



Medical Privacy Survey

2018 Nationally Representative Phone Survey

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March, 2018

INTRODUCTION

In February 2018, the Consumer Reports Survey Group conducted a nationally representative phone survey to assess the opinion of Americans on a range of medical privacy issues. Opinion Research Corporation (ORC) of Princeton, New Jersey administered the survey to a nationally representative sample of 1,007 U.S. residents through its CARAVAN Omnibus Survey. Respondents were selected by means of random-digit dialing and were interviewed via phone. The data were statistically weighted so that respondents in the survey are demographically and geographically representative of the U.S. population.

An abridged version of this survey was conducted in 2015. This previous survey was administered using the same methodology to a nationally representative sample of 1,012 U.S. residents in May, 2015.

REPORT HIGHLIGHTS

- Nearly two thirds of Americans have searched the Internet or visited medical websites about medical conditions in the past year. Among this group, 62% are aware that their searches may be stored and shared with third parties.
- Forty five percent of Americans have seen online advertising that is personalized based on their health information or medical searches. Among this group, half found this advertising to be creepy the first time they noticed it.
- Six out of 10 Americans have requested a copy of their medical records from a doctor. Among this group, most (76%) say the process was simple and quick.
- Half of Americans currently have access to their medical records online from a website or app managed by a doctor's office, hospital, insurance company, or testing lab. Among this group, popular methods to access their records within the past year include laptops, desktop computers, and smartphones.
- More than half of Americans think the government is likely to share their medical information without their consent. Nearly half say online health resources/organizations or pharmaceutical companies are likely to do this.
- In the case of a data breach, or a breach of confidence with their physician, 39% of Americans are most concerned about their information being shared with retailers, advertisers, or other companies like Google or Amazon. Among those who are concerned about their information being shared during a data breach, 59% are most concerned about their social security number being shared.
- The vast majority of Americans (95%) agree that their consent should be required whenever their health information is shared. Only 12% of Americans agree that health information should be shared more readily overall.
- When asked about what they hoped new legislation regarding medical records would accomplish, 43% of Americans say the current level of protection works.
- When given a list of potential advantages of increased sharing of medical records, two thirds say this would ease communicating data from one facility to another. Many (63%) say it would increase the ability to track illnesses through a population.

ONLINE MEDICAL SEARCHES & ADVERTISING

62%

AWARE ONLINE MEDICAL SEARCHES
MAY BE SHARED WITH THIRD PARTIES

Nearly two thirds of Americans have searched the Internet or visited medical websites about medical conditions in the past year. Among this group, 62% are aware that their searches may be stored and shared with third parties.

HALF THINK THAT PERSONALIZED ONLINE HEALTH ADVERTISING IS CREEPY

Forty-five percent of Americans have seen online advertising that is personalized based on their health information or medical searches. Among this group, half found this advertising to be creepy the first time they noticed it.

INITIAL PERCEPTION OF PERSONALIZED ONLINE HEALTH ADS		
	2018	2015
	%	%
Thought it was creepy	50	48
Thought it was convenient	17	21
Thought it was a coincidence	9	12
Because of the advertising, found a valuable solution to the medical issue they were researching	8	7
Other	11	7
Don't remember	2	3
Don't know/Refused	3	2
<i>Base: All respondents who have seen personalized online health ads</i>	454	360

MEDICAL RECORDS REQUESTS

60%

HAVE REQUESTED MEDICAL RECORDS FROM DOCTOR

Six out of 10 Americans have requested a copy of their medical records from a doctor. Among this group, most (76%) say the process was simple and quick.

DESCRIPTION OF PROCESS OF REQUESTING MEDICAL RECORDS		
	2018	2015
	%	%
It was quite simple and quick	76	74
It was a complicated process, but received them in the end	16	16
Though made the request, ultimately did not receive records	6	8
Don't know/Refused	2	2
<i>Base: All respondents who have requested medical records</i>	607	568

MEDICAL RECORDS ACCESS

PRINT IS MOST COMMON METHOD FOR RECEIVING MEDICAL RECORDS

In the past year, nearly half of Americans have received print copies of their medical records from their doctor's office, hospital, insurance company, or testing lab. Over a third have not accessed their medical records within the past year.

METHODS OF ACCESSING MEDICAL RECORDS		
	2018	2015
	%	%
Received print copies from doctor's office, hospital, insurance company, or testing lab	47	44
Website or app managed by a doctor's office	28	20
Website or app managed by a hospital	18	14
Website or app managed by an insurance company	13	12
Website or app managed by a testing lab, such as Quest Diagnostics	13	8
Have not accessed medical records within the past year	35	43
Don't know/Refused	1	2
<i>Base: All respondents</i>	1007	1012

HALF CURRENTLY HAVE ONLINE ACCESS TO THEIR MEDICAL RECORDS

Half of Americans currently have access to their medical records online from a website or app managed by a doctor's office, hospital, insurance company, or testing lab. Most of those who currently do not have online access do not wish they had online access. Among those who have access to their medical records online, popular methods to access those records within the past year include laptops, desktop computers and smartphones. The percentage of those accessing their records via smartphone has increased since 2015 (47% in 2018 versus 36% in 2015).

METHODS USED TO ACCESS MEDICAL RECORDS ONLINE		
	2018	2015
	%	%
Laptop	54	59
Desktop computer	54	51
Smartphone	47	36
Tablet	20	23
Other	1	3
<i>Base: All respondents who have accessed medical records online in the past year</i>	372	256

MEDICAL RECORDS SHARING

OVER HALF SAY GOVERNMENT LIKELY TO SHARE MEDICAL INFORMATION WITHOUT CONSENT

More than half of Americans think the government is likely to share their medical information without their consent. Nearly half say online health resources/organizations or pharmaceutical companies are likely to do this.

LIKELIHOOD ENTITY WOULD SHARE MEDICAL INFORMATION WITHOUT CONSENT <i>(Percentage that think entity likely to share information without consent)</i>	
	2018
	%
Government	53
Online health resources or organizations	49
Pharmaceutical companies	49
Health insurance companies	48
Life insurance companies	47
Law enforcement	38
Hospitals	32
Pharmacists	26
Your primary care physician	25
Doctor's office staff	23
Psychologists or counselors	19
<i>Base: All respondents</i>	1007

FOUR IN 10 WOULD BE MOST CONCERNED ABOUT RETAILERS/COMPANIES GETTING THEIR INFORMATION IF THERE WAS A DATA BREACH

In the case of a data breach, or a breach of confidence with their physician, 39% of Americans are most concerned about their information being shared with retailers, advertisers, or other companies like Google or Amazon. Over a quarter of Americans are most concerned about their information being shared with the government.

PERCENTAGE MOST CONCERNED ABOUT INFORMATION BEING SHARED WITH ENTITY IF THERE WAS A DATA BREACH	
	2018
	%
Retailers, advertisers, or other companies like Google or Amazon	39
Government	27
Co-workers	22
Employers	20
Friends or peers	18
Health insurance companies	18
Law enforcement	16
Pharmaceutical companies	16
Life insurance companies	16
Doctor's office staff	11
Hospitals	8
Pharmacists	5
Specialists	4
Psychologists or counselors	3
Other	4
None of these/not highly concerned about my medical information being made available	10
Don't know/Refused	1
<i>Base: All respondents</i>	<i>1007</i>

MANY CONCERNED ABOUT SOCIAL SECURITY NUMBER BEING SHARED IF THERE WAS A DATA BREACH

Among those who are concerned about their information being shared if there was a data breach, 59% are most concerned about their social security number being shared, 11% are most concerned about their medical diagnoses/history being shared, 7% are most concerned about their personal contact information or financial information being shared, and 6% are most concerned about their medications/treatments being shared.

MOST AGREE THAT THEIR CONSENT SHOULD BE REQUIRED WHEN HEALTH INFORMATION IS SHARED

The vast majority of Americans (95%) agree that their consent should be required if their health information is shared. The clear majority also agree that only health professionals with whom they have a relationship should have access to their health information. Only 12% of Americans agree that health information should be shared more readily overall.

PERCENTAGE THAT AGREE WITH STATEMENT	
	2018
	%
Consent should be required whenever health information is shared	95
Only health professionals with whom have a relationship should have access to health information	88
Only the necessary parts of medical records should be shared	80
Comfortable with any medical professional having access to health information	37
Health information should be shared more readily overall, including with business entities	12
<i>Base: All respondents</i>	1007

THREE OUT OF TEN WANT MORE STRINGENT LEGISLATION REGARDING MEDICAL INFORMATION SHARING

When asked about what they hoped new legislation regarding medical records would accomplish, 43% of Americans say the current level of protection works. A notable percentage (29%) say they would hope the new legislation would make it more difficult for health professionals to share or gain access to personal medical information.

HOPES FOR NEW MEDICAL RECORDS LEGISLATION	
	2018
	%
Make it MORE DIFFICULT for health professionals to share or gain access to personal medical information	29
Make it EASIER for health professionals to share or gain access to personal medical information	24
Neither, the current level of protections works	43
Don't know/Refused	4
<i>Base: All respondents</i>	1007

TWO THIRDS SAY INCREASED MEDICAL RECORDS SHARING WOULD EASE COMMUNICATING DATA BETWEEN FACILITIES

When given a list of potential advantages of increased sharing of medical records, two thirds say this would ease communicating data from one facility to another. Many (63%) say it would increase the ability to track illnesses through a population. About six out of 10 say it would give more data points for medical research or save time filling out forms when going to other doctors.

HOPES FOR NEW MEDICAL RECORDS LEGISLATION	
	2018
	%
Ease of communicating data from one facility to another	66
Increased ability to track illnesses through a population	63
More data points for medical research	61
Saving time filling out forms when going to other doctors	61
Ability to find other patients with similar medical conditions	47
Other	1
None of these/I don't see any advantage of increased sharing of medical records	8
Don't know/Refused	1
<i>Base: All respondents</i>	1007

SUMMARY

Our survey found that Americans are concerned about a range of medical privacy issues. Some have a negative view towards personalized online health advertising; among those who have seen these ads, half found these ads to be creepy the first time they noticed them.

Americans are also aware that their medical information may be shared. Many (62%) who have searched online about medical conditions are aware that these searches may be stored and shared with third parties. More than half of Americans think the government is likely to share their medical information without their consent. Nearly half say online health resources or organizations or pharmaceutical companies are likely to do this.

With this awareness of the lack of privacy of their medical information, our findings suggest, Americans want some control over the sharing of their medical information. Nearly all Americans (95%) say consent should be required before their health information is shared. In fact, only a small percentage (12%) say that health information should be shared more readily.

METHODOLOGY

This phone survey was fielded by ORC using a nationally representative sample. The survey fielded from February 22-25, 2018. The margin of error is +/- 3.1 percentage points at the 95% confidence level.