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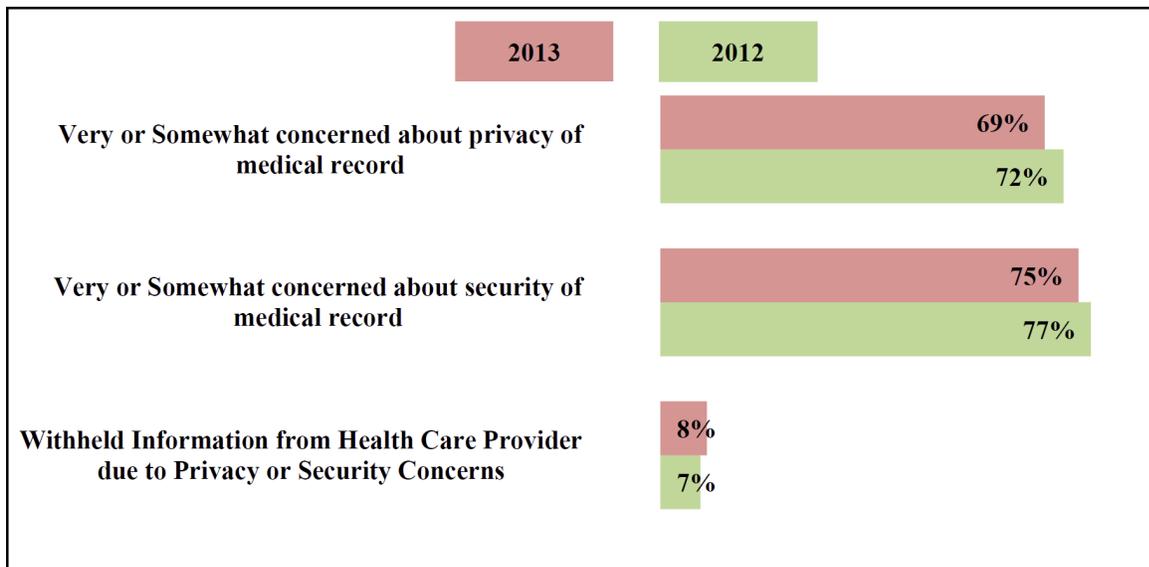
Individuals' Perceptions of the Privacy and Security of Medical Records

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The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 emphasizes the importance of inspiring public trust and confidence in health information technology (IT) (1). In 2013, approximately three-quarters of physicians used any electronic health record (EHR). As EHR adoption rates increase, it is important for policymakers to understand individuals' privacy and security concerns (2). To assess the growing impact of EHR adoption on individuals' privacy and security concerns, this data brief examines whether privacy and security concerns have increased with increased rates of EHR adoption between 2012 and 2013. We will also assess how privacy and security concerns may differ among individuals whose provider has a paper versus an electronic medical record.

Many individuals express privacy and security concerns, but less than 1 in 10 withhold information from their health care providers due to those concerns.

Figure 1: Proportion of individuals who expressed concerns regarding the privacy and security of their medical record and withheld information from their healthcare provider due to those concerns, 2012-2013.



NOTE: The number of respondents for the above items ranged from n=2040 to n=2097. Differences between 2012 and 2013 are not statistically significant.

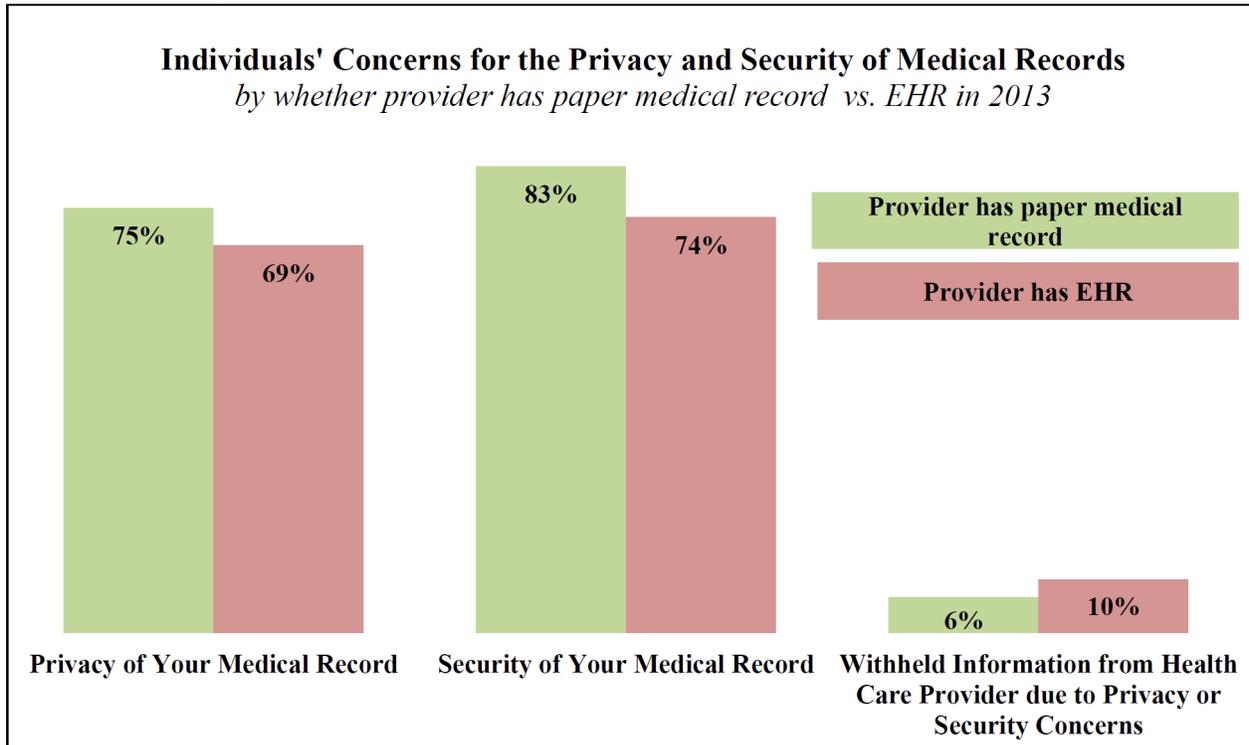
SOURCE: 2012-2013 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange.

- ★ In 2013, about 7 out of 10 individuals had concerns about the privacy of their medical records and about 3 out of 4 had concerns about the security of their medical records. These concerns have not significantly changed between 2012 and 2013.
- ★ Less than 1 in 10 individuals report withholding information from their healthcare providers. This did not significantly change between 2012 and 2013.



Privacy and security concerns are no different between individuals whose providers have paper medical records and those whose providers have an EHR.

Figure 2: National levels of privacy and security concerns and withholding information from healthcare providers due to those concerns by whether their provider had a paper or electronic health record (EHR), 2013



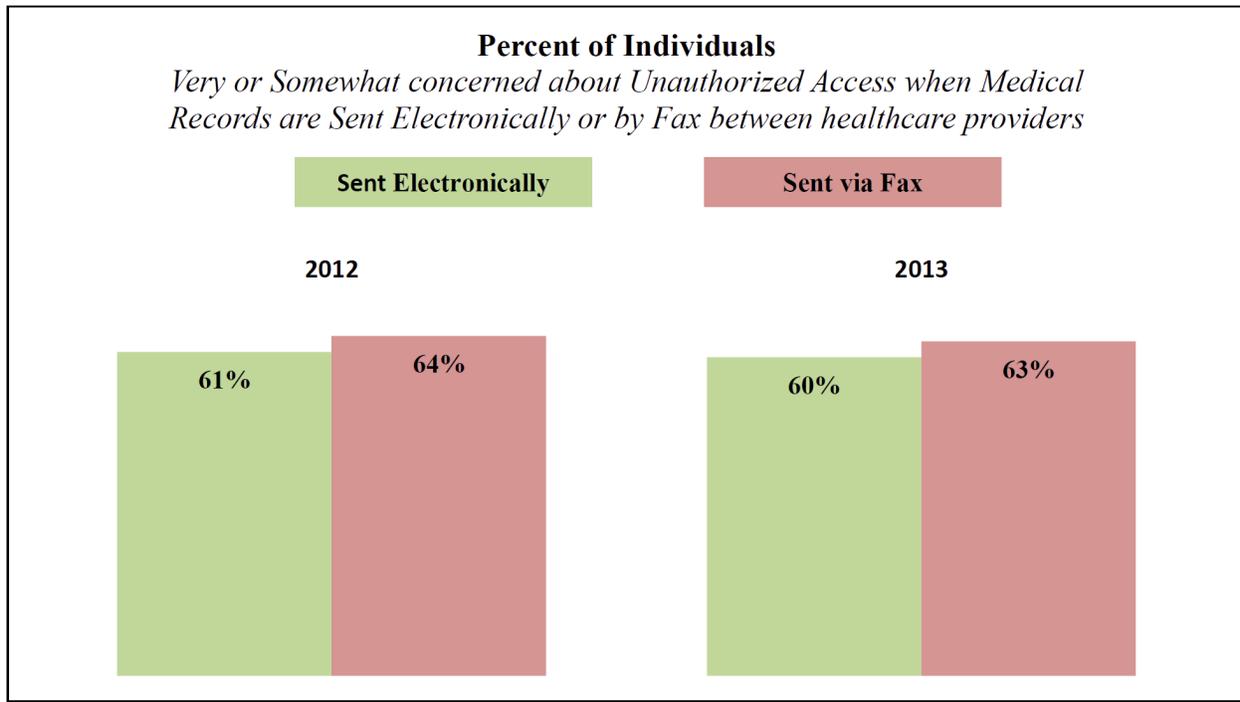
NOTE: The number of respondents for the above items ranged from n= 1772 to n=1767. Differences between paper medical record vs. EHRs are not statistically significant.

SOURCE: 2013 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange.

- ★ Although individuals with paper medical records reported slightly higher levels of privacy and security concerns compared to individuals whose provider had an EHR, the difference is not statistically significant.
- ★ Individuals whose provider uses an EHR had slightly higher rates of withholding information from their provider due to privacy or security concerns. The difference, however, is not statistically significant.

Individuals' concerns regarding sending medical records between health care providers do not differ by whether they are sent electronically or by fax.

Figure 3: The proportion of individuals who expressed concerns regarding unauthorized viewing of their medical record when shared between healthcare providers electronically vs. by fax, 2012-2013.

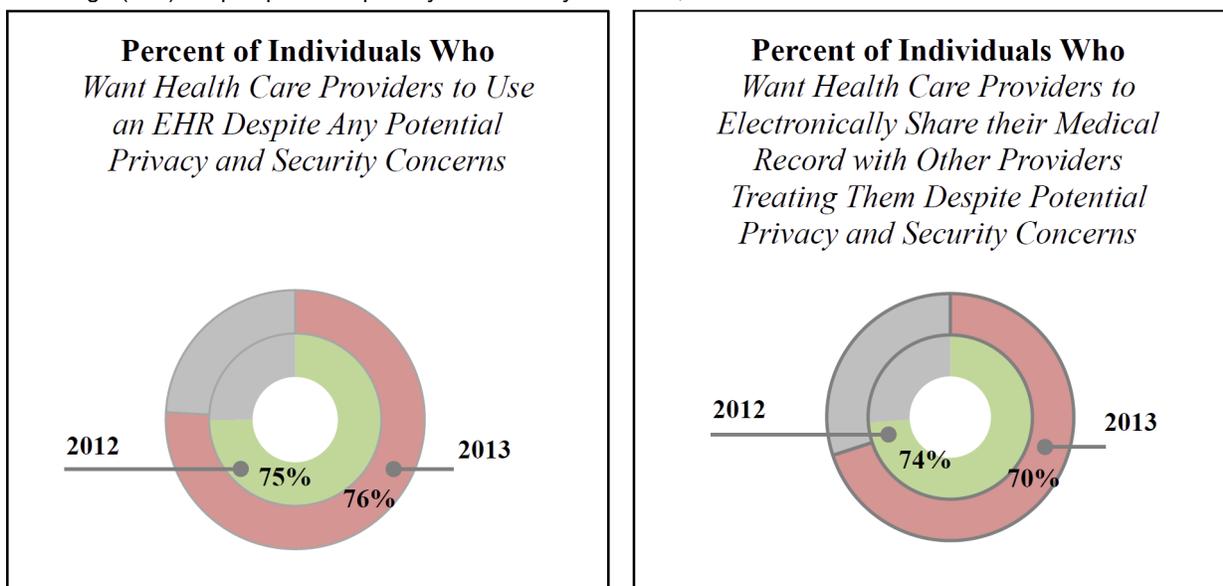


NOTE: Number of respondents range from n=2035 to n=2094. Differences between fax vs. electronic and between 2012 and 2013 are not statistically significant. Electronically means from computer to computer; not telephone, mail, or fax machine
SOURCE: 2012-2013 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange.

- ★ In 2013, 6 in 10 individuals indicated they were very or somewhat concerned about unauthorized viewing when their medical records are sent electronically between health care providers; a similar proportion of individuals expressed concerns about unauthorized viewing when their provider sends their medical records via fax.
- ★ There were no statistically significant changes between 2012 and 2013 in the proportion of individuals who expressed concerns regarding unauthorized viewing of their medical information when their medical records were sent between health care providers electronically or by fax.

Individuals' support for EHRs and HIE is high despite potential privacy or security concerns.

Figure 4: The proportion of individuals who support their providers' use of an EHR and electronic health information exchange (HIE) despite potential privacy and security concerns, 2012-2013.



NOTE: The number of respondents for the above items ranged from n= 2009 to n=2048. Differences between 2012 & 2013 are not statistically significant.
SOURCE: 2012-2013 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

- ★ In 2013, about 3 out of 4 individuals wanted their provider to use an EHR, despite any potential privacy or security concerns.
- ★ In 2013, about 7 in 10 individuals supported their providers' use of electronic HIE when sharing their medical records with other providers treating them, despite any possible privacy and security concerns.
- ★ There were no statistically significant differences between 2012 and 2013 in the proportion of individuals who supported EHRs or electronic HIE, despite potential privacy and security concerns.



Summary

Building public trust is vital to ensure that all stakeholders are comfortable engaging in electronic health information exchange (HIE) and the adoption of health IT to achieve the benefits of an interoperable health care system. Findings from national surveys conducted by ONC in 2012 and 2013 show that the privacy and security of medical records are significant and important concerns for individuals nationwide. About 7 in 10 individuals express concerns about privacy and security although less than one in 10 individuals have withheld information from their providers due to these concerns. Evidence from this survey suggests that increased adoption of EHRs is not associated with individuals' privacy and security concerns. Levels of privacy and security concerns and rates of withholding have not significantly changed between 2012 and 2013, despite increases in the adoption of any EHR among providers during the same time period.² Furthermore, individuals whose providers use an EHR have similar levels of concerns about the privacy and security of their medical records as compared to individuals whose providers use paper records. Continuing to assess this pattern will be important as evidence is still emerging. Two recent analyses using other national surveys have found similar findings but another study found an association between EHRs and rates of withholding (3,4,5).

A majority of individuals nationwide also expressed concerns regarding unauthorized viewing of medical records when information is shared between health care providers. In 2013, about 6 in 10 individuals expressed concerns about their provider sharing their health information with other providers. However, this level of concern did not significantly differ by whether the information was sent between health care providers by fax or through electronic means. Additionally, individuals' level of concern for sharing of health information through these means did not change significantly between 2012 and 2013.

Furthermore, we found that individuals' support for the use of EHRs and electronic HIE, despite any concerns they may have about the privacy and security of their medical record, continues to remain strong. In 2013, at least three-quarters of individuals wanted their provider to use an EHR, and 7 in 10 wanted to share their medical records electronically with other providers treating them, despite any privacy or security concerns. This suggests consumers' awareness that the potential risks associated with electronic health information may be balanced by the significant benefits (4).

In summary, we found that the concerns individuals may have about the privacy and security of their medical records are not unique or limited to EHRs. More importantly, in spite of potential concerns, a majority of individuals want their providers to use an EHR and to share appropriate medical information electronically with the individual's other health care providers.



Definitions

The definitions for the items related to security and privacy were developed from the National Committee on Vital and Health Statistics (NCVHS). According to NCVHS, health information privacy is an individual's right to control the acquisition, uses, or disclosures of his or her identifiable health data. Security refers to physical, technological, or administrative safeguards or tools used to protect identifiable health data from unwarranted access or disclosure.

Privacy of Medical Record: Privacy concerns were assessed with the question “Privacy means you have a say in who can collect, use and share your medical record. How concerned are you about the privacy of your medical record?” Individuals were considered concerned if they reported they were either very or somewhat concerned.

Security of Medical Record: Security concerns were assessed with the question “Security means having safeguards to keep your medical record from being seen by people who aren’t permitted to see them. Safeguards may include technology. How concerned are you about the security of your medical record?” Individuals were considered concerned if they reported they were either very or somewhat concerned.

Withholding of information was assessed by asking: “Have you ever kept information from your healthcare provider because you were concerned about the privacy or security of your medical record?” Individuals were considered to have withheld information from their healthcare provider if they reported “Yes.”

Electronically was defined as “from computer to computer, instead of by telephone, mail, or fax machine.”

Data Source and Methods

Data are from The Office of the National Coordinator for Health Information Technology’s (ONC) Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange. The survey was conducted by NORC at the University of Chicago with MITRE.

The respondent universe for the survey was the civilian, non-institutionalized population ages 18 years old and older within the 50 states and the District of Columbia. This survey utilized a dual random digit dialing (RDD) frame of landline phone numbers and wireless/mobile phone numbers developed by Survey Sampling International (SSI). In order to reduce sampling variability and to represent the nation, NORC stratified the landline RDD frame by Census Region. The 2013 survey oversampled Hispanic, Asian and Black populations. From each household with a selected phone number in a given frame only one adult was selected to complete the telephone interview. A total of 2,107 surveys were completed in 2013 and 2,050 surveys were completed in 2012.



References

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About the Authors

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Appendix

Data presented in this data brief are weighted national estimates. Items used for this data brief are listed in Appendix Table A1 below.

Appendix Table A1. Selected Items from the ONC Consumer Survey of Attitudes Toward the Privacy and Security Access of Electronic Health Records and Health Information Exchange, 2013, used for this analysis

| Question Text | Response Options |
|--|--|
| 1. Privacy means you have a say in who can collect, use and share your medical record. How concerned are you about the privacy of your medical record? | Very Concerned Somewhat Concerned Not Very Concerned Not Concerned at All |
| 2. Security means having safeguards to keep your medical record from being seen by people who aren't permitted to see them. Safeguards may include technology. How concerned are you about the security of your medical record? | Very Concerned Somewhat Concerned Not Very Concerned Not Concerned at All |
| 3. Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record? | YES/NO |
| 4. If your medical record is sent by fax from one health care provider to another, how concerned are you that an unauthorized person would see it? | Very Concerned Somewhat Concerned Not Very Concerned Not Concerned at All |
| 5. If your medical record is sent electronically from one health care provider to another, how concerned are you that an unauthorized person would see it? Electronically means from computer to computer, instead of by telephone, mail, or fax machine. | Very Concerned Somewhat Concerned Not Very Concerned Not Concerned at All |
| 6. I want my health care providers to use an electronic medical record to store and manage my health information despite any concerns I might have about privacy and security. | Strongly Agree Agree Disagree Strongly Disagree |
| 7. I want my health care providers to use a computer to share my medical record with other providers treating me despite any concerns I might have about privacy and security. | Strongly Agree Agree Disagree Strongly Disagree |
| 8. As far as you know, do any of your health care providers maintain your medical records in an electronic system? | YES/NO |