



Americans' Opinions about Healthcare Privacy

Sponsored by Crowe Horwath LLP

Independently conducted by Ponemon Institute LLC

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Americans trust healthcare providers far more than they trust the government with the privacy of their medical records.

I. Executive Summary

In a recent national survey of 883 adult-aged Americans independently conducted by Ponemon Institute, Americans appear to be wary about increasing government's control over their electronic health records. Further, most respondents in the study are not aware that the U.S. government is considering the implementation of national databases for managing their personal health records. According to our study:

- More than 73 percent of respondents **do not** trust the federal government, including departments such as the U.S. Department of Health and Human Services, to protect the privacy of their health records.
- In contrast, 71 percent of respondents **do** trust healthcare providers such as hospitals, clinics and physicians to protect the privacy of their health records.

The protection of healthcare record privacy is considered very important or important by 75 percent of respondents. Sixty-seven percent believe it is very important or important not to share their health records without their consent.

Respondents considered the following two measures the most important for protecting the privacy of their health records: ensuring that only professionally trained medical practitioners have access to their health records (74 percent) and allowing their direct control of individual health records (71 percent). Significantly fewer respondents (54 percent) believe it is very important or important to have stricter laws to prevent private companies from having access to health records without the respondents' consent.

Notably, 84 percent of Americans are not aware that the U.S. government is considering implementing a national database for the management of health records. Accordingly, the findings of the study indicate that there is uncertainty about who should be responsible for managing a national database containing Americans' health information.

Almost half (45 percent) would not pick any of the options offered in the study to manage the government database. Only 6 percent say it should be an existing federal department or agency such as Health and Human Services, while 8 percent say it should be a new government department or agency especially charged with managing the national database, 10 percent would like to see one private company with government contracts, and 31 percent prefer many private companies with government contracts.

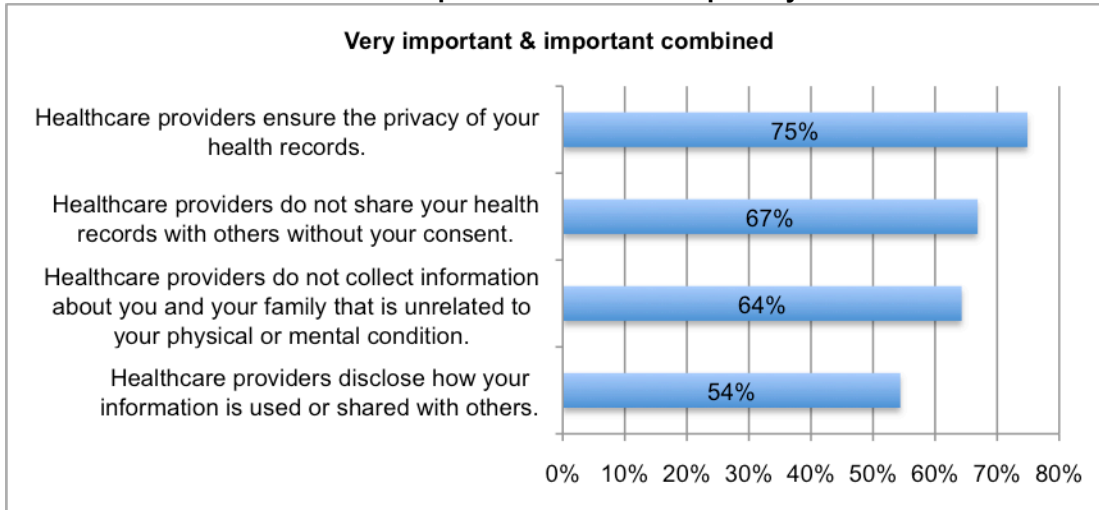
According to Americans in our study, 75 percent of respondents think such a database is *not* a good idea. However, if such a database were to be created, almost all respondents (98 percent) believe the individual's primary care physician and 90 percent of respondents believe all medical personnel treating them should have access to their health records. Only 38 percent of respondents strongly agree or agree that federal departments and agencies should have access to their electronic health records.

The respondent's political orientation appears to be unrelated to his or her opinions about a government-mandated national healthcare database. Of the respondents, 35 percent self-reported they are Democrats, 28 percent Republicans and 31 percent Independents. More than half (56 percent) of the respondents have private insurance, 19 percent have Medicare/Medicaid, and 15 percent are not insured.

II. Key Findings

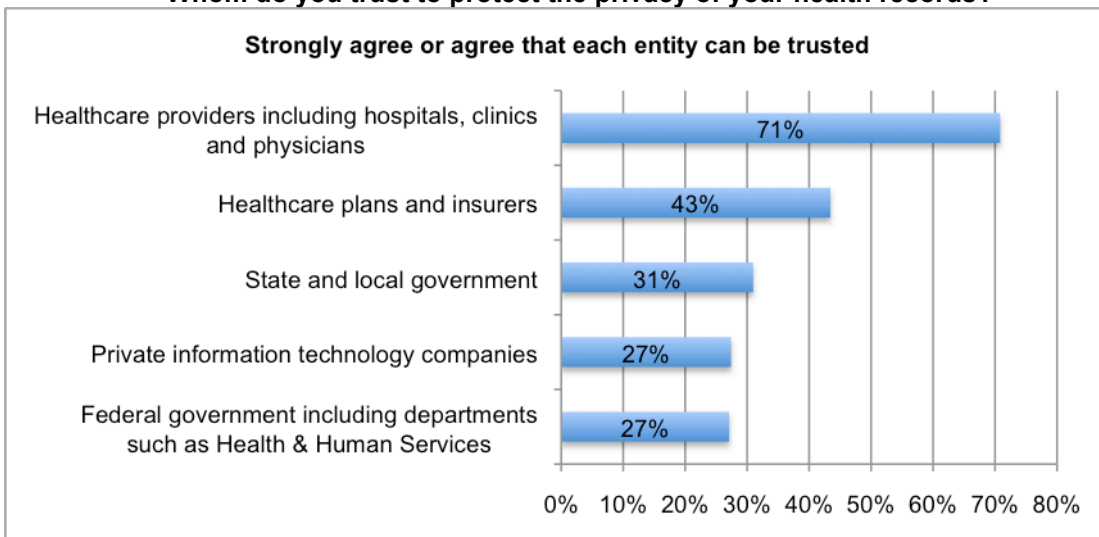
Bar Chart 1 reports four significant issues concerning patient privacy rights. Each bar summarizes the combined very important and important responses. As can be seen, 75 percent of respondents believe protecting the privacy of their health records is important. Sixty-seven percent believe it is very important or important for healthcare providers not to share health information with others without their consent, and 64 percent believe it is important for healthcare providers not to collect more information than necessary (that is, extraneous information).

Bar Chart 1
How important is healthcare privacy?



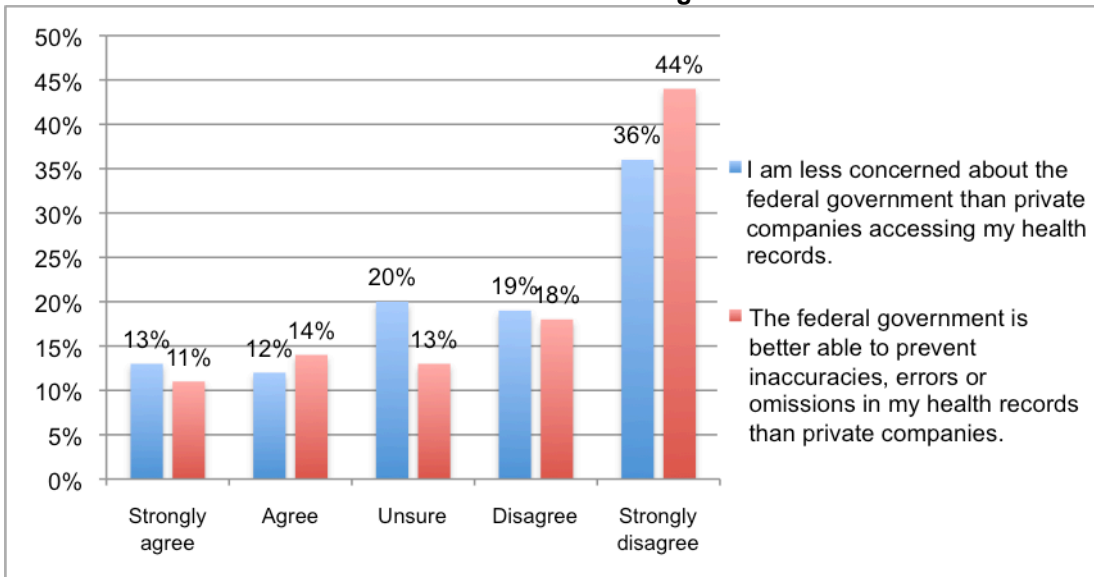
Bar Chart 2 lists five custodians or data repositories for health information. Each bar reflects the average trust level respondents hold for each entity's privacy commitment. Seventy-one percent of respondents trust healthcare providers – such as hospitals, clinics and primary care physicians – to protect their health records. In sharp contrast, only 27 percent trust the federal government and private IT companies to protect the privacy of their health records.

Bar Chart 2
Whom do you trust to protect the privacy of your health records?



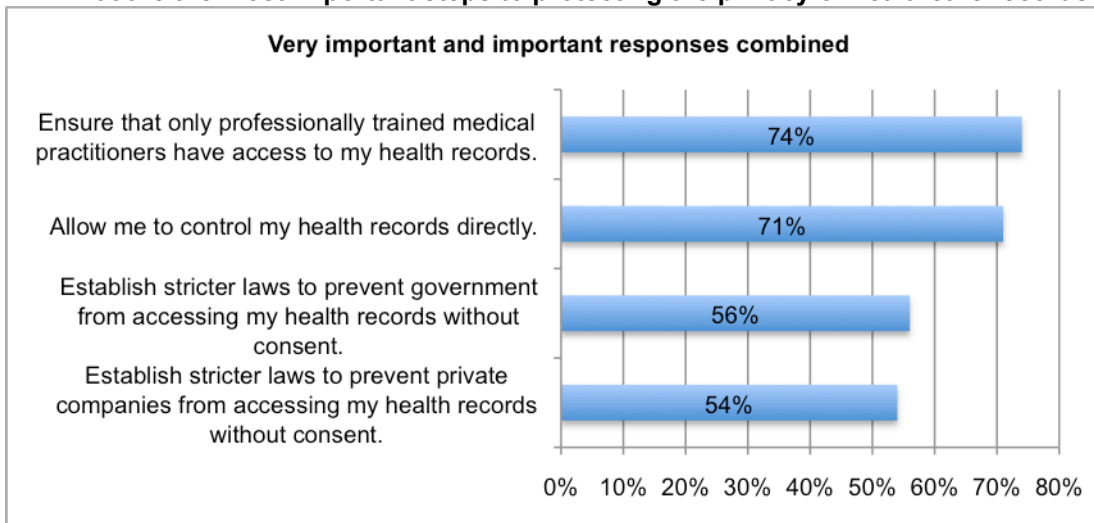
Bar Chart 3 compares respondents' attitudes about the U.S. federal government versus private companies in accessing and maintaining health records. As shown, 44 percent strongly disagree with the statement, "I am less concerned about the federal government than private companies accessing my health records." Similarly, 36 percent strongly disagree with the statement, "The federal government is better able to prevent inaccuracies, errors or omissions in my health records than private companies."

Bar Chart 3
Attitudes about the federal government



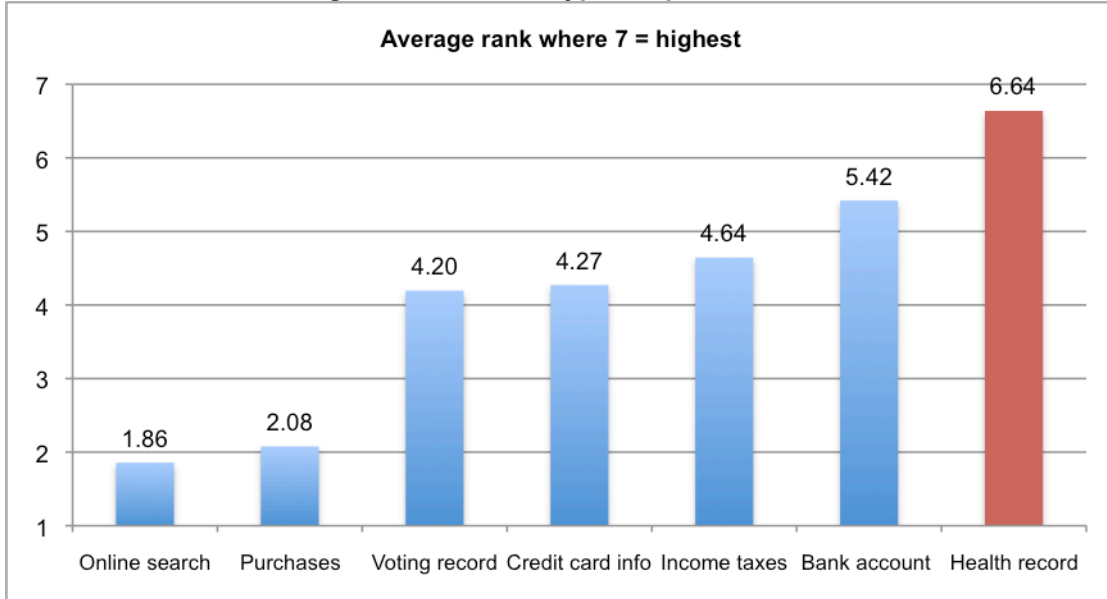
Bar Chart 4 summarizes what respondents believe are the most important steps to protecting the privacy of their private health information. Seventy-four percent believe only professionally trained medical practitioners should have access to health records. About 71 percent believe that assigning control of the medical record to the individual patient would improve privacy. Fifty-six percent of respondents believe stricter laws are needed to prevent government access without the consent of the individual. Similarly, 54 percent believe that stricter laws are needed to prevent private companies from accessing health information without proper consent.

Bar Chart 4
What are the most important steps to protecting the privacy of healthcare records?



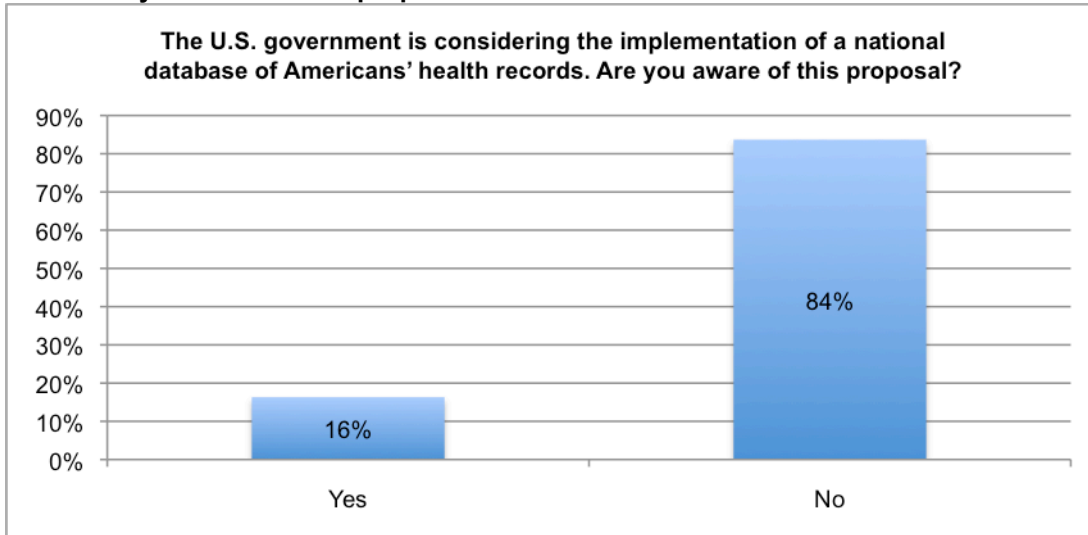
Bar Chart 5 summarizes the average rank attributed by respondents to seven types of private information according to privacy sensitivity. In terms of rank ordering, the most privacy-sensitive information type is 7 and the least privacy-sensitive type of information is a 1. As can be seen, respondents view health records (with an average rank of 6.64) as most privacy-sensitive and online search (with an average rank of 1.86) as least privacy-sensitive.

Bar Chart 5
Average rank for seven types of private information



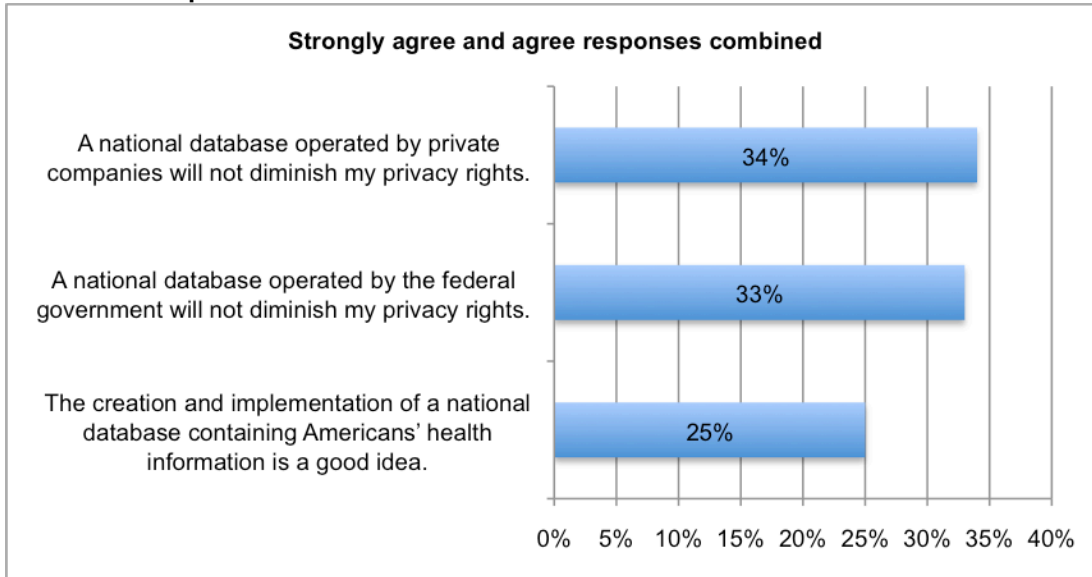
Respondents were asked whether they were aware of the proposal to create a national database of health records as part of healthcare reform. As shown in Bar Chart 6, only 16 percent of the respondents said they were aware of this proposal.

Bar Chart 6
Are you aware of the proposal to establish a national health record database?



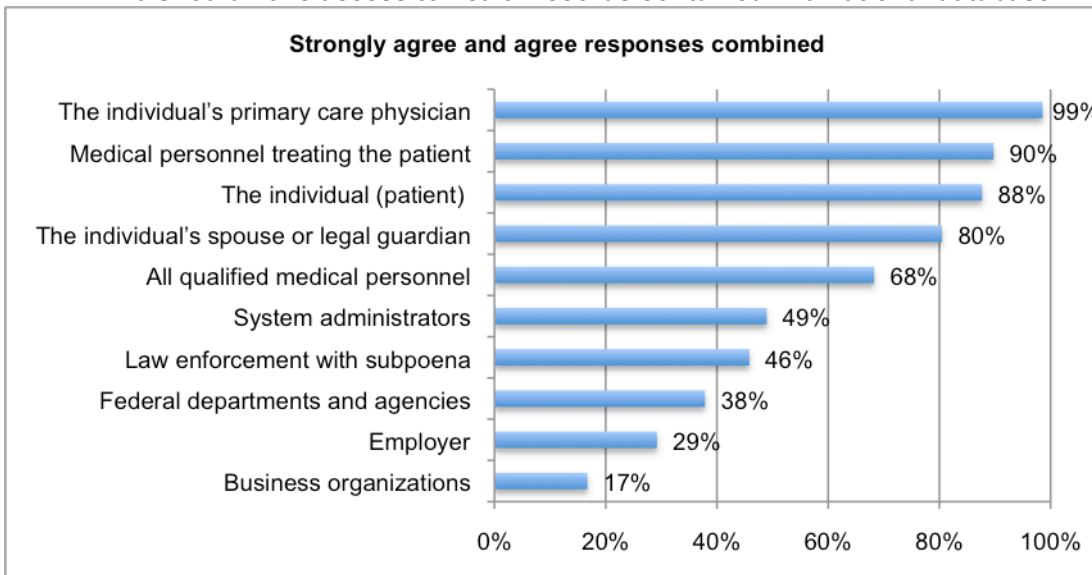
Bar Chart 7 summarizes the respondents' opinions about the creation of a national database of healthcare records. As reported, only 25 percent believe this proposal is a good idea. Sixty-seven percent (100-33%) believe that such a database managed by the federal government will diminish their privacy rights.

Bar Chart 7
Opinions about a national database of Americans' health records



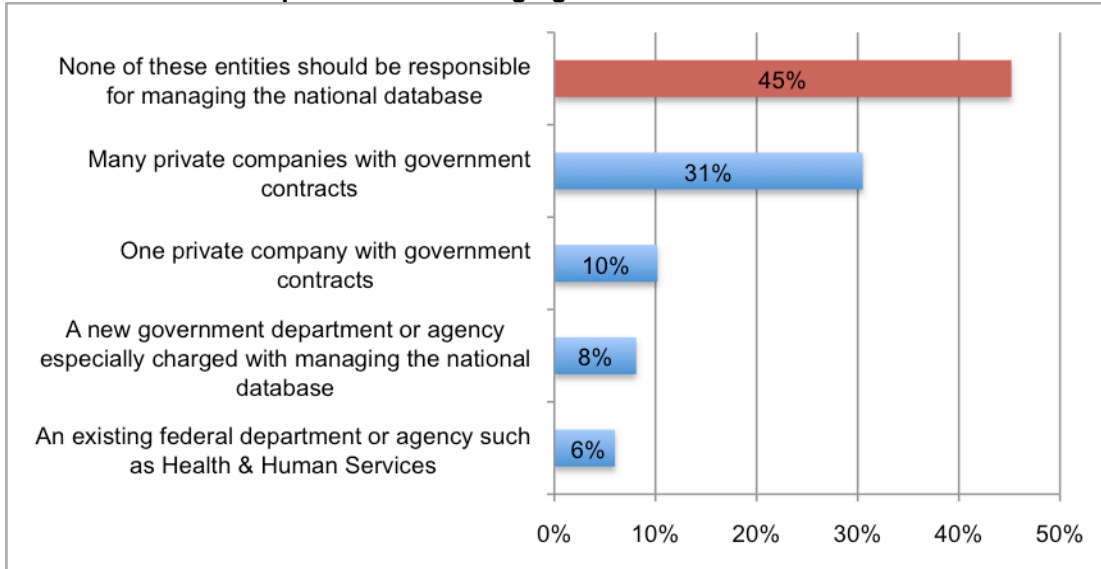
Bar Chart 8 summarizes 10 entities that may have access to an individual's health information contained in a national database. As reported, respondents see medical practitioners, the patient and close family members as having legitimate rights to access records contained in a national database. On the other hand, system administrators, law enforcement, federal departments, employers and business organizations do not have a legitimate right to these records.

Bar Chart 8
Who should have access to health records contained in a national database?



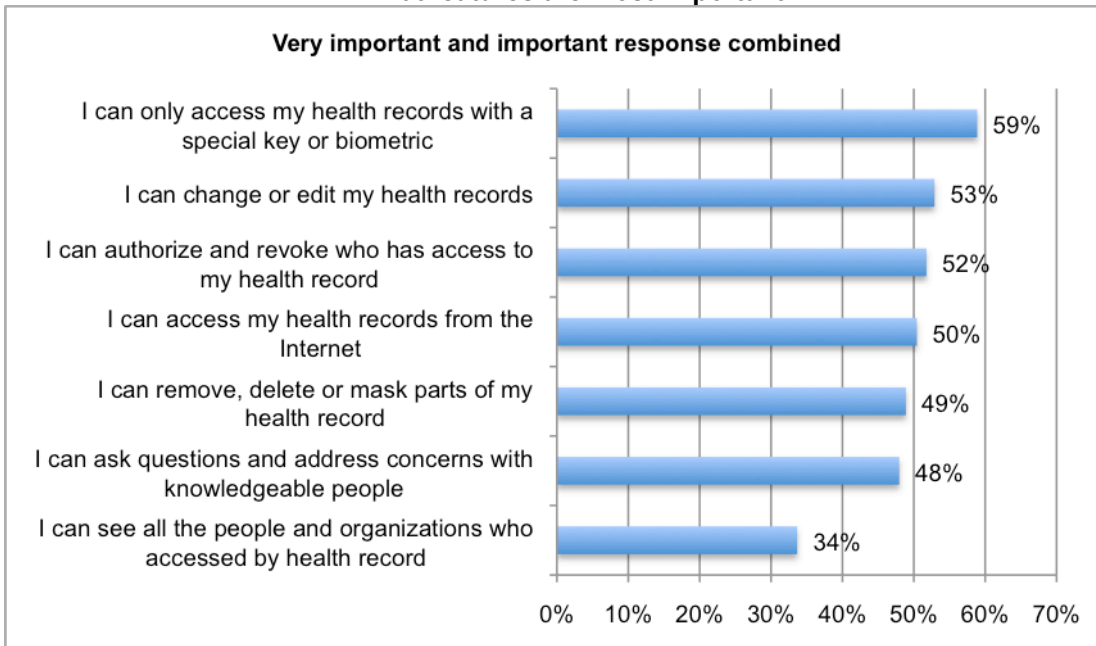
Bar Chart 9 reports four choices pertaining to who will be assigned the overall responsibility for managing personal health information contained in a national database. More than 45 percent of respondents selected “none of the above,” suggesting either concern or confusion about this issue.

Bar Chart 9
Who should be responsible for managing a national database of healthcare records?



Bar Chart 10 summarizes what respondents see as very important or important features assuming a national database of Americans’ health information is created. As can be seen, 59 percent of respondents believe access through the use of a special key or biometric would be important. In addition, 53 percent want the ability to change and edit health information directly, and 52 percent want to have direct authority to permit or revoke who has access to their confidential health data.

Bar Chart 10
What features are most important?



III. Caveats to this study

There are inherent limitations to survey research that need to be considered carefully before inferences are drawn from the findings. The following items are specific limitations that are germane to most telephone surveys.

- Non-response bias: The current findings are based on a sample of survey returns. We contacted a representative sample of individuals, resulting in a large number of usable returned responses. Despite non-response tests, it is always possible that individuals who did not participate are substantially different in terms of underlying beliefs from those who completed the telephone interview.
- Sampling-frame bias: The accuracy is based on contact information and the degree to which the list is representative of individuals who are adult-aged Americans. We also acknowledge that the results may be biased by external events such as media coverage. We also acknowledge bias caused by compensating subjects to complete the telephone interview. Finally, because we used a telephone collection method, it is possible that other collection methods would result in a different pattern of findings.
- Self-reported results: The quality of survey research is based on the integrity of confidential responses received from subjects. While certain checks and balances can be incorporated into the survey process, there is always the possibility that a subject did not provide a truthful response.

IV. Survey methods

Table 1 reports our sample response using a telephone interview collection method. Our sampling frame was a representative list of 14,599 individuals more than 17 years of age. As reported, 883 adult-aged individuals across the nation completed the survey. This represents a 6 percent response rate. Respondents were paid nominal compensation or participation in a lottery. All interview data was collected over a four-week period ending on December 23, 2009. Additional survey analysis and respondent debriefings were conducted through January 4, 2010. On average, 93 percent of respondents completed all questions within 20 minutes.

Table 1: Sample response	Freq.	Pct%
Sampling frame	14,599	100.0%
Total responses	955	6.5%
Rejections (incomplete responses)	72	0.5%
Final sample	883	6.0%

Table 2 reports the healthcare status of all respondents. As can be seen, over 56 percent say they have private health insurance and 19 percent are covered under Medicare or Medicaid. Approximately 15 percent of respondents say they are presently uninsured.

Table 2: Respondents' healthcare status:	Pct%
Private insurance	56%
Medicare/Medicaid	19%
Health savings account	6%
Co-op member	3%
Not insured	15%
Other (specify)	1%
Total	100%

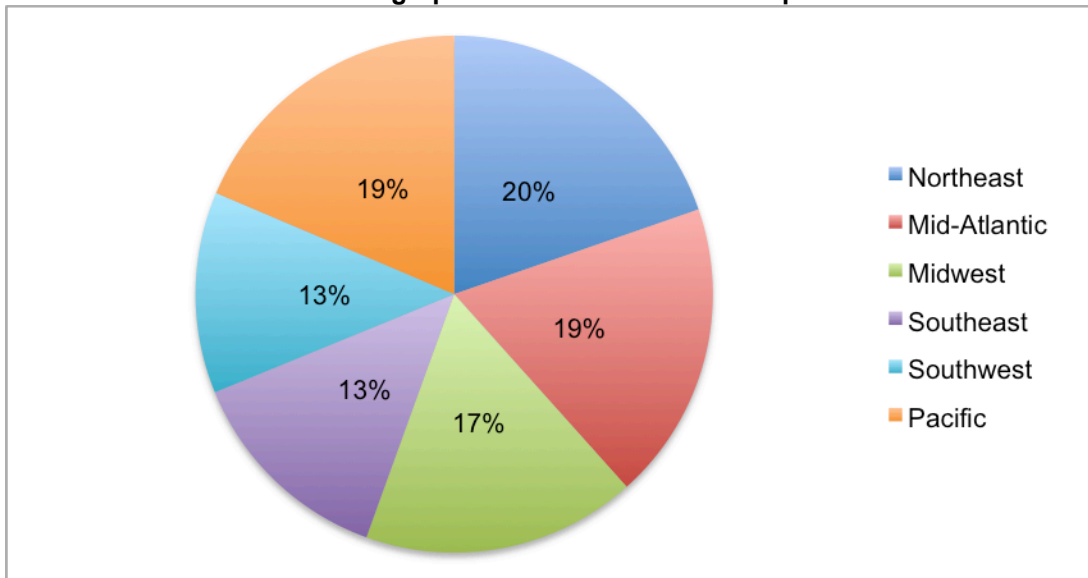
Fifty-two percent of respondents are female, and 51 percent are head of household. Approximately 56 percent of respondents say they have private health insurance, while 15 percent say they are uninsured. The median age of respondents in this study is 33.3 years.

Table 3 reports the self-reported political affiliation of respondents. Accordingly, 35 percent say they are democrat, 31 percent are independent and 28 percent of republican.

Table 3: Political affiliation of respondents	Pct%
Democrat	35%
Republican	28%
Independent	31%
Other (specify)	6%
Total	100%

Pie Chart 1 provides the geographic distribution of our sample. In total, individuals from 45 states are represented in this research.

Pie Chart 1
Geographic distribution of the sample



The percentage frequencies of all survey questions are provided in Appendix 1.

¹It is interesting to note that respondents' political affiliation was not significantly correlated with survey responses on government trust or involvement in patient privacy protections.

Appendix 1: Survey Responses

Fieldwork completed on Dec. 23, 2009

Q1. How important are the following issues? Please use the scale provided below to rate each statement.	Very important	Important	Somewhat important	Not important	Irrelevant
Q1a. Healthcare providers ensure the privacy of your health records.	54%	21%	14%	11%	1%
Q1b. Healthcare providers do not share your health records with others without your consent to do so.	51%	16%	11%	11%	11%
Q1c. Healthcare providers disclose how your information is used or shared with others.	34%	20%	20%	14%	12%
Q1d. Healthcare providers do not collect information about you and your family that is unrelated to your physical or mental condition.	43%	21%	13%	14%	9%

Q2. Who do you trust to protect the privacy of your health records? Please use the scale provided below to rate each statement.	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
Q2a. I trust the federal government including agencies such as Health and Human Services to protect the privacy of my health records.	10%	17%	12%	21%	41%
Q2b. I trust my state or local government to protect the privacy of my health records.	11%	20%	12%	23%	34%
Q2c. I trust private healthcare plans and insurers to protect the privacy of my health records.	23%	20%	11%	14%	32%
Q2d. I trust healthcare providers such as hospitals, clinics and physicians to protect the privacy of my health records.	42%	29%	6%	20%	3%
Q2e. I trust private information technology companies to protect the privacy of my health records.	14%	13%	16%	20%	37%

Q3. I am less concerned about the federal government than private companies accessing my health records.	13%	12%	20%	19%	36%
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Q4. The federal government is better able to prevent inaccuracies, errors or omissions in my health records than private companies.	11%	14%	13%	18%	44%
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Q5. What do you see as the most important steps to protecting the privacy of your health records? Please use the scale provided below to rate each statement.	Very important	Important	Somewhat important	Not important	Irrelevant
Q5a. Allow me to control my health records directly.	33%	38%	11%	12%	6%
Q5b. Establish stricter laws to prevent private companies from accessing my health records without consent.	30%	24%	12%	23%	11%

Q5c. Establish stricter laws to prevent government from accessing my health records without consent.	31%	25%	13%	17%	14%
Q5d. Ensure that only professionally trained medical practitioners have access to my health records.	35%	39%	11%	9%	6%

Q6. How important is the protection of your personal information? Please rank the following types of personal information from 1 = least important to 7 = most important.	Average rank	Order
Health record	6.64	1
Credit card number and related information	4.27	4
Bank account	5.42	2
Purchase history	2.08	6
Income tax record	4.64	3
Online search history	1.86	7
Voting record	4.20	5
Average	4.16	

Q7. The U.S. government is considering the implementation of a national database of Americans' health records. This national database is believed to create greater efficiency and provide cost savings.

Q7a. Are you aware of this proposal?	Pct%
Yes	16%
No	84%
Total	100%

Opinion about a national database.	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
Q7b. The creation and implementation of a national database containing Americans' health information is a good idea.	12%	13%	19%	24%	32%
Q7c. A national database operated by the federal government will not diminish my privacy rights.	14%	19%	19%	15%	33%
Q7d. A national database operated by private industry will not diminish my privacy rights.	13%	21%	29%	13%	24%

Q8. Who should have access to your electronic health records assuming that a national database of Americans' health information is created? Please use the scale provided below each choice.	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
Q8a. The individual (patient)	70%	18%	9%	2%	2%
Q8b. The individual's spouse or legal guardian	64%	17%	15%	4%	2%
Q8c. The individual's primary care physician	90%	8%	1%	0%	0%
Q8d. All medical personnel treating the individual (patient)	78%	12%	6%	4%	0%

Q8e. All qualified medical personnel for research purposes	40%	28%	20%	8%	3%
Q8f. Federal departments and agencies such as Health and Human Services (HHS), Homeland Security (DHS), Veterans Affairs (VA), Internal Revenue Service (IRS) and so forth	17%	21%	20%	13%	29%
Q8g. Law enforcement with valid subpoena or court order	21%	25%	33%	11%	10%
Q8h. System administrators who maintain the national database	29%	20%	19%	20%	12%
Q8i. Business organizations that may wish to advise you of new products or services based on your health condition	9%	7%	10%	16%	57%
Q8j. The individual's employer	12%	18%	32%	22%	17%

Q9. How important is the security of a national database of Americans' health information?	Pct%
Critically important	64%
Very important	22%
Important	11%
Not important	3%
Total	100%

Q10. In your opinion, who should be responsible for managing a national database of Americans' health information?	Pct%
An existing federal department or agency such as Health and Human Services	6%
A new government department or agency especially charged with managing the national database	8%
One private company with government contracts	10%
Many private companies with government contracts	31%
None of the above should be responsible for managing a national database	45%

Q11. Please rate the importance of the following features assuming a national database of Americans' health information is created.	Very important	Important	Somewhat important	Not important	Irrelevant
Q11a. I can access my health records from the Internet.	25%	25%	19%	18%	12%
Q11b. I can only access my health records with a special key or biometric (such as voice or fingerprint recognition).	30%	29%	18%	13%	10%
Q11c. I can change or edit my health records.	26%	27%	21%	13%	13%
Q11d. I can remove, delete or mask parts of my health record.	25%	24%	23%	14%	13%
Q11e. I can see all the people and organizations that accessed my health record.	19%	15%	35%	17%	15%

Q11f. I can authorize and revoke who has access to my health record.	25%	27%	21%	16%	11%
Q11g. I can ask questions and address concerns with knowledgeable database administrators or other personnel.	27%	21%	15%	18%	18%

Demographics

Following are variables that will be used to analyze results. Please check the most appropriate response to each demographic item listed below.

Please check your present healthcare status:	Pct%
Private insurance	56%
Medicare/Medicaid	19%
Health savings account	6%
Co-op member	3%
Not insured	15%
Other (specify)	1%
Total	100%

What is your present employment status?	Pct%
Full-time employee	49%
Part-time employee	10%
Business owner	8%
Retired	9%
Student	9%
Active military	3%
Unemployed	12%
Total	100%

What best describes your political affiliation?	Pct%
Democrat	35%
Republican	28%
Independent	31%
Other (specify)	6%
Total	100%

What is your highest level of education attained?	Pct%
High school	24%
Vocational	21%
University or College	43%
Postgraduate	10%
Doctorate	2%
Total	100%

Please check your age range:	Pct%
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18 to 25	14%
26 to 35	23%
36 to 45	22%
46 to 55	21%
56 to 65	15%
66 to 75	4%
Total	100%

Please check gender:	Pct%
Female	52%
Male	48%
Total	100%

Are you the head of household?	Pct%
Yes	51%
No	49%
Total	100%

Region of the United States	Pct%
Northeast	20%
Mid-Atlantic	19%
Midwest	17%
Southeast	13%
Southwest	13%
Pacific	19%
Total	100%

If you have any questions or comments about this research, please contact research@ponemon.org or 800.877.3118.

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