO NOT READ)

17. How concerned are you that medical claims information you provide to a health insurance plan might be seen by an employer and used to limit your job opportunities or affect your job status. Are you...?

Very concerned

Somewhat concerned

Not very concerned

Not at all concerned

Don't know/Refused (DO NOT READ)

[Q18 FOR Q16=YES]

18. Have you ever been concerned about interacting with your health plan while at work because you did not want your employer to have access to that information? Interacting could be filing a claim, asking a question, discussing a treatment plan.

Yes

No

Don't know/Refused (DO NOT READ)

19. Have you ever asked a doctor not to write down your health problem in your medical records, or asked the doctor to put a less serious or less embarrassing diagnosis into the record than was actually the condition?

Yes

No

Don't know/Refused (DO NOT READ)

20. Have you ever gone to another doctor for care in order to avoid telling your regular doctor about a particular health condition or health need?

Yes

No

Don't know/Refused (DO NOT READ)

21. Have you ever decided not to be tested for a medical condition because you were concerned that other might find out about the results?

Yes

No

Don't know/Refused (DO NOT READ)

22. Have you ever personally paid for a medical test, medical procedure, or counseling rather than submit a bill or claim under a health insurance plan because you didn't want your employer or someone else to have access to your personal medical information?

Yes

No

Don't know/Refused (DO NOT READ)

23. Now, please tell me how secure you think that your medical records are when they are stored in each of the following ways. First, when they are (INSERT - READ AND ROTATE)? Are they...

Stored on paper	Very secure
Stored electronically	Somewhat secure
	Only a little secure
	Not secure at all
	Don't know/refused (DO NOT READ)

24. Some health care providers are shifting to computer-based systems for keeping medical records and payment information. Do you think computerization will have the following effects? (First,) what about this possible result from computerization... (INSERT -- READ AND ROTATE)

Giving doctors and nurses quicker, easier access to information about patients' past medical experiences, test results, and health conditions	Yes No
Reducing the time and cost required to process medical records and claims	
Give pharmacies and drug companies more information to give you advertising and special offers	
Increasing communication between hospitals, doctor's offices, or for a health plan	
Reducing errors that could occur in medical treatment	
Increasing the occurrence of unauthorized personnel who break into computer systems or payment systems	

25. As far as you know, are there now any federal laws in place that protect the privacy and confidentiality of personal medical records?

Yes
No
Don't know/Refused (DO NOT READ)

26. Have you received a notice from your health plan or doctor notifying you of your rights related to your personal medical records?

Yes
No
Don't know/Refused (DO NOT READ)

[Q27 FOR Q26=YES]

27. Do you feel that the rights outlined in this notice gave you ...

More rights than you had before you received the notification
The same level of rights that you had before you received the notification
Fewer rights than you had before you received the notification
Don't know/Refused (DO NOT READ)

28. A unique health identifier is a personal identification number (like a Social Security Number) which can be used to link medical records on computer networks used by health care providers. These unique health identifiers could be used to make it easier for doctors to find your personal medical records and expedite care but it could also make it easier for people not involved with your health care to get access to your information. Do you support the use of such unique health identifiers?

Yes

No

29. Are you aware of any specific incidents where the privacy of peoples' personal information was compromised?

Yes
No

[Q30 ONLY FOR Q29 =YES]

30. How have these incidents affected your concern over the privacy of your personal medical records? Are you...

Significantly more concerned about my personal medical records
Slightly more concerned about my personal medical records
It hasn't changed my level of concern about my personal medical records
Slightly less concerned about my personal medical records
Significantly more concerned about my personal medical records

Introduction: Now we'd like to ask you a couple of questions about your use of technology.

31. How often do you go online? This includes access from home, work, or elsewhere. (READ ANSWER OPTIONS)

Don't have online access at all
Have access but never use
Less often than once a month
About once a month
Several times a month
About once a week
Several times a week
Daily

[Q32 ONLY IF Q31~=DO NOT HAVE ONLINE ACCESS AT ALL]

32. Please indicate how frequently you do each of the following online. Do you (INSERT ANSWER OPTIONS --ROTATE) once a week or more, less than once a week, or never?

Purchase goods or services	Once a week or more Less than once a week Never Don't know/Refused (DO NOT READ)
Pay bills	
Make transfers between bank accounts, check bank account balances	
Research specific medical conditions	
Research specific drugs/medications	
Purchase prescription drugs for your own use	
Visit general health/fitness Websites	
Visit government health or disease association Websites	
Visit health plan/HMO Websites	
Visit doctor or other health care professional Websites	

33. The following are a list of statements that may or may not be used to describe your attitudes towards technology. Please indicate to what extent each statement describes your attitudes on a scale from 1 to 5, where 1 means "Does not describe your attitudes at all" and 5 means "Describes your attitudes completely."

Technology is important to me	1- Does not describe my attitudes at all 2 3 4 5- Describes my attitudes completely
I like technology	
I worry about the effects of computers on our lives	
Technology sometimes intimidates me	
Technology has made my life easier	

Introduction: Finally, I have a few questions about you and your household...

34. Which of the following diseases or medical conditions have you been diagnosed with? (First,) do you have...(INSERT -- READ AND ROTATE)

Allergies
Arthritis
Migraine headaches
High cholesterol
High blood pressure
Diabetes
Gastrointestinal (e.g. IBS, acid reflux, ulcers)
Depression/Anxiety
Weight problems/Obesity
HIV/AIDS
Substance abuse
Cancer

35. Are you married, living as married, divorced, separated, widowed, or have you never been married?

Married
Living as married
Divorced
Separated
Widowed
Never married/single
Refused (DO NOT READ)

36. Are you currently self-employed, employed by someone else, retired, or not employed for pay?

Self-employed
Employed by someone else
Retired
Not employed
Refused (DO NOT READ)

37. Gender (PLEASE RECORD BASED ON VOICE, ASK IF NECESSARY)

Male
Female

38. What is the LAST grade or class that you COMPLETED in school? (DO NOT READ ANSWER OPTIONS)

None, or grade 1-8
High school incomplete (grades 9-11)
High school graduate (grade 12 or GED certificate)
Business, technical, or vocational school AFTER high school
Some college, no 4-year college degree
College graduate (B.S., B.A., or other 4 year-degree)
Post-graduate training or professional schooling after college (e.g. toward a master's degree or Ph.D.; law or medical school)
Don't know (DO NOT READ)
Refused (DO NOT READ)

39. What is your age? (RECORD ACTUAL AGE)

40. Geographic region. (DO NOT READ -- RECORD FROM AREA CODES)

New England
Middle Atlantic
South Atlantic
East South Central

West South Central
East North Central
West North Central
Mountain
Pacific

41. **What is the primary language you speak in your home? (RECORD RESPONSE)**
42. **How children aged 18 or younger currently live in your household? (RECORD RESPONSE)**
43. **What is your race? Are you white, black, Asian, or some other race? (IF RESPONDENT SAY 'HISPANIC' OR 'LATINO(A)' ASK) Do you consider yourself a white Hispanic/Latino(a) or a black Hispanic/Latino(a)? (THEN CODE AS WHITE OR BLACK. IF RESPONDENT DOES NOT CHOOSE, CODE AS OTHER)**

White
Black/African-American
Asian
Other or mixed race
Don't know (DO NOT READ)
Refused (DO NOT READ)

45. **Are you of Hispanic origin?**

Yes
No
Don't know (DO NOT READ)
Refused (DO NOT READ)

45. **What was your total household income from all sources before taxes last year? Just stop me when I get to the right category. (READ ANSWER OPTIONS)**

Less than \$10,000
\$10,000 to less than \$20,000
\$20,000 to less than \$30,000
\$30,000 to less than \$50,000
\$50,000 to less than \$75,000
\$75,000 to less than \$100,000
\$100,000 or more
Don't know (DO NOT READ)
Refused (DO NOT READ)