

# Concern about security and privacy, and perceived control over collection and use of health information are related to withholding of health information from healthcare providers

Israel T Agaku,<sup>1</sup> Akinyele O Adisa,<sup>2</sup> Olalekan A Ayo-Yusuf,<sup>1,3</sup> Gregory N Connolly<sup>1</sup>

<sup>1</sup>Department of Social and Behavioral Sciences, Center for Global Tobacco Control, Harvard School of Public Health, Boston, Massachusetts, USA

<sup>2</sup>Department of Oral Pathology, University of Ibadan, Ibadan, Oyo State, Nigeria

<sup>3</sup>Department of Community Dentistry, University of Pretoria, Pretoria, South Africa

## Correspondence to

Dr Israel Agaku, Department of Social and Behavioral Sciences, Center for Global Tobacco Control, Harvard School of Public Health, Boston, MA 02115, USA; [iagaku@post.harvard.edu](mailto:iagaku@post.harvard.edu)

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## ABSTRACT

**Introduction** This study assessed the perceptions and behaviors of US adults about the security of their protected health information (PHI).

**Methods** The first cycle of the fourth wave of the Health Information National Trends Survey was analyzed to assess respondents' concerns about PHI breaches. Multivariate logistic regression was used to assess the effect of such concerns on disclosure of sensitive medical information to a healthcare professional ( $p < 0.05$ ).

**Results** Most respondents expressed concerns about data breach when their PHI was being transferred between healthcare professionals by fax (67.0%; 95% CI 64.2% to 69.8%) or electronically (64.5%; 95% CI 61.7% to 67.3%). About 12.3% (95% CI 10.8% to 13.8%) of respondents had ever withheld information from a healthcare provider because of security concerns. The likelihood of information withholding was higher among respondents who perceived they had very little say about how their medical records were used (adjusted OR=1.42; 95% CI 1.03 to 1.96).

**Conclusions** This study underscores the need for enhanced measures to secure patients' PHI to avoid undermining their trust.

## INTRODUCTION

Breaches in the security of protected health information (PHI) have a significant impact on patients and healthcare organizations. It has been estimated that lost or stolen PHI may cost the US healthcare industry up to US\$7 billion annually.<sup>1</sup> In addition, patients whose PHI is breached may be susceptible to having their confidential health records disclosed and may also suffer from financial or medical identity theft.<sup>2</sup> Theft of patients' health credentials to obtain medical treatment, services or goods (ie, medical identity theft) may have long-term economic and health consequences on patients, since these false changes made to their medical files and histories can remain undiscovered for years.<sup>2-3</sup> Victims of medical identity theft may receive inappropriate medical treatment (including potentially harmful medication), exhaust their health insurance benefits, or fail pre-employment medical screening examinations because of the presence of bogus health conditions in their health records.

Relatively new technologies that may be difficult to secure (eg, mobile devices, file-sharing applications, and cloud-based services) and the growing reliance on them may further increase the vulnerability of patients' PHI to malicious intrusions.<sup>1</sup>

A potentially bigger problem is that these technologies make it possible to lose/steal an unlimited number of records rather than the number that can be carried by hand.

Besides the aforementioned inappropriate disclosures of PHI, authorized disclosures of health data exist, which patients may be unaware of at some points during care, and, when they find out about these disclosures, may feel violate their privacy. Ready access to treatment and efficient payment for healthcare—both of which require use and disclosure of PHI—are essential to the effective operation of the healthcare system. As such, the Health Insurance Portability and Accountability Act (HIPAA) generally prohibits a covered entity from using or disclosing PHI unless authorized by patients, except where this prohibition would result in unnecessary interference with access to quality healthcare or with certain other important public benefits or national priorities.<sup>4-6</sup>

Despite these developments, very little is known about patients' perceptions about the security of their PHI and the effect of such perceptions on patient–healthcare provider interactions with regard to disclosure of sensitive health information. To fill this gap in our knowledge, this study analyzed data from the first cycle of the fourth wave of the Health Information National Trends Survey (HINTS 4) to assess patients' concerns and behaviors about security and privacy of their PHI.

## METHODS

### Data source/sampling

The HINTS is a biennial, nationally representative survey of non-institutionalized US adults aged  $\geq 18$  years that collects information on the American public's need for, access to, and use of health-related information and health-related behaviors, perceptions, and knowledge.<sup>7-9</sup> HINTS 4 is the most recent wave of the survey and included four mail-mode data-collection cycles over the course of 3 years. The first of these cycles was administered to 3959 respondents (overall response rate=36.7%) during October 2011 to February 2012.

### Measures

Perception about presence of safeguards to protect patients' medical records

Confidence about the presence of safeguards to protect patients' medical records was defined as a response of 'very confident' or 'somewhat

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confident' (vs 'not confident') to the question: 'How confident are you that safeguards are in place to protect your medical records from being seen by people who aren't permitted to see them?'

Perception about security and privacy of electronically transferred or faxed health information

Concerns about the security and privacy of electronically transferred or faxed medical information were assessed separately and were defined as a report by a respondent that they were 'very concerned' or 'somewhat concerned' (vs 'not concerned') that an unauthorized person would see their medical information if sent electronically or by fax from one healthcare provider to another.

Perceived control over collection, use, and sharing of personal medical information

Perception of control over the collection and use of personal medical information was defined as a response of 'very confident' or 'somewhat confident' (vs 'not confident') to the question: 'How confident are you that you have some say in who is allowed to collect, use, and share your medical information?'

Withholding of health information because of concerns over security and privacy of health information

Information withholding by patients because of concerns over security and privacy of health information was defined as a 'yes' response to the question: 'Have you ever kept information from your healthcare provider because you were concerned about the privacy or security of your medical record?'

#### Sociodemographic characteristics

Sociodemographic characteristics assessed included: gender (male or female); self-reported general health condition (poor/fair or excellent/very good/good); age ( $\leq 24$ ; 25–44; 45–64 or  $\geq 65$  years); place of birth (foreign-born or US-born); education ( $<$ high school; high school diploma; some college; or  $\geq$ college degree); race/ethnicity (Hispanic; white; black; other, or unknown); marital status (married/living with partner; widowed/divorced/separated; or single). Considering that smoking status could be a good proxy for sensitivities about disclosure of PHI, we also recorded participants' smoking status. Current smokers were respondents who reported smoking  $\geq 100$  cigarettes during their lifetime and, at the time of interview, reported smoking every day or some days. Former smokers were respondents who reported smoking  $\geq 100$  cigarettes during their lifetimes but currently did not smoke.

#### Data analysis

All data were weighted to yield nationally representative estimates by using final sample weights and a set of jackknife replicate weights from the HINTS database. The proportion of respondents who reported concerns about the safety of their PHI was assessed overall and by sociodemographic characteristics. Within-group comparisons were made using  $\chi^2$  statistics ( $p < 0.05$ ).

Logistic regression was used to assess the effect of patient perceptions about the security and privacy of PHI on their withholding of medical information from a healthcare provider. The final multivariate logistic regression model included all variables that were significant on bivariate analysis at  $p < 0.2$ , including gender, general health condition, age, birthplace, current smoking status, education, race/ethnicity and marital status. All analyses were performed with Stata V.11.

## RESULTS

### Patient concerns about security and privacy of health information

Overall, 75.4% (95% CI 73.4% to 77.5%) of respondents were confident that some safeguards were in place to protect their PHI from being accessed by unauthorized persons. However, most respondents were concerned about a breach in the security and privacy of their PHI while being transferred between health professionals by fax (67.0%; 95% CI 64.2% to 69.8%) or electronically (64.5%; 95% CI 61.7% to 67.3%). About two-thirds of respondents (75.4%; 95% CI 73.1% to 77.7%) were confident that they had a say in the collection, use and sharing of their medical information (table 1).

### Concerns over security and privacy of PHI as a predictor of non-disclosure of medical information

Overall, 12.3% (95% CI 10.8% to 13.8%) of all respondents reported ever withholding information from a healthcare professional out of concern for the security and privacy of their medical records (table 1). After adjustment for all other factors, concerns about a breach in the security of PHI while being faxed (adjusted OR (aOR)=4.29; 95% CI 2.27 to 8.14) or electronically transferred (aOR=2.16; 95% CI 1.13 to 4.14), as well as the perception of a respondent that they had very little say in how their PHI was used (aOR=1.42; 95% CI 1.03 to 1.96), were all associated with significantly higher odds of withholding medical information from a healthcare professional.

In addition, never smokers had significantly lower odds of withholding information compared with current smokers (aOR=0.53; 95% CI 0.32 to 0.86). However, there was no significant difference between former and current smokers ( $p=0.552$ ) (table 2). No significant differences in withholding medical information because of concerns over security or privacy of medical records were found by gender, general health condition, age, birthplace, education level, race/ethnicity or marital status (table 2).

## DISCUSSION

This study showed that about two-thirds of US adults were concerned about a breach in the security of their PHI during transfer between healthcare professionals by fax or electronically. In addition, 12.3% of US adults reported that they had withheld information from a healthcare professional during 2011–2012, which was similar to the proportion that had engaged in similar privacy protective behaviors in 2005 (13%) and 1999 (15%).<sup>10 11</sup> This unabated trend may be due to fact that PHI security breaches have become increasingly more prevalent in recent times in the USA.<sup>1 2</sup> This study showed that concerns over the safety of PHI was associated with higher likelihood of withholding medical information from a healthcare professional, thus underscoring the need for enhanced and sustained measures to ensure the confidentiality, integrity, and availability of PHI.<sup>12 13</sup> This is particularly important considering the sensitivity of certain information such as sexually transmitted diseases, mental health, and drug misuse issues.

The fact that never smokers had significantly lower odds of withholding information from a healthcare provider compared with current smokers may be associated with non-disclosure of smoking behavior among patients who smoke, possibly because of a perception of the social undesirability of smoking or for fear of health insurance penalties.<sup>14 15</sup>

Notifiable disease reporting at the local level protects the public's health by ensuring the proper identification and

**Table 1** Perceptions and behavior of US adults aged ≥18 years regarding security and privacy of medical records, October 2011 to February 2012

Characteristic	Sample % (n)	% who were concerned about unauthorized access to their medical information when transferred electronically between healthcare providers (95% CI)	% who were concerned about unauthorized access to their medical information when faxed between healthcare providers (95% CI)	% who felt confident that safeguards were present to protect their medical information from unauthorized access (95% CI)	% who felt confident they had a say in the collection, use and sharing of their medical information (95% CI)	% who had ever withheld information from a healthcare professional out of concern for the security or privacy of their medical records (95% CI)	p Value*
<b>Gender</b>							
Male	48.5 (1552)	63.7 (59.5 to 68.0)	65.0 (60.1 to 69.8)	72.2 (68.5 to 75.9)	71.3 (67.2 to 75.4)	10.4 (8.2 to 12.5)	0.015
Female	51.5 (2304)	65.4 (62.6 to 68.2)	69.1 (66.2 to 71.9)	78.6 (76.5 to 80.7)	79.3 (76.7 to 81.9)	13.9 (11.9 to 15.8)	
<b>General health condition</b>							
Poor or fair	15.1 (632)	69.1 (61.3 to 76.9)	72.3 (65.5 to 79.2)	67.3 (59.3 to 75.2)	69.3 (62.2 to 76.4)	15.4 (10.6 to 20.1)	0.173
Excellent, very good or good	84.9 (3291)	63.4 (60.4 to 66.4)	65.8 (63.0 to 68.7)	77.3 (75.2 to 79.5)	76.2 (73.9 to 78.5)	11.8 (10.2 to 13.4)	
<b>Age, years</b>							
≤24	11.3 (143)	55.5 (36.2 to 74.8)	56.9 (41.3 to 72.5)	80.9 (70.3 to 91.5)	70.8 (56.2 to 85.3)	8.9 (3.8 to 14.0)	<0.001
25–44	33.6 (932)	63.1 (58.2 to 68.0)	68.3 (63.1 to 73.6)	80.0 (76.8 to 83.2)	81.7 (78.5 to 84.8)	12.9 (10.0 to 15.9)	
45–64	37.5 (1582)	67.6 (63.5 to 71.7)	69.6 (65.8 to 73.4)	72.0 (68.8 to 75.2)	71.1 (67.4 to 74.8)	14.6 (11.8 to 17.5)	
≥65	17.6 (972)	62.3 (57.7 to 67.0)	62.9 (58.9 to 66.9)	77.2 (73.6 to 80.7)	76.7 (73.1 to 80.2)	6.2 (3.8 to 8.6)	
<b>Birthplace</b>							
Foreign-born	14.4 (535)	70.1 (62.1 to 78.1)	76.0 (68.6 to 83.4)	74.7 (67.2 to 82.1)	71.7 (64.5 to 79.0)	18.3 (14.1 to 22.6)	0.004
US-born	85.6 (3377)	63.8 (60.7 to 67.0)	65.9 (62.9 to 69.0)	75.6 (73.2 to 77.9)	75.9 (73.3 to 78.5)	11.4 (9.7 to 13.0)	
<b>Cigarette smoking status</b>							
Current smoker	17.8 (615)	68.8 (61.9 to 75.8)	69.4 (61.7 to 77.0)	72.1 (64.7 to 79.4)	73.9 (66.5 to 81.3)	15.7 (12.0 to 19.5)	0.125
Former smoker	20.5 (1000)	61.8 (57.7 to 65.8)	61.5 (56.7 to 66.2)	73.6 (69.4 to 77.8)	74.4 (71.3 to 77.6)	12.0 (9.1 to 14.9)	
Never smoker	61.7 (2262)	64.4 (60.3 to 68.4)	68.4 (64.5 to 72.4)	77.4 (74.6 to 80.1)	76.3 (73.2 to 79.4)	11.4 (9.5 to 13.2)	
<b>Education</b>							
Less than High school	12.9 (391)	67.5 (56.0 to 78.9)	66.4 (56.4 to 76.4)	82.4 (76.2 to 88.7)	78.3 (67.7 to 88.9)	12.6 (7.6 to 17.5)	0.041
High school graduate	23.1 (785)	65.3 (59.0 to 71.7)	70.2 (63.8 to 76.7)	74.9 (67.5 to 82.3)	77.8 (72.3 to 83.4)	8.4 (5.6 to 11.3)	
Some college	31.2 (1167)	66.3 (61.0 to 71.7)	68.3 (63.5 to 73.2)	77.8 (74.2 to 81.3)	77.4 (72.7 to 82.0)	13.8 (11.2 to 16.4)	
College graduate or higher	32.9 (1531)	61 (57.0 to 64.9)	63.9 (60.0 to 67.8)	71.7 (68.2 to 75.2)	71.1 (67.6 to 74.6)	12.9 (11.0 to 14.7)	
<b>Race/ethnicity</b>							
Hispanic	13.8 (461)	66.1 (54.6 to 77.6)	69.8 (58.1 to 81.4)	83.1 (76.6 to 89.6)	80.2 (73.7 to 86.6)	15.4 (10.3 to 20.5)	0.004
White, non-Hispanic	63.8 (2431)	61.4 (58.3 to 64.4)	63.8 (60.7 to 66.8)	72.7 (69.9 to 75.5)	74.0 (71.1 to 76.9)	10.2 (8.6 to 11.9)	
Black, non-Hispanic	10.9 (576)	77.5 (69.4 to 85.6)	76.8 (65.5 to 88.1)	83.5 (76.8 to 90.2)	81.1 (73.1 to 89.1)	14.9 (8.6 to 21.3)	
Other, non-Hispanic†	7 (271)	69.2 (57.6 to 80.8)	76.3 (67.7 to 84.9)	73.5 (62.0 to 85.0)	69.8 (58.9 to 80.6)	22.0 (14.2 to 29.8)	
Unknown	4.4 (220)	68.9 (59.8 to 78.0)	71.2 (62.7 to 79.7)	79.6 (72 to 87.3)	78.6 (72.2 to 85.1)	12.0 (6.3 to 17.7)	
<b>Marital status</b>							
Married/living together	54.6 (2156)	61.4 (58.9 to 64.0)	65.5 (62.5 to 68.5)	76.1 (73.4 to 78.9)	76.2 (73.4 to 78.9)	12.5 (10.6 to 14.4)	0.178
Divorced, widowed, or separated	16.8 (1072)	70.3 (66.3 to 74.3)	71.1 (67.5 to 74.7)	70.8 (67.1 to 74.4)	72.0 (68.9 to 75.1)	14.1 (11.7 to 16.4)	
Single	28.6 (620)	68.2 (58.6 to 77.8)	68.9 (60.0 to 77.8)	78.2 (72.7 to 83.8)	76.7 (69.4 to 84.0)	10.6 (7.4 to 13.7)	
<b>Overall</b>	100.0 (3959)	64.5 (61.7 to 67.3)	67.0 (64.2 to 69.8)	75.4 (73.4 to 77.5)	75.4 (73.1 to 77.7)	12.3 (10.8 to 13.8)	

All data were weighted to account for the complex survey design.

\*Bivariate assessment of the relationship between selected sociodemographic factors and withholding of information from a healthcare professional out of concern for the security or privacy of medical records. Variables significant at p<0.2 were included in the final multivariate logistic regression model.

†Includes non-Hispanic American Indian/Alaska natives, native Hawaiian/other Pacific Islanders, Asians, and non-Hispanic multiple races.

**Table 2** Factors associated with withholding medical information from a healthcare professional among US adults aged  $\geq 18$  years, October 2011 to February 2012

Characteristic	Crude ORs (95% CI)	Adjusted ORs (95% CI)
Confidence about security and privacy of faxed health records		
'Not concerned'	1.00 (Referent)	1.00 (Referent)
'Very concerned' or 'somewhat concerned'	6.54 (4.04 to 10.61)	4.29 (2.27 to 8.14)*
Confidence about security and privacy of electronically transferred health records		
'Not concerned'	1.00 (Referent)	1.00 (Referent)
'Very concerned' or 'somewhat concerned'	4.78 (3.22 to 7.09)	2.16 (1.13 to 4.14)*
Confidence about control over personal health records		
'Very confident' or 'somewhat confident'	1.00 (Referent)	1.00 (Referent)
'Not confident'	1.93 (1.49 to 2.50)	1.42 (1.03 to 1.96)*
Gender		
Male	1.00 (Referent)	1.00 (Referent)
Female	1.39 (1.06 to 1.83)	1.32 (0.93 to 1.90)
General health condition		
Poor or fair	1.00 (Referent)	1.00 (Referent)
Excellent, very good or good	0.74 (0.49 to 1.12)	1.05 (0.52 to 2.10)
Age, years		
$\leq 24$	1.00 (Referent)	1.00 (Referent)
25–44	1.51 (0.76 to 3.00)	1.48 (0.50 to 4.37)
45–64	1.74 (0.90 to 3.38)	1.46 (0.50 to 4.24)
$\geq 65$	0.68 (0.31 to 1.48)	0.59 (0.19 to 1.82)
Birthplace		
Foreign-born	1.00 (Referent)	1.00 (Referent)
US-born	0.57 (0.41 to 0.79)	0.84 (0.46 to 1.54)
Cigarette smoking status		
Current smoker	1.00 (Referent)	1.00 (Referent)
Former smoker	0.73 (0.50 to 1.07)	0.85 (0.49 to 1.48)
Never smoker	0.69 (0.49 to 0.96)	0.53 (0.32 to 0.86)*
Education		
Less than high school	1.00 (Referent)	1.00 (Referent)
High school graduate	0.64 (0.35 to 1.19)	0.67 (0.30 to 1.52)
Some college	1.11 (0.70 to 1.77)	1.14 (0.57 to 2.28)
College graduate or higher	1.03 (0.63 to 1.68)	1.09 (0.52 to 2.27)
Race/ethnicity		
Hispanic	1.00 (Referent)	1.00 (Referent)
White, non-Hispanic	0.63 (0.41 to 0.96)	0.68 (0.34 to 1.33)
Black, non-Hispanic	0.96 (0.47 to 1.99)	1.11 (0.46 to 2.68)
Other, non-Hispanic†	1.55 (0.85 to 2.82)	1.77 (0.80 to 3.94)
Unknown	0.75 (0.35 to 1.60)	0.87 (0.32 to 2.36)
Marital status		
Married/living together	1.00 (Referent)	1.00 (Referent)
Divorced, widowed, or separated	1.15 (0.89 to 1.47)	1.07 (0.74 to 1.58)
Single	0.83 (0.57 to 1.19)	0.60 (0.34 to 1.05)

All data were weighted to account for the complex survey design.

\*Statistically significant at  $p < 0.05$ .

†Includes non-Hispanic American Indian/Alaska natives, native Hawaiian/other Pacific Islanders, Asians, and respondents of multiple races.

follow-up of cases for the prevention and control of the disease.<sup>5</sup> While healthcare professionals are not required to obtain consent from patients before reporting cases of notifiable diseases to public health authorities, it may be considerate (if possible and appropriate) for healthcare providers to inform such patients that their test results or medical condition will be reported to the health department. This courtesy might prevent such patients from being unnecessarily alarmed or shocked when the health department contacts them later to follow up. In addition, this may help foster trust and confidence between patients and their healthcare providers.

Patients' withholding medical information from healthcare professionals may not only impact negatively on the patient

directly, but could also potentially compromise the health of others and the quality of healthcare surveillance systems. The consequences to the individual patient may range from relatively minor ones (such as missed opportunities for tobacco cessation counseling or treatment because of non-disclosure of smoking status) to more serious medical consequences (such as potential compromise in the timeliness, quality, and appropriateness of medical care). Patients with infectious, notifiable conditions who withhold all or part of necessary medical information (including relevant travel or social history) may inadvertently put the lives of others at increased risk. Furthermore, non-disclosure, under-information or misinformation may jeopardize the data quality of healthcare surveillance systems. This is of significant public

health concern, since such surveillance systems depend on accurate data to monitor existing and emerging trends in health outcomes and provide the basis for policy and population-based interventions.<sup>16</sup>

This study has implications for patients, the healthcare industry, and policy makers. Healthcare consumers and their advocates should gain a deeper understanding of privacy rules and take action to protect their own information by only selecting providers or health insurers that actively support privacy rights or by demanding higher levels of information privacy protection from health industry stakeholders.<sup>10</sup> The findings also underscore the need for healthcare organizations to comply with HIPAA standards for administrative, physical, and technical safeguards to protect patients' PHI.<sup>6 17</sup> In addition, annual privacy and security risk assessments may help healthcare organizations to understand what practices may be putting patients' PHI at risk, particularly as employee-related mistakes or unintentional actions have been shown to be the leading cause of medical data breaches.<sup>1</sup> Finally, enhanced and sustained efforts by policy makers to address privacy issues by broadening the scope of federal protection and more vigorously enforcing current federal laws may help to protect patients' PHI.

This study has some limitations. First, all information was self-reported, which may have resulted in recall bias for some measures. Second, questionnaires were administered only in English and Spanish, which may have resulted in non-response among persons who speak neither of those languages. In addition, considering the relatively low overall response rate (36.7%), there is a possibility of selection bias if there were systematic differences between the respondents and the non-respondents. However, the magnitude of this bias was reduced by using weighting adjustments for unit non-response.<sup>7</sup> Finally, the cross-sectional nature of the study does not permit causal inferences. Nonetheless, this study underscores the need for enhanced measures to protect patients' records from inadvertent disclosure.

## CONCLUSION

This study shows that most US adults are concerned about the security and privacy of their PHI, and such concerns are associated with an increased likelihood of non-disclosure of sensitive information to a healthcare professional. This underscores the need for intensified efforts to ensure the confidentiality, integrity, and availability of patients' PHI in order to foster trustful patient-physician interactions.

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**Contributors** ITA initiated the study design, analyzed the data, and prepared the initial draft of the manuscript. OA-AY, ADA, and GNC critically reviewed and revised the manuscript. All authors read and approved the final manuscript.

**Competing interests** None.

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**Data sharing statement** All data used for this study are publicly available secondary data.

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