

National Consumer Health Privacy Survey 2005

Conducted for the California HealthCare
Foundation by Forrester Research, Inc.



November 9, 2005



CALIFORNIA
HEALTHCARE
FOUNDATION

About CHCF

The California HealthCare Foundation, based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. For more information, visit **www.chcf.org**.

About Forrester Research

Forrester Research is an independent technology and market research company that provides pragmatic and forward-thinking advice about technology's impact on business and consumers. For more information, visit **www.forrester.com**.



CALIFORNIA
HEALTHCARE
FOUNDATION

2005 Health Privacy Survey Objective

To investigate emerging consumer health privacy issues to inform and strengthen the national health information technology agenda



Survey Methodology

- Telephone-based survey with approximately 2,100 U.S. respondents over the age of 18
 - California residents were oversampled (N~1,000)
 - People with HIV and substance abuse were oversampled (N~100)
- Fielded summer 2005 in English and Spanish populations
- The overall margin of error is approximately +/- 3% for the national and California respondent groups
- National respondents and California respondents were weighted separately by several demographic factors to be representative of their respective populations



Key Findings

Despite new federal protections, consumers are:

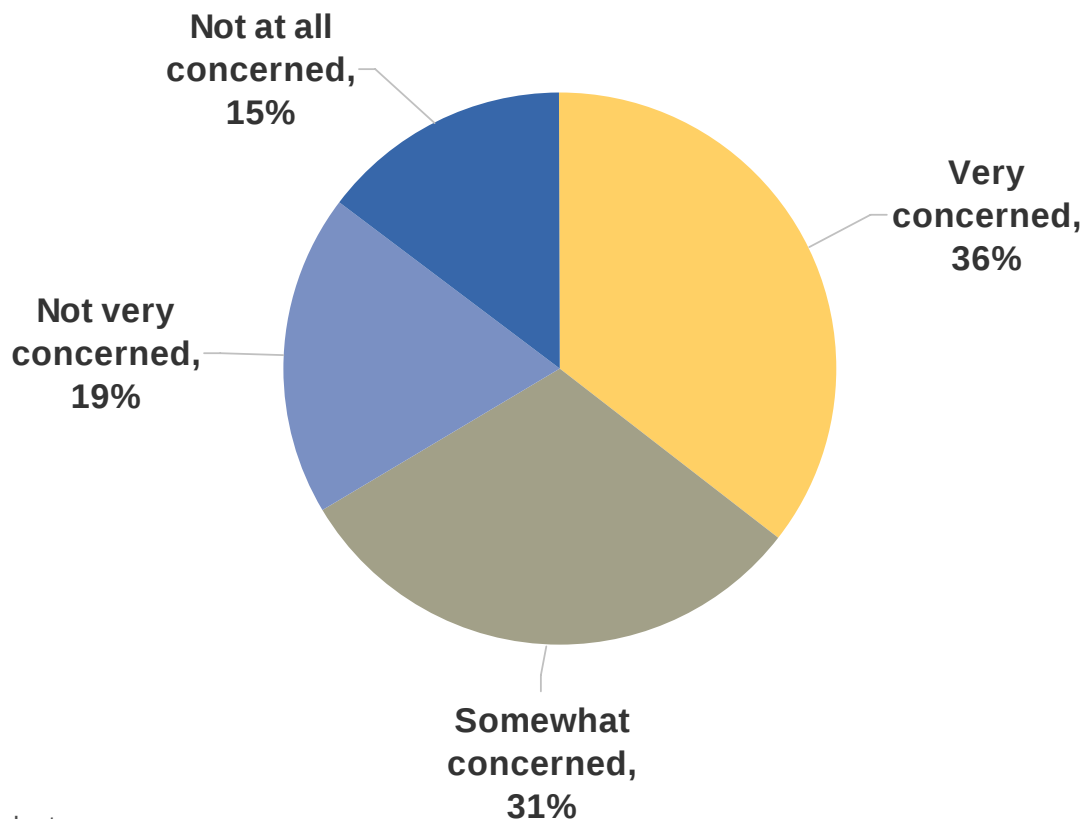
- Concerned about the privacy of their personal health information
- Unaware of their rights
- Practicing “privacy-protective behaviors”
- Willing to share their personal health information to receive certain benefits



Consumers Are Concerned About the Privacy of Their Personal Health Information

Nationally, two thirds of consumers continue to show high levels of concern about personal health information (PHI) privacy...

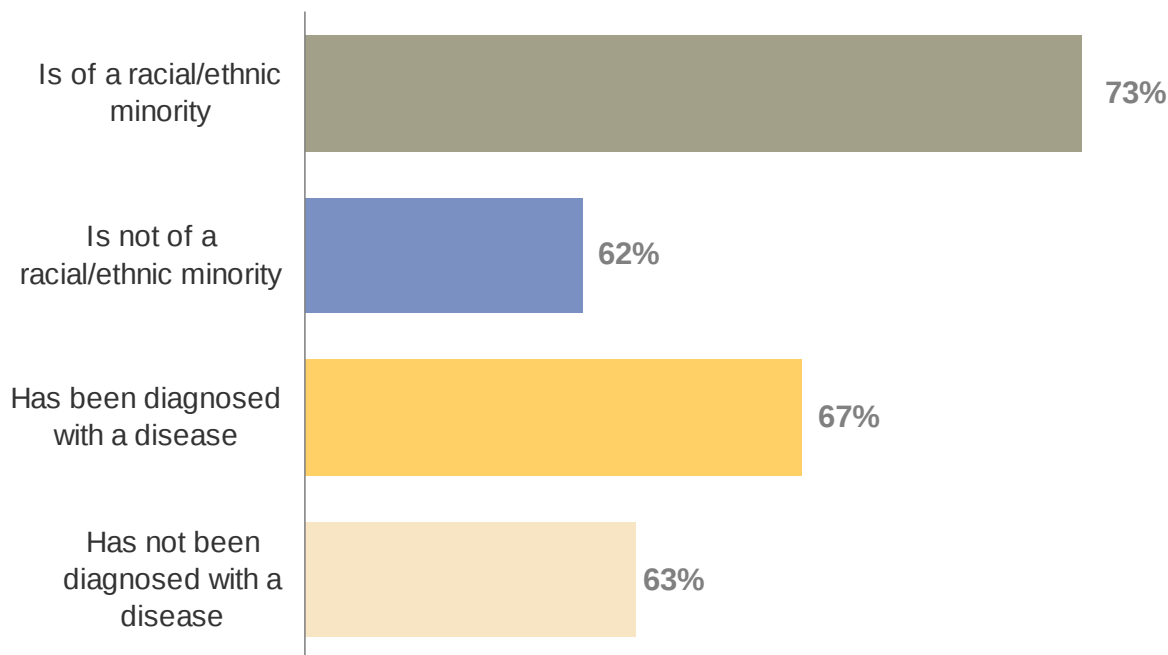
Q. How concerned are you with the privacy of your personal medical records?



Base: National respondents.

...And ethnic and racial minorities and the chronically ill show the greatest concern

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

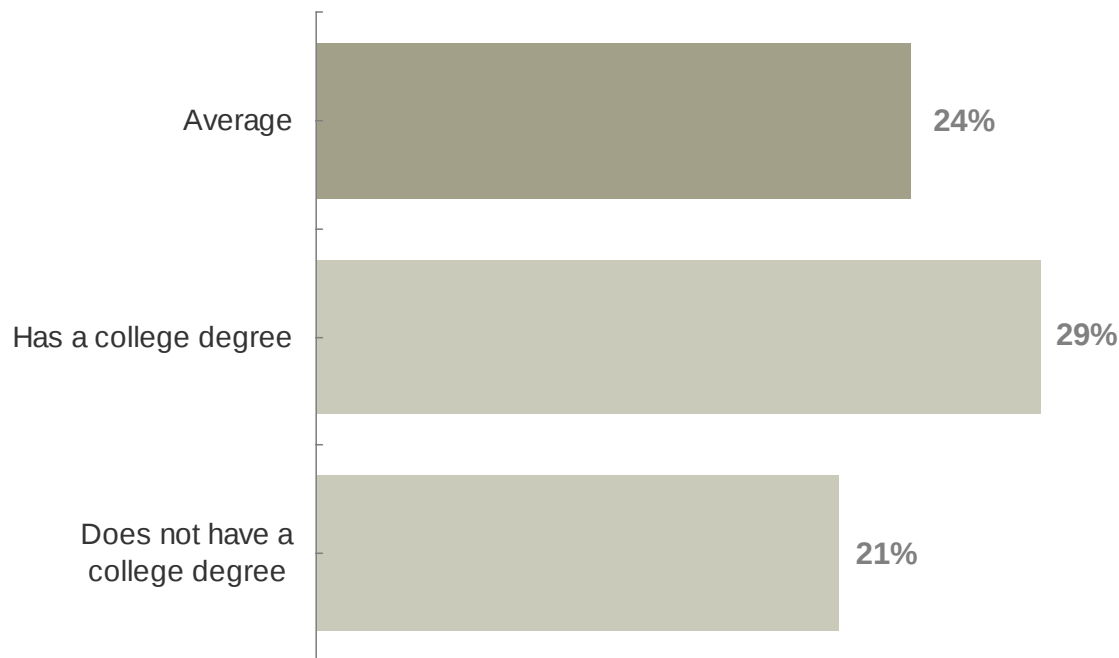


*Concerned aggregates "very concerned" or "somewhat concerned."

Base: National respondents.

One in four consumers is aware of recent privacy breaches

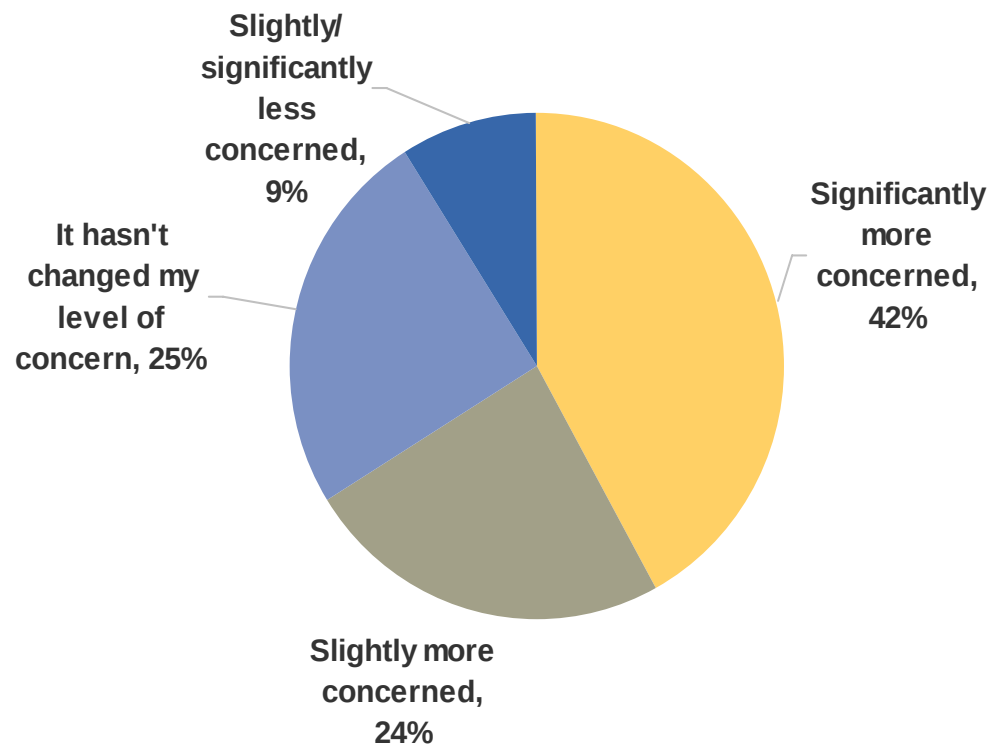
Q. Percentage of respondents aware of specific incidents where the privacy of personal information was compromised:



Base: National respondents.

Recent incidents have increased privacy concerns among aware consumers

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



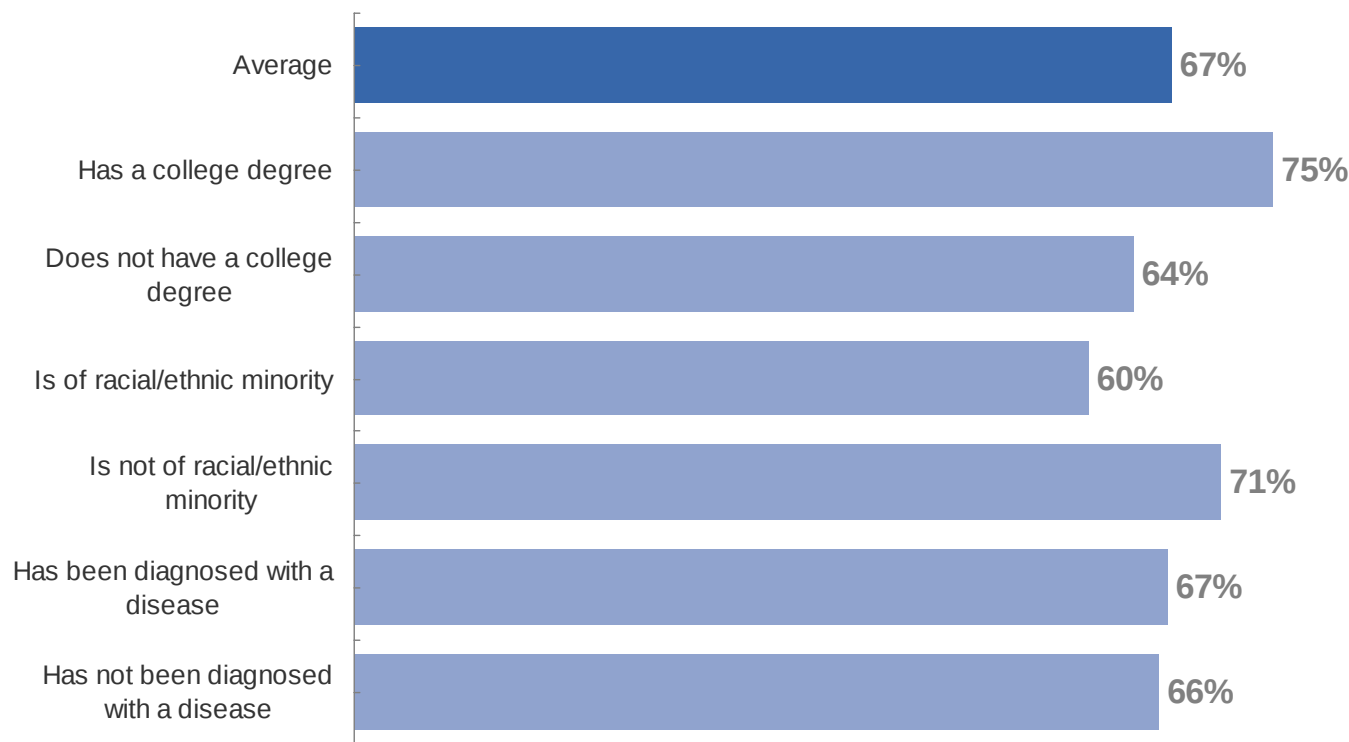
Base: National respondents aware of recent privacy breaches.



Consumers Are Unaware of Their Rights

Consumer awareness of federal regulations varies with education and race

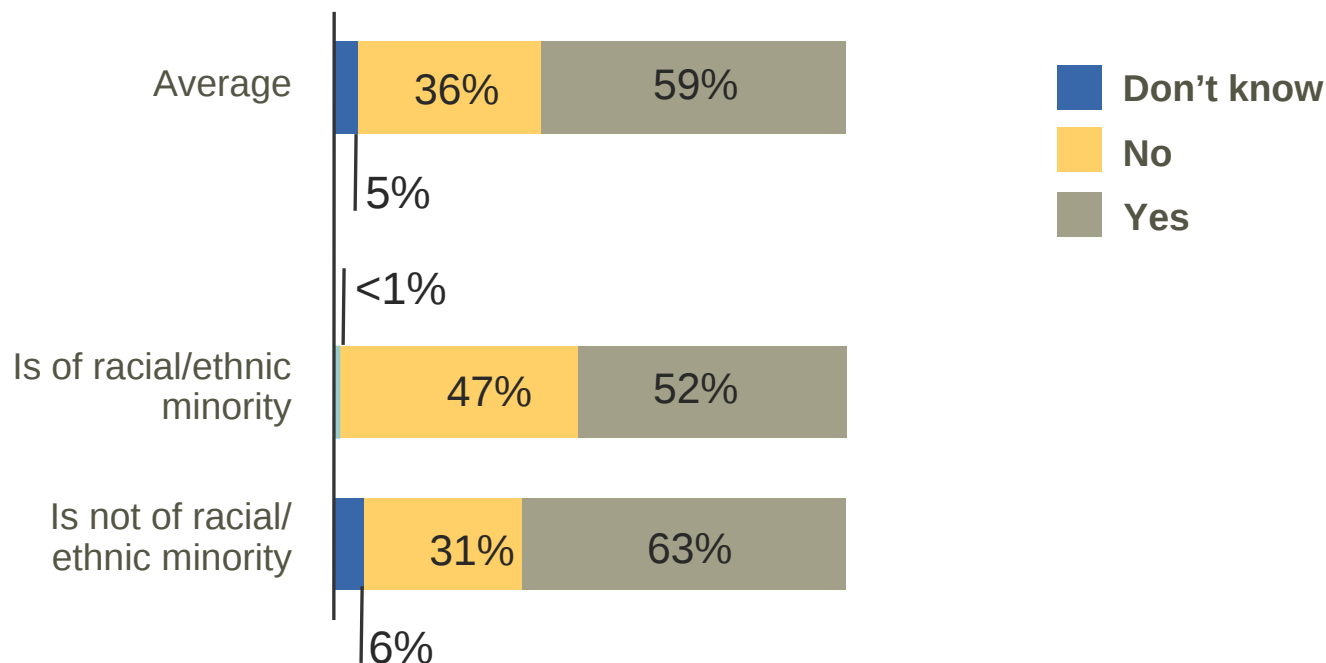
Is aware of federal laws that protect the privacy and confidentiality of personal medical records:



Base: National respondents.

Racial or ethnic minorities are least likely to acknowledge or recall receiving notification of privacy rights

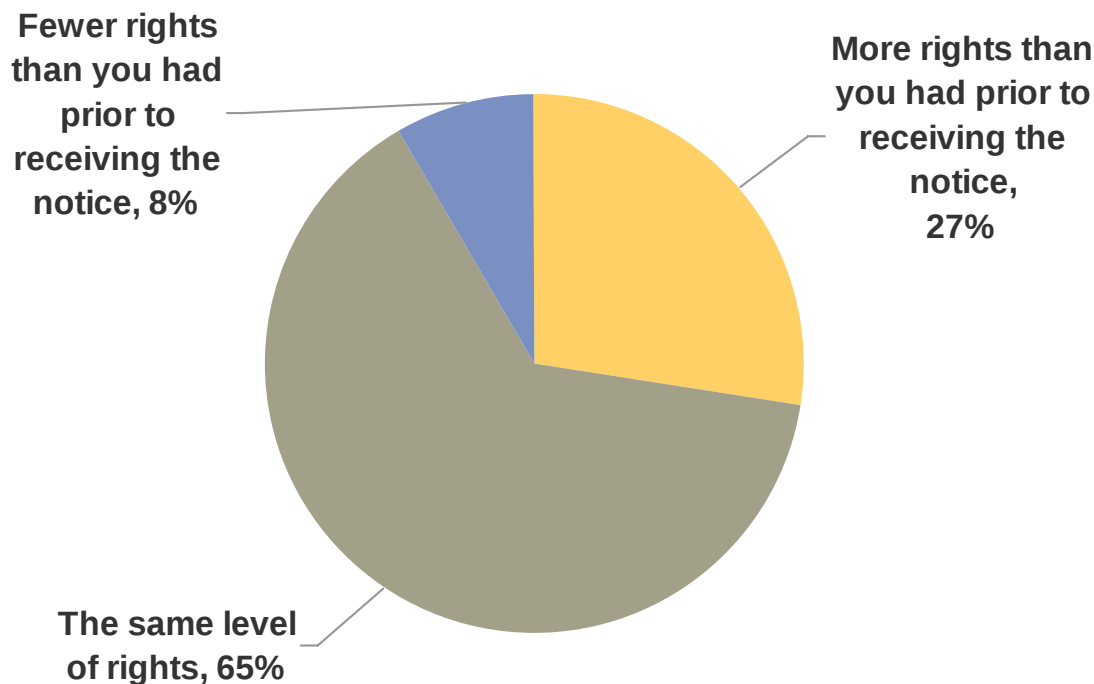
Q. Have you received a notice from a health plan or doctor notifying you of your rights related to your personal medical records?



Base: National respondents.

Of those who received a HIPAA notice, only a quarter are aware of the new rights

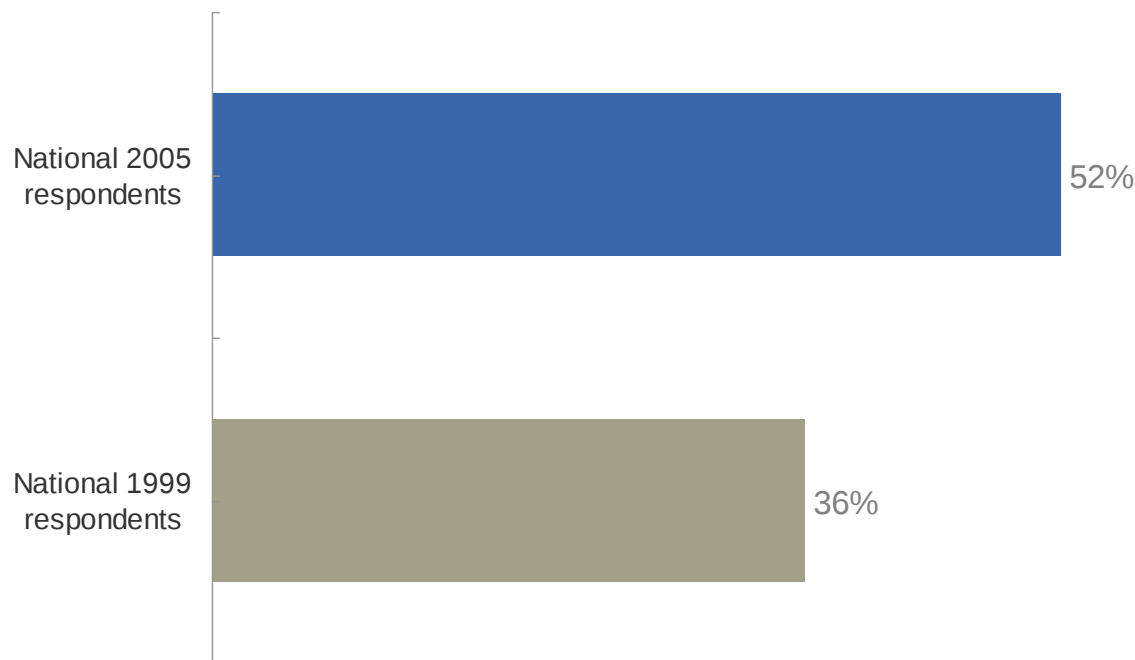
Q. Did you feel the rights outlined in the notice gave you...



Base: All national respondents who received a notice from a plan/physician.

Concerns about employer use of medical claims information has increased significantly since 1999...

Q. How concerned are you that claims information you provide an insurer might be seen by an employer and used to limit job opportunities?*

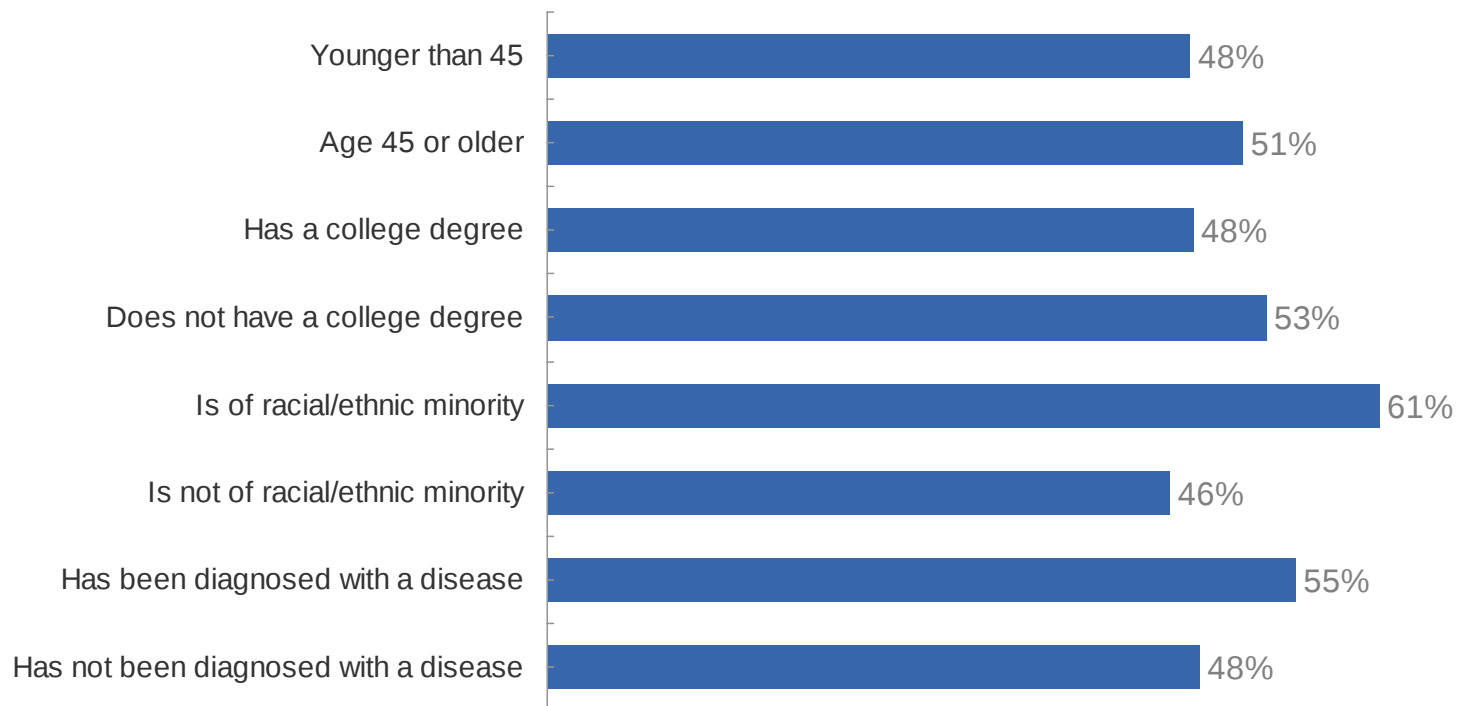


*Concerned aggregates "very concerned" or "somewhat concerned."

Base: National respondents enrolled in a health plan through a current employer

Racial and ethnic minorities and those with chronic disease are most concerned about employer misuse of PHI

Q. How concerned are you that claims information you provide an insurer might be seen by an employer and used to limit job opportunities?*



Base: National respondents enrolled in a health plan through a current employer.



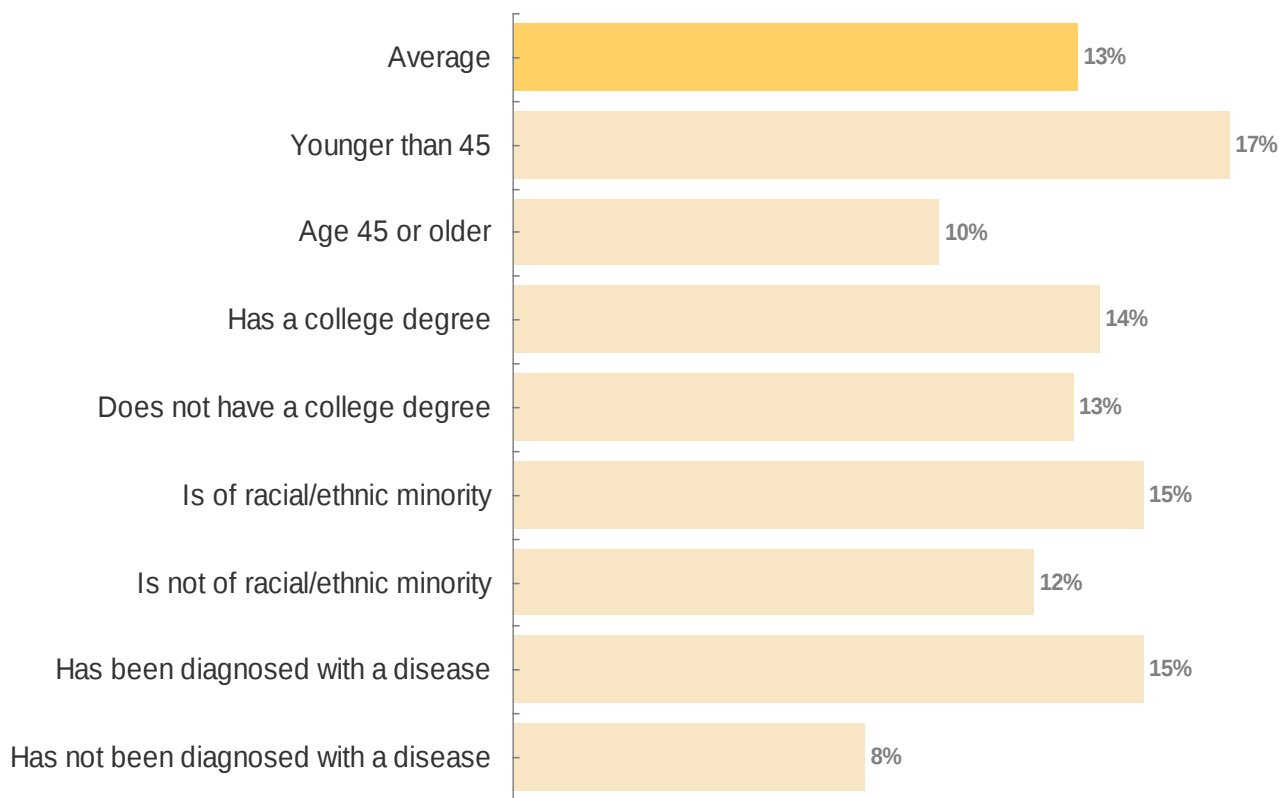
Consumers Are Practicing Privacy-Protected Behaviors

Consumers practicing “privacy-protective behaviors”

- Asked a doctor not to record a health problem or record a less serious/embarrassing diagnosis
- Gone to another doctor to avoid telling your regular MD about a health condition
- Personally paid for a test, procedure or counseling rather than submit a claim out of concern someone else would access information
- Decided not to be tested out of concern that others might find out about the results

One out of eight consumers has engaged in a behavior intended to protect his or her privacy

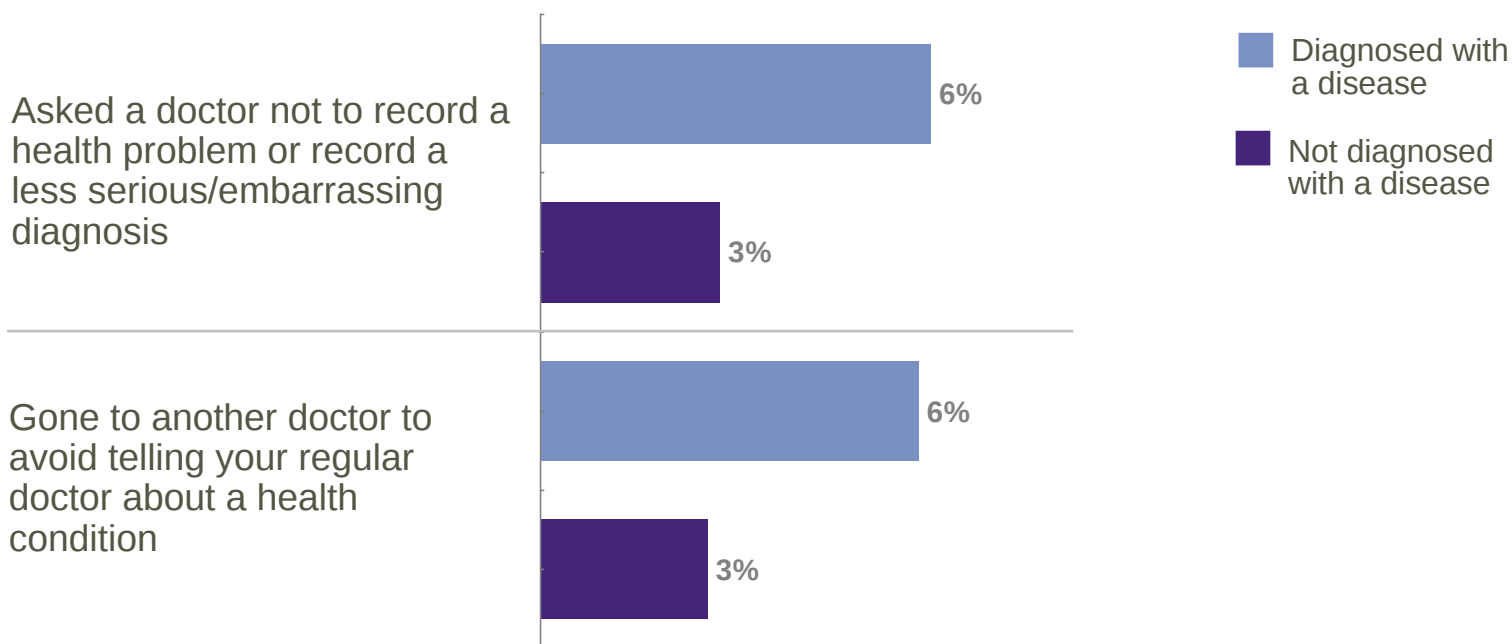
Q. Have you ever performed *at least one* privacy protection activity?



Base: National respondents.

Chronically ill consumers are more likely to risk their health over privacy concerns

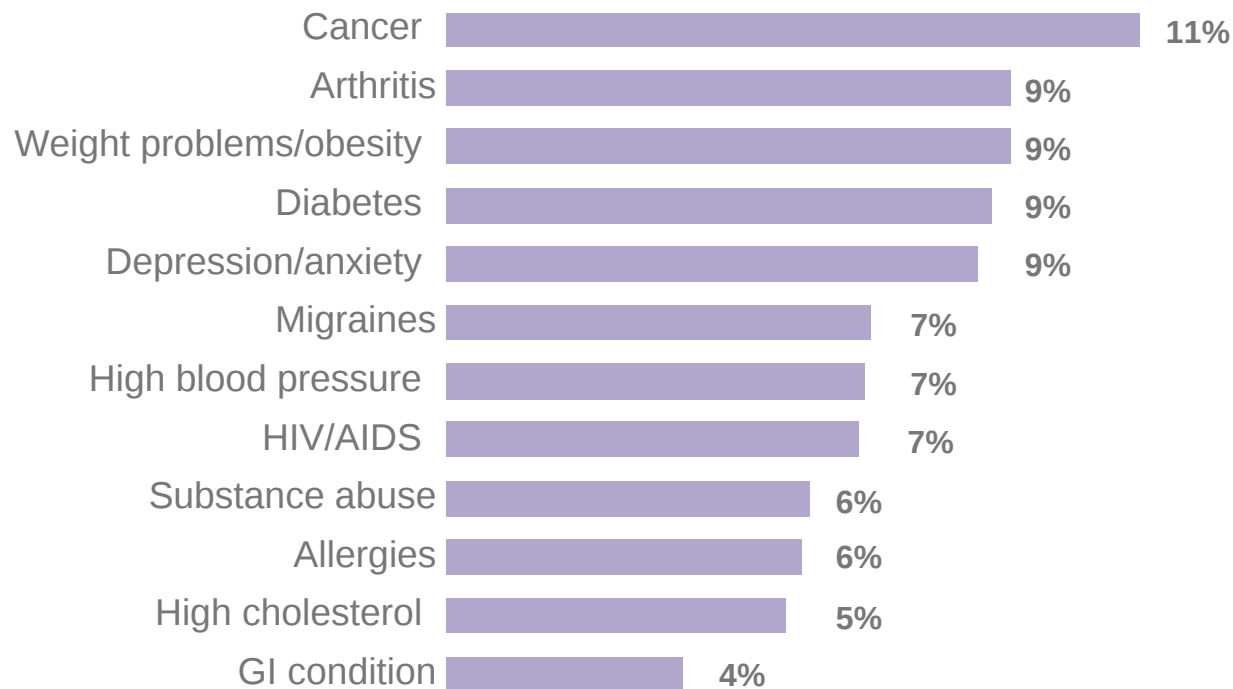
Q. Have you ever...



Base: National respondents.

Privacy-protective behavior increases for people with certain diseases

Q. Have you ever personally paid for a test, procedure, or counseling rather than submit a claim out of concern that your employer / someone else would access the information?



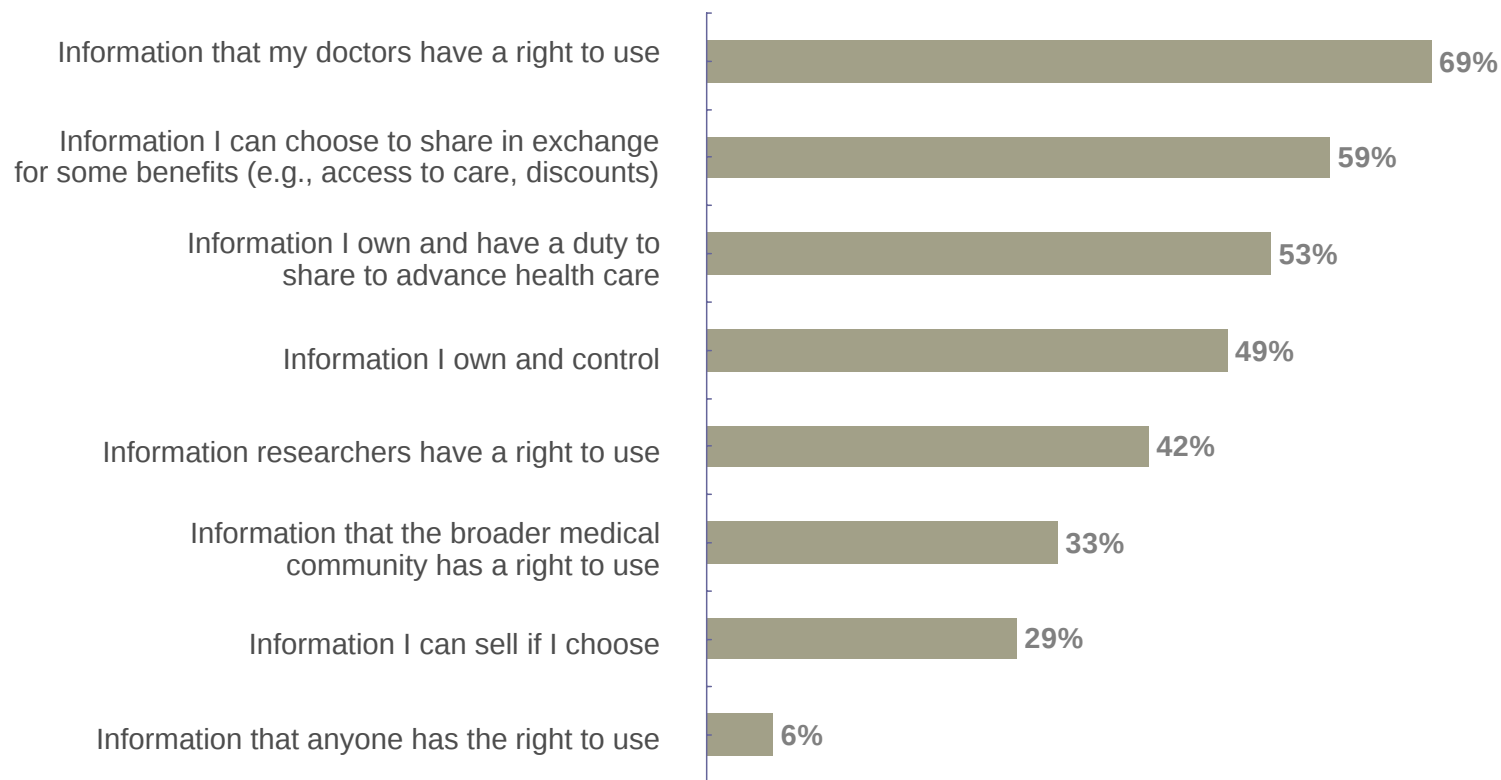
Base: California respondents within specific disease groups.



Consumers Are Willing to Share
Their Personal Health Information

Consumers feel their doctors have a right to use their medical records

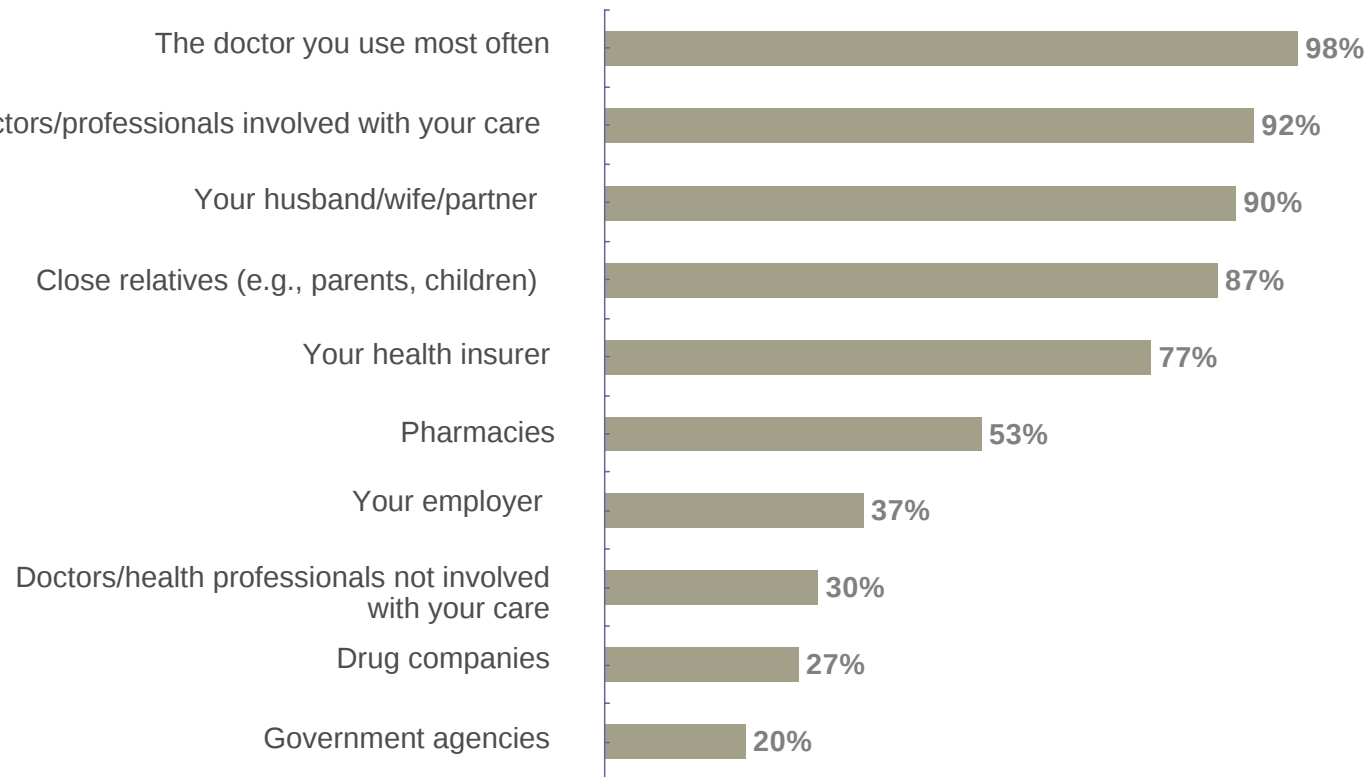
Q. How do you view your personal medical records?



Base: National respondents with multiple responses accepted.

Consumers are willing to share PHI with providers, less willing with drug companies and government agencies

Is willing to share PHI with...



Base: National respondents.

Better treatment coordination would motivate most chronically ill consumers to share PHI with doctors other than their personal physician

**Would be likely to share PHI with doctors
not involved in their care in exchange for:**

	Diagnosed with a disease	Not diagnosed with a disease
Better coordination of medical treatment	60%	50%
Enhanced coverage/benefits	59%	53%
Access to experimental treatment	58%	48%
Current information on medical developments	54%	50%
Financial incentives	52%	49%
Access to personalized treatment	49%	34%
Lower insurance premiums	48%	38%
Access to preventative health programs	47%	44%

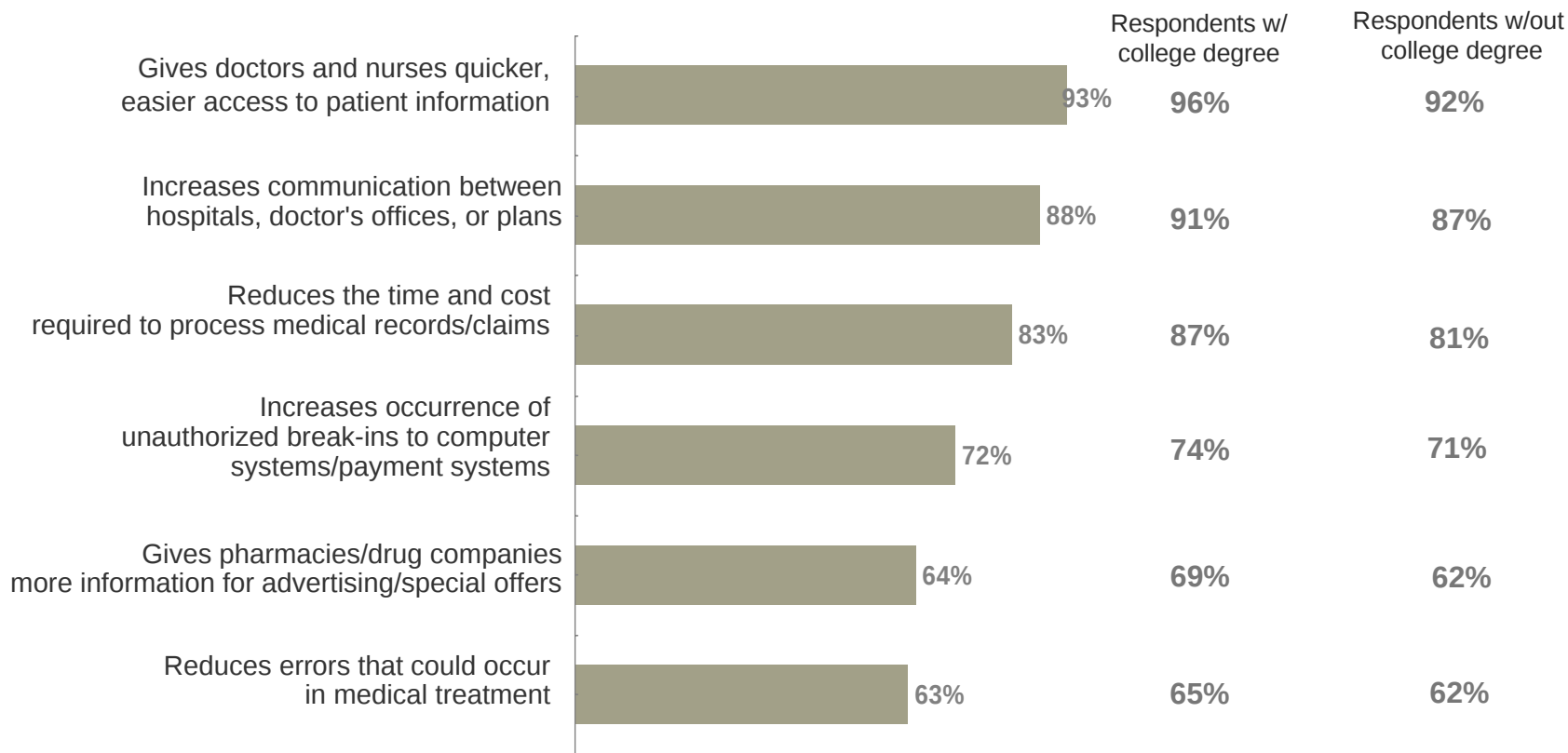
Base: National respondents not willing to share information with doctors not involved in their care.



CALIFORNIA
HEALTHCARE
FOUNDATION

Consumers recognize the benefit of computerization in hospitals or doctors' offices

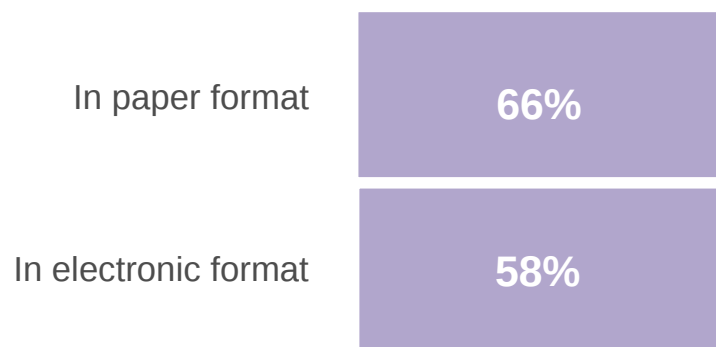
Q. Some providers are shifting to computer based systems...which of the following effects do you think computerization will have?



Base: National respondents

The implementation of health information technology must address consumers' perceptions

Q. How secure* do you think your medical records are when they are stored...



*Secure aggregates "very secure" and "somewhat secure."

Base: National respondents.



Implications



Consumer Implications

- Despite new federal protections, consumers are still concerned about their health care privacy, are misinformed about new protections, and are behaving in “privacy-protective” ways
- Some consumers are putting their health at increased risk
- Consumers unaware of their rights can’t take action to protect or demand them



Industry Implications

- Providers' and health plans' initial and ongoing notice of HIPAA and the new privacy protections have not been effective at educating consumers
- Many consumers don't trust their employers to protect the confidentiality of personal health information; industry has missed an opportunity to reassure a concerned public about health care privacy safeguards



Policy Implications

- Public health messages that link technology, privacy, and health benefits are not reaching consumers
- The health IT agenda is at risk for lack of consumer appreciation of its full potential and primary intent
- Chronically ill, aging, ethnic and racial minorities, and less educated consumers need the most help in understanding the health IT agenda



Recommendations



Recommendations

1. HHS should develop and execute a public awareness campaign to educate consumers about the privacy rights and protections provided under HIPAA.
2. Employers should ensure that stringent safeguards are in place to protect workers' confidential medical and health information, and communicate these policies/practices to employees.
3. Federal privacy protections should be broadened and existing laws should be more vigorously enforced.



Recommendations

4. Strong privacy and security safeguards should be built into new health IT initiatives and emergency-preparedness plans.



CALIFORNIA
HEALTHCARE
FOUNDATION

Contacts

Sam Karp, Chief Program Officer
California HealthCare Foundation
skarp@chcf.org

Brad Holmes, Vice President
Forrester Research
bholmes@forrester.com

More information about this survey is available at
[www.chcf.org / privacy](http://www.chcf.org/privacy)