

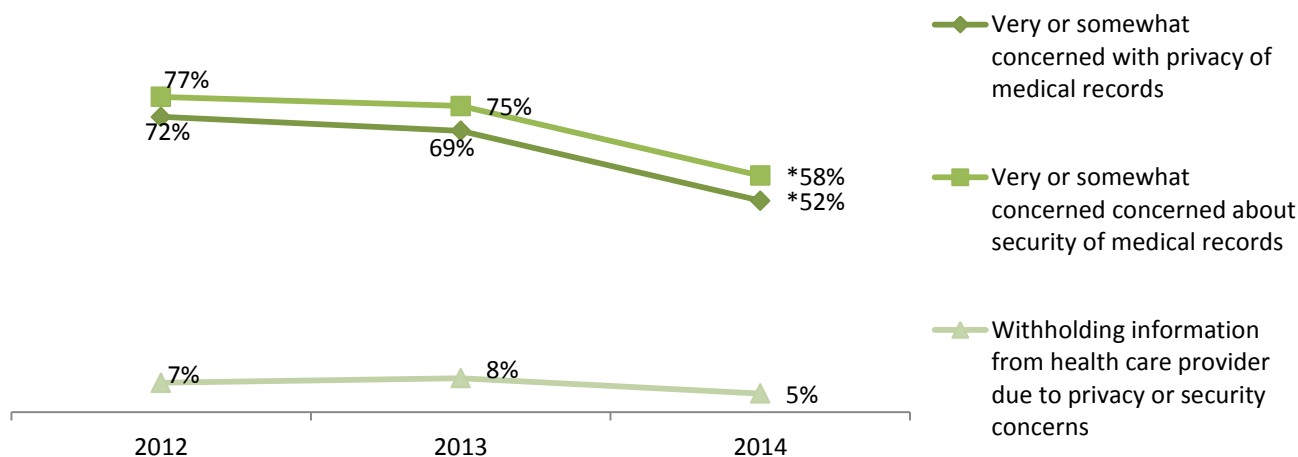
Trends in Individuals' Perceptions regarding Privacy and Security of Medical Records and Exchange of Health Information: 2012-2014

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Preserving patient trust in the privacy and security of health information is a critical element in achieving an interoperable health IT infrastructure (1). As adoption of certified health IT and electronic exchange of health information grows across hospitals and office-based physicians, it is important to assess the impact of these changes on consumers' perceptions regarding the privacy and security of their health information (2,3). From 2012 – 2014, ONC conducted a nationwide survey of consumers to examine privacy and security concerns and preferences regarding electronic health records (EHRs) and health information exchange (HIE) (4,5). This data brief summarizes trends from 2012 – 2014 related to individuals' privacy and security concerns and preferences.

Individuals' concerns about the privacy and security of both paper and electronic medical records declined significantly between 2013 and 2014.

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, 2012-2014



NOTE: *Significantly different from 2013 and 2012 ($p < .05$)

SOURCE: 2012 – 2014 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

- ★ In 2014, a similar proportion of individuals – a little over half of individuals nationwide – expressed concerns regarding the privacy of their medical records and the security of their medical records.
- ★ Five percent of individuals withheld information from their health care provider due to either privacy or security concerns related to their medical records in 2014; this did not represent a significant change from the prior year.



In 2014, a similar number of individuals—about one in five—expressed lack of concern about both the privacy and the security of their medical records.

Figure 2: Proportion of individuals who expressed concerns regarding the privacy and security of their medical records, 2012-2014.



NOTE: *Significantly different from 2013 and 2012 ($p < .05$)

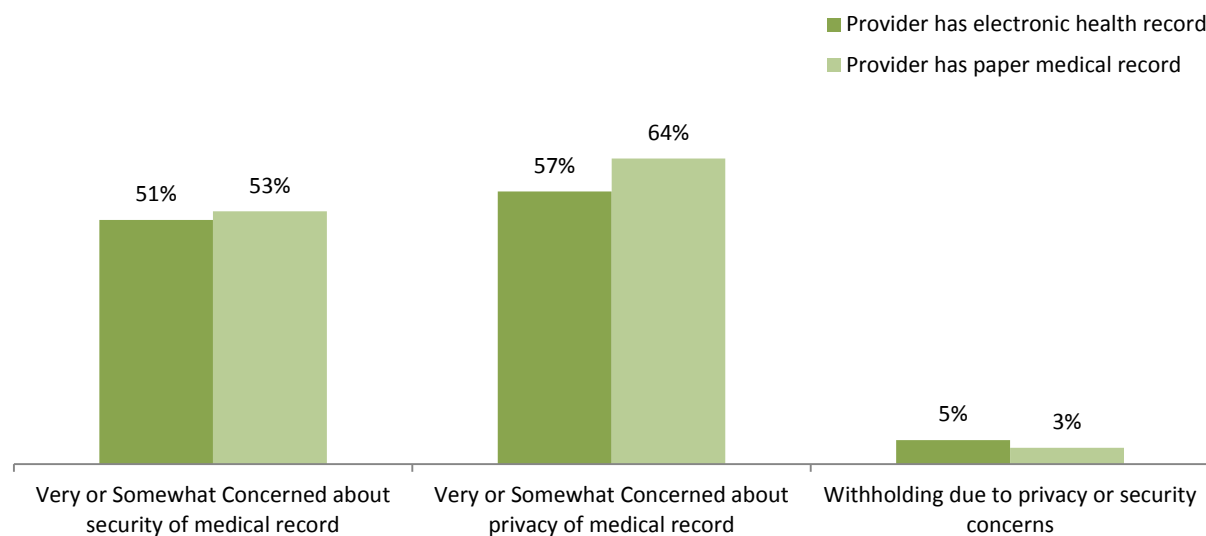
SOURCE: 2013-2014 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

- ★ Between 2013 and 2014, the proportion of individuals who expressed no concerns about the privacy or security of their medical records increased significantly.
- ★ In 2012 and 2013, a little under half of individuals were “very concerned” about the privacy of their medical records, compared to 30% in 2014.
- ★ In 2012 and 2013, approximately half of individuals were “very concerned” about the security of their medical records compared to 36% of individuals in 2014.
- ★ The proportion of individuals who were “very concerned” about the privacy of their medical records decreased by about fifteen percentage points between 2013 and 2014; the proportion who were “very concerned” about the security of their medical records also declined by a similar percentage over this period.
- ★ The proportion of individuals who expressed no concerns about the security of their medical records almost doubled between 2013 and 2014, from 11% to 19%.



Individuals' concerns regarding the privacy and security of their medical record do not significantly differ by whether they have an electronic versus paper medical record.

Figure 3: 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 by whether their provider had a paper or electronic health record (EHR), 2014



NOTE: There were no statistically significant differences between paper vs. electronic health records.

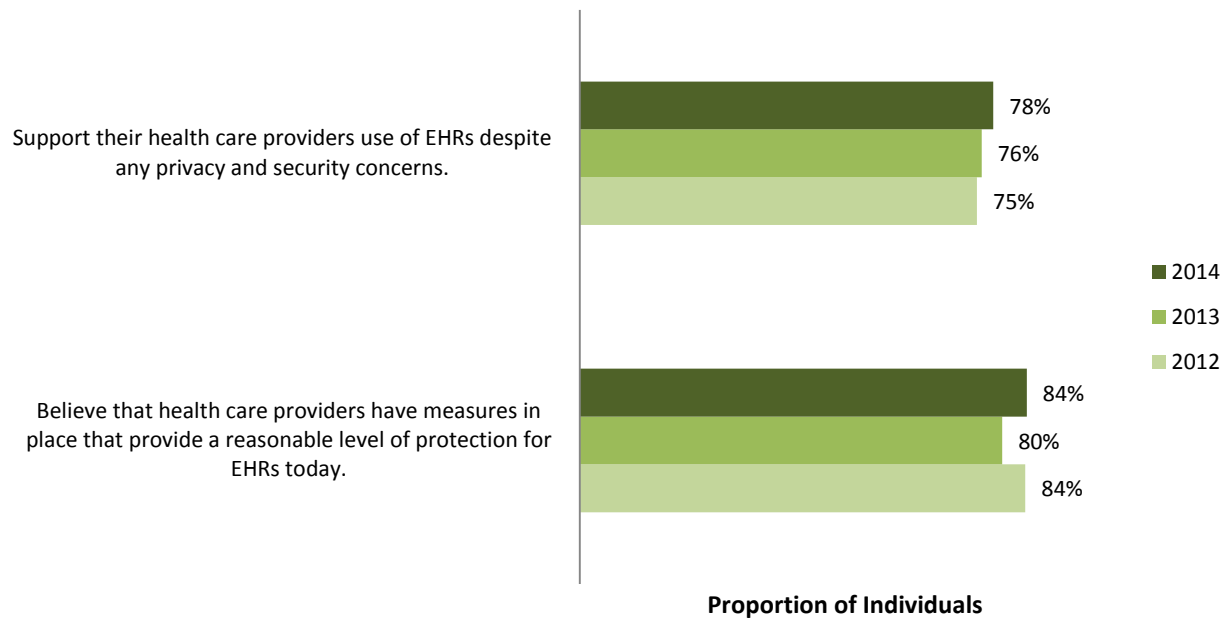
SOURCE: 2014 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

- ★ Individuals who reported withholding of information from their health care provider due to privacy or security concerns did not significantly differ by whether their provider has an electronic versus a paper medical record.



Between 2012 and 2014, at least three-quarters of individuals supported their health care providers' use of EHRs despite any potential privacy or security concerns.

Figure 4: Trends in individuals' perceptions regarding support for providers' use of EHRs in spite of privacy and security concerns and whether health care providers provide a reasonable level of protection for EHRs, 2012-2014.

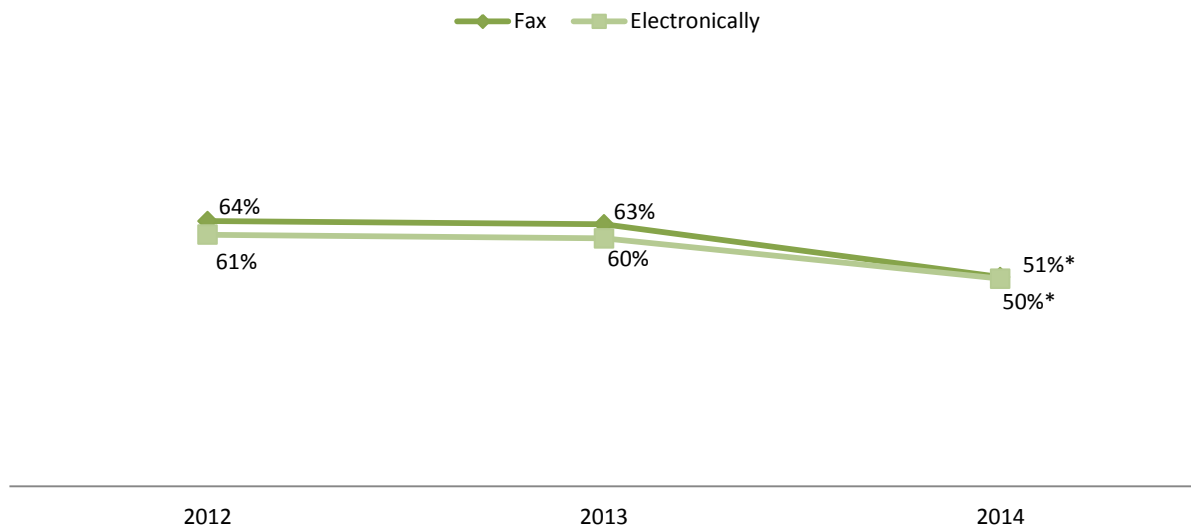


NOTE: This graphic reports on the proportion of individuals who strongly agree or agree with statements (See appendix for related survey questions).
SOURCE: 2013-2014 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

- ★ Consistently between 2012 and 2014, 80% or more of individuals believed health care providers had measures in place to reasonably protect EHRs.

Individuals' concerns regarding unauthorized viewing of medical records when sent by fax or electronic means declined significantly between 2013 and 2014.

Figure 5: Trends in Individuals' Concern regarding Unauthorized Viewing of Medical Record if Medical Record Sent by Fax vs. Electronically for Treatment Purposes, 2012-2014.



NOTE: *Significantly different from 2013 and 2012 ($p < .05$).

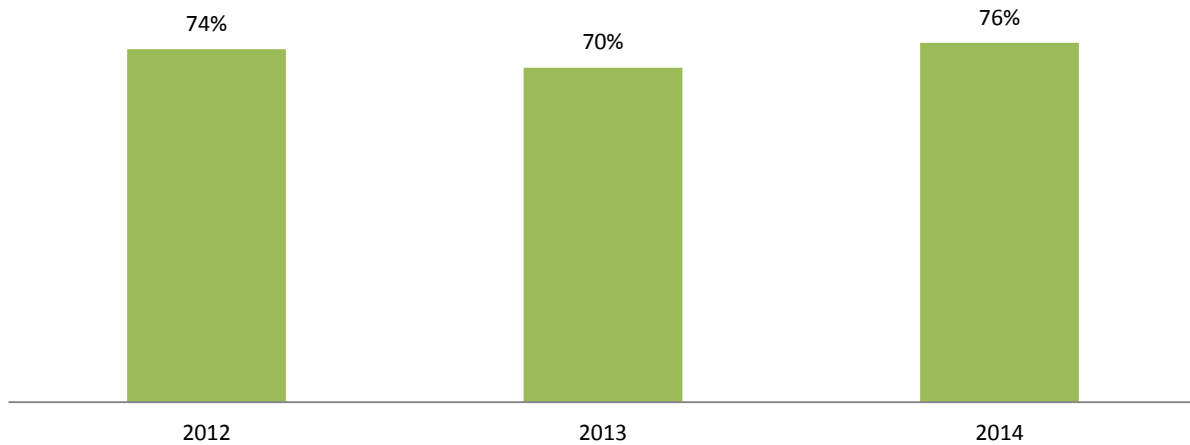
SOURCE: 2013-2014 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

- ★ In 2014, a similar proportion of individuals—about half—expressed concerns regarding unauthorized individuals viewing their medical record whether it was sent by fax or electronic means.
- ★ Between 2013 and 2014, concerns regarding having medical records sent by fax declined by 20% and concerns regarding medical records sent by electronic means declined by 16%.



Between 2012 and 2014, at least 7 in 10 individuals have supported electronically exchanging their health records despite potential privacy or security concerns.

Figure 6: Trends in individuals support for electronic health information exchange (HIE) in spite of privacy and security concerns, 2012-2014.



NOTE: No significant differences between years ($p < 0.05$). This graphic reports on the proportion of individuals who strongly agree or agree with statement (See appendix for related survey questions).

SOURCE: 2012-2014 Consumer Survey of Attitudes Toward the Privacy and Security Aspects of Electronic Health Records and Health Information Exchange

- ★ In 2014, over three-quarters of individuals indicated that they wanted their health care providers to electronically share their medical record with other providers treating them despite any potential privacy or security concerns they may have.



Summary

Patient trust in the privacy and security of health information is considered foundational to the development of an interoperable health IT infrastructure. In 2014, a little over half of individuals had concerns regarding the privacy and security of their medical records, and about half expressed concerns regarding unauthorized viewing of their medical records when sent electronically or by fax. This represents a significant decrease from the prior year. However, there were no significant differences in individuals' withholding information from their health care provider due to privacy or security concerns during this period. In 2014, five percent of individuals nationwide withheld information from their health care provider due to privacy or security concerns.

Consistent with prior analyses, in 2014, individuals' privacy and security concerns regarding their medical records, and withholding of information from health care providers due to those concerns, did not differ by whether individuals had paper versus electronic medical records (4). Similarly, in 2014, individuals' concerns did not differ by whether a health care provider would send their medical record to another health care provider treating them by either electronic means or fax.

Between 2012 and 2014, individuals expressed high levels of support for providers using EHRs and engaging in HIE for treatment purposes despite any potential privacy or security concerns. HIPAA, the general federal health information privacy law, supports HIE for treatment and care planning (6). Individuals' high level of support for EHRs and HIE may be related to their belief that their health care providers were already taking the steps necessary to protect their medical records (5). Between 2012 and 2014, 80% or more of individuals believed health care providers had measures in place to reasonably protect EHRs. Providing ongoing guidance to health care providers on cybersecurity and other issues to protect EHRs may help ensure that health care providers implement the most up-to-date measures to protect health information (7).

In summary, as EHR adoption and HIE increased among hospitals and physicians, consumers' concerns regarding HIE and the privacy and security of medical records declined. However, it is important to note that these perceptions reflect individuals' points of view prior to announcement in 2015 of several large health care information breaches (8). Whether these recent breaches may negatively impact individuals' perceptions related to the privacy and security of their medical records and exchange of their health information is unclear and warrants monitoring. Additionally, it is unclear as to whether the significant decreases in concerns between 2013 and 2014 are an anomaly or whether this represents the beginning of a trend towards decreasing privacy and security concerns.



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, and the 2012 and 2014 oversampled for Hispanic and Black populations. A total of 2,123 were completed in 2014; 2,107 surveys were completed in 2013; and 2,050 surveys were completed in 2012. Data presented in this data brief are weighted national estimates.

Appendix Table A1. Selected Items used for this analysis, 2014

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
9. Health care providers have measures in place that provide a reasonable level of protection for electronic medical records today.	Strongly agree Agree Disagree Strongly disagree



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About the Authors

The authors are with the Office of the National Coordinator for Health Information Technology, Office of Planning, Evaluation, and Analysis and the Office of the Chief Privacy Officer. Lisa Moon, MPH is a graduate student at the University of Minnesota.

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