

France: How Privacy Considerations Drive Patient Decisions and Impact Patient Care Outcomes

Trust in the confidentiality of medical records influences when, where, who and what kind of medical treatment is delivered to patients

Research and analysis conducted by New London Consulting

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Purpose of the Study and Executive Overview Report

In September 2011, **FairWarning®** commissioned New London Consulting to develop a survey of French patients of care providers to determine how ***patient privacy considerations impact the actual delivery of healthcare and to what degree patients believed healthcare executives and managers should be held accountable for healthcare privacy protections and breaches***. The survey was designed to garner a baseline understanding of patient beliefs relative to a care providers' legal, ethical and moral responsibility to protect patient privacy. More importantly, the survey sought to measure how privacy considerations affect patient behaviors and decisions and influence patient care outcomes.

The survey was conducted using an online platform. Survey invitations were sent to more than 1,500 patients across France. Invitations to participate were sent to residents of various regions in France including urban metropolitans and rural communities. The survey resulted in responses from participants of varying educational level, economic class, age and gender. The survey invitation resulted in participation of 1,002 respondents. The survey was live for 6 days. The full survey methodology is detailed in Appendix 1.

Purpose of the Survey

A series of 30 questions were posed that sought to reveal how privacy concerns impact patients' healthcare decisions and, more specifically, measure to what degree:

- ***Privacy considerations influence from whom patients seek care***
- ***Privacy considerations influence when they receive care***
- ***Privacy considerations influence from where they seek care***
- ***Privacy considerations influence what information they disclose, thereby affecting the care they receive***
- ***Should healthcare executives and managers be held accountable for privacy protections and privacy breaches***

This research documents how privacy concerns influence the healthcare decisions of French patients. These concerns and expectations impact when, where and from which care providers patients seek medical treatment as well as their truthfulness with their provider regarding sensitive medical conditions due to privacy concerns. Additionally, the research maps the privacy expectations of the patient to healthcare practices and technologies employed to protect patient privacy as previously examined in FairWarning®'s report "[Industry Best Practices for Patient Privacy in Electronic Health Records,](#)" released April 15, 2011.

The Executive Overview Report highlights several noteworthy findings and reveals patient attitudes, expectations, and actions regarding the protection of privacy. Additionally, this report provides insights for care providers to change the course of care through the integration of privacy initiatives, the adoption of a privacy-based culture and effective communication with patients about privacy.

Executive Overview - Summary of Key Findings

Trust in the confidentiality of medical records is influencing when, where, from whom and what kind of medical treatment is delivered to patients. These privacy concerns affect the flow of information to providers to use in the diagnosis and care of their patients.

54.5 percent of French patients surveyed stated they would withhold information from their care provider based on privacy concerns. 22 percent stated they have postponed or would postpone seeking care for a sensitive medical condition due to privacy concerns. Nearly 1 out of 3 patients, 32.3 percent indicated they would seek care outside of their community due to privacy concerns with 40.1 percent indicating they would travel substantial distances, 50 kilometers or more, to avoid being treated at a hospital they did not trust, in order to keep sensitive information confidential. By withholding medical information, French patients are impacting the care received and hence the outcome. 41.2 percent of patients reported that, if there were serious or repeated breaches of patients' personal information at a hospital where they had treatment, it would reduce their confidence in the quality of healthcare offered by the hospital. More specific industry and academic research and study are required to fully appreciate the extent to which patient outcomes are influenced by privacy. Accurate information is the bedrock upon which physicians assess medical conditions, and hence determines the treatment patients receive. When this information is withheld or even falsified, fundamental treatment assumptions are impacted.

More than half of French patients stated that, if they had a sensitive medical condition, they would withhold information from their care provider. 1 out of 5 stated they would postpone seeking care out of privacy concerns.

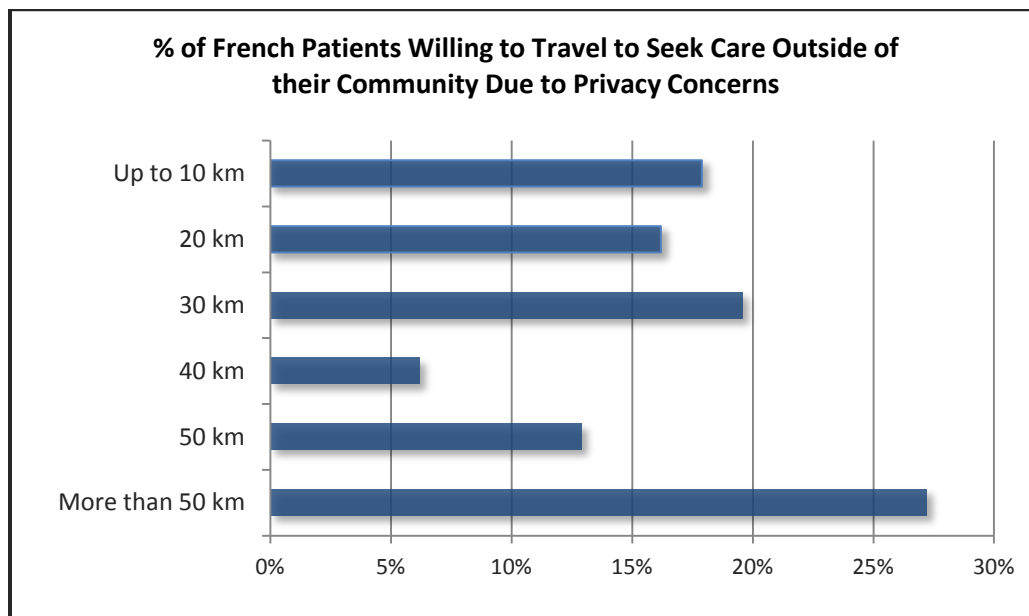


Figure 1. Patients' Willingness to Travel to Avoid Privacy Concerns

Patients expect healthcare providers and hospital executives to aggressively protect patient privacy. Patients have a significant negative response when privacy violations occur and expect healthcare executives to be held accountable for breaches.

92.8 percent of patients think that chief executives and top managers of healthcare providers have a legal and ethical responsibility to protect patients' medical records and private information from being breached. 90.6 percent of patients agreed that patient data security should be regularly discussed at board meetings to make sure that the chief executive and senior managers know of any risks, while 93.1 percent agreed that, where there are significant risks of privacy breaches, the chief executives and top management should take appropriate action to minimize or eliminate the risks. 89.6 percent of respondents stated that chief executives and top managers need to do more to stop unauthorized access to medical records, while 89.7 percent stated that healthcare providers should currently monitor who looks at medical records and detect unauthorized access to personal information. 90.8 percent of patients agreed that, if the chief executive and senior management were made aware of risks but failed to act and there is a serious breach, they should be fined or lose their jobs. 72.1 percent of poll respondents stated that there should be a public listing hosted by the French government that lists which hospitals have had breaches of patient health records.

9 out of 10 French patients stated that, if a healthcare executive knowingly failed to act to reduce the risk of breach and a breach occurs, they should be fined or fired.

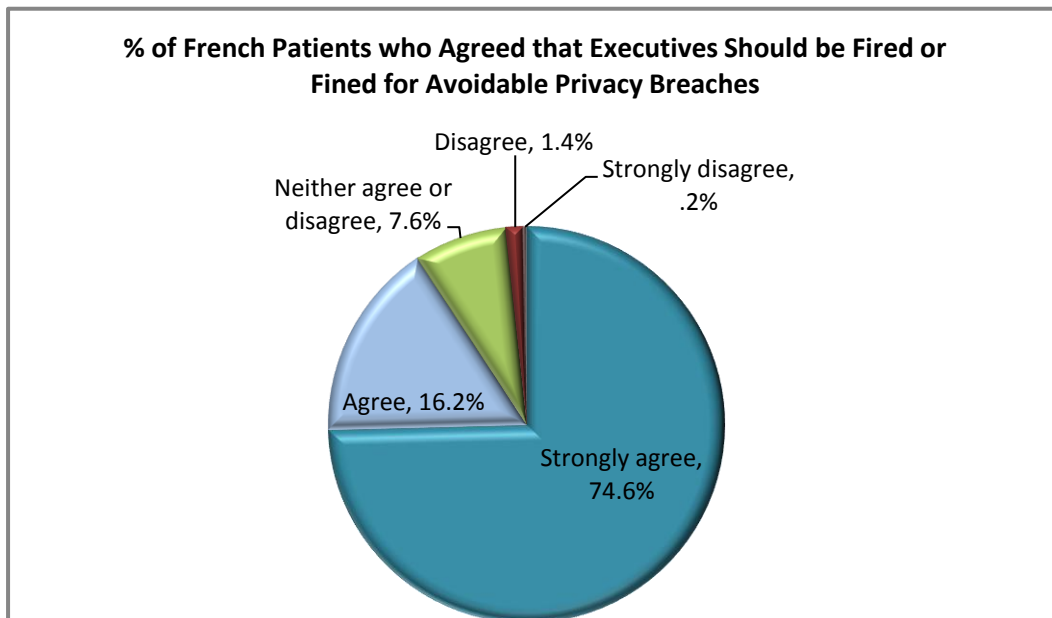


Figure 2. Patients call for executive accountability for privacy breaches

The majority of patients believe healthcare providers are committed to protecting their personal data however, patients report privacy breaches result in damage to the healthcare provider's reputation.

62.8 percent of patients agreed that healthcare providers are committed to protecting their privacy while 83.8 percent overall noted they have never been worried about the security of their personal information at a hospital or healthcare provider that has provided the patient treatment. On the contrary, 23.9 percent of patients, when specifically asked about privacy safeguards, stated they do not believe their hospital/healthcare provider has proper privacy safeguards.

Poll results revealed that leaks and theft of personal data could do significant damage to the reputation of the health service. 46.7 percent of patients stated that privacy breaches in health services reduce their trust in healthcare providers and hospitals. Of significant note, this question was not specific to breaches within their own provider but within health care overall. 85.2 percent of patients stated that, if there were breaches of patients' personal information at a specific hospital, the effect on their reputation would be considerable to severe. 41.2 percent stated that serious or repeated privacy breaches would reduce their confidence in the quality of care provided by a hospital while 61.3 percent stated that personal information breaches would make them want to seek treatment at another hospital.

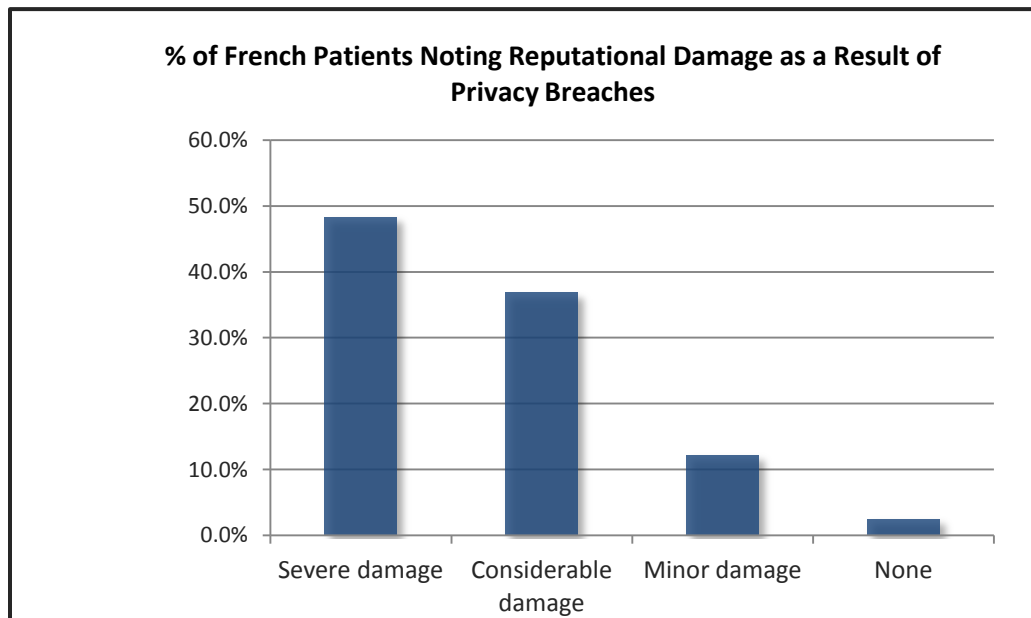


Figure 3. Patient perception of reputational damage as a result of privacy breaches

Patients who had experienced a breach of their private medical information validate industry studies on both the privacy vulnerabilities within healthcare and the consequences suffered by the victim as a result of a privacy breach.

4.4 percent of French patient respondents indicated they had been alerted or discovered on their own that their medical records had been compromised. The healthcare industry has long known that inappropriate accessing of patient records is most commonly perpetrated by healthcare provider staff. Polled patient victims of privacy breaches reported that in 33.3 percent of cases it was a family member who breached their records, in 21.4 percent of cases it was an unknown employee of the hospital or healthcare provider where the patient sought care, in 14.3 percent of cases it was a co-worker and in 7.2 percent of cases it was a friend who breached the record.

21 percent of respondents noted they did not experience any negative consequences of the breach. However, the remaining 79 percent of respondents noted the most common consequences they experienced as a result of the breach were, respectively:

- A sensitive medical issue was no longer private
- It required a significant amount of personal time to correct the situation
- They became the subject of gossip in their social circle or workplace
- The victim required account monitoring to ensure their identity was not compromised

Further academic and industry study is needed to more completely understand the emotional, financial, family and career impact to the lives of patients who have suffered loss of privacy. This subject is deserving of greater research regarding long-term impact.

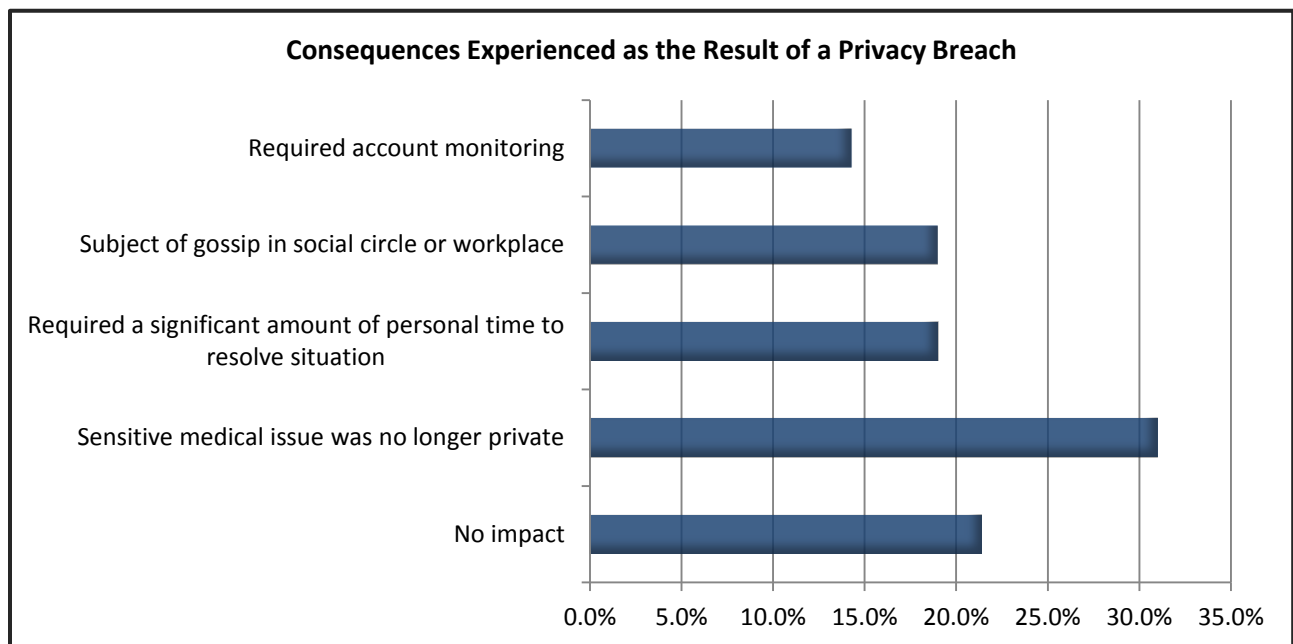


Figure 4. Patient Consequences Resulting from a Privacy Breach

Survey responses suggest the French population is technologically savvy and comprehensively aware of the benefits of electronic records over paper records, however, responses indicate strong emotions regarding potential risks of breaches.

92.7 percent of patients noted there are significant benefits to Electronic Health Records. The top four benefits noted are, respectively:

- It is easy for people to access patient records, 78.7 percent
- A patient's records can always be kept up to date, 75.7 percent
- Doctors can freely share patients' medical information with other medical professionals who need it for patient treatment, 65.9
- Healthcare providers can prevent people from seeing a patient's record without expressed permission from the patient, 22.9 percent

When asked about several possible negative consequences if patient records are breached, nearly 1 out of 2 French patients responded that they were very worried. 45.1 percent of patients stated they were very worried that criminals could use their name, address and other details to target them, their family or their home, while an additional 23.2 percent stated they were worried. 43.9 percent of patients stated they were very worried that their identity could be stolen and used to commit fraud, while an additional 24.6 noted they were worried.

Nearly 1 out of 2 French patients noted they were very worried about the negative consequences of a privacy breach.

Global comparative data is detailed in the Complete Survey Findings Section.

Complete Survey Findings

Trust in the confidentiality of medical records is influencing when, where, from whom and what kind of medical treatment is delivered to French patients. Patients demonstrate that privacy concerns impact how quickly they seek care, the medical information they share with their provider, and from whom they seek care. These privacy concerns affect how providers can diagnose medical conditions and deliver appropriate care.

- 54.5 percent of patients stated they would withhold information from their care provider based on privacy concerns
- 22 percent stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns.
- Nearly 1 out of 3 patients indicated they would seek care outside of their community due to privacy concerns, with 40.1 percent indicating they would travel a substantial distance, 50 km or more, to avoid being treated at a hospital they did not trust in order to keep sensitive information private.
- 41.2 percent of patients reported that, if there were serious or repeated breaches of patients' personal information at a hospital where they had treatment, it would reduce their confidence in the quality of healthcare offered by the hospital.

Patients expect healthcare providers and hospital executives to aggressively protect patient privacy. Patients have a significant negative response when privacy violations occur and expect healthcare executives to be held accountable for breaches.

- 92.8 percent of patients think that chief executives and top managers of healthcare providers have a legal and ethical responsibility to protect patients' medical records and private information from being breached.
- 90.6 percent of patients agreed that patient data security should be regularly discussed at board meetings to make sure that the chief executive and senior managers know of any risks.
- 93.1 percent agreed that, where there are significant risks of privacy breaches, the chief executives and top management should take appropriate action to minimize or eliminate the risks.
- 89.6 percent of respondents stated that chief executives and top managers need to do more to stop unauthorized access to medical records.
- 89.7 percent stated that healthcare providers should currently monitor who looks at medical records and detect unauthorized access to personal information.
- 90.8 percent of patients agreed that, if the chief executive and senior management were made aware of risks but failed to act and there is a serious breach, they should be fined or lose their jobs.
- 72.1 percent of poll respondents stated that there should be a national league table showing which hospitals have the most breaches of patient health records.

- When a care provider suffers a major privacy breach or a series of privacy breaches, 85.2 percent of survey respondents stated it damages or severely damages the reputation of the care provider, while 12.2 percent noted it mildly damages the provider’s reputation.

French patients who had experienced a breach of their private medical information validate industry studies on both the privacy vulnerabilities within healthcare and the consequences suffered by the victim as a result of a privacy breach.

- 4.4 percent of patient respondents indicated they had been alerted their medical records had been compromised.
- The top four consequences of the breach most commonly reported included (1) a sensitive medical issue was no longer private, (2) it required a significant amount of personal time to resolve the situation, (3) the patient became the subject of gossip in their social circle or workplace, and (4) the patient required account monitoring to ensure their identity was not compromised.
- 21 percent of respondents noted they did not experience any negative consequences as a result of the breach.
- 19 percent of victims were notified immediately by the healthcare provider, 21.4 percent were notified within 30 days. 9.8 percent of victims were alerted between 30 and 60 days. 40.5 percent of breach victims reported they were not alerted but rather discovered the breach on their own.
- Polled patient victims of privacy breaches reported that in 33.3 percent of cases it was a family member that breached their records; in 21.4 percent of cases it was an unknown employee of the hospital or healthcare provider where the patient sought care; 14.3 percent of cases it was a co-worker and in 7.2 percent of cases it was a friend who breached the record. These numbers are consistent with industry studies on healthcare privacy breaches ([Best Practices & Breach Findings Report](#)).
- Less than half, 42.9 percent of the victims stated they were satisfied with the care provider’s resolution of the breach.

Survey responses reveal the French population is technologically savvy and comprehensively aware of the benefits of electronic records over paper records, however, responses indicate strong emotions regarding potential risks of breaches.

- 92.7 percent of patients noted there are significant benefits to electronic health records. The top four benefits noted are respectively:
 - It is easy for people to access patient records, 78.7 percent
 - A patient’s records can always be kept up to date, 75.7 percent
 - Doctors can freely share patients’ medical information with other medical professionals who need it for patient treatment, 65.9 percent
 - Healthcare providers can prevent people from seeing a patient’s record without expressed permission from the patient, 22.9 percent

- Nearly 1 out of 2 French patients responded that they were very worried about the specific consequences of a privacy breach notably, 45.1 percent of patients stated they were very worried that criminals could use their name, address and other details to target them, their family or their home, while an additional 23.2 percent stated they were worried.
- 43.9 percent of patients stated they were very worried that their identity could be stolen and used to commit fraud while an additional 24.6 percent noted they were worried.

Patients have high expectations with regard to care providers' confidential treatment of their medical records and care providers have an opportunity to change the course of patient care by utilising best practices for protecting patient privacy and initiating a dialog with patients regarding how they proactively protect patient privacy.

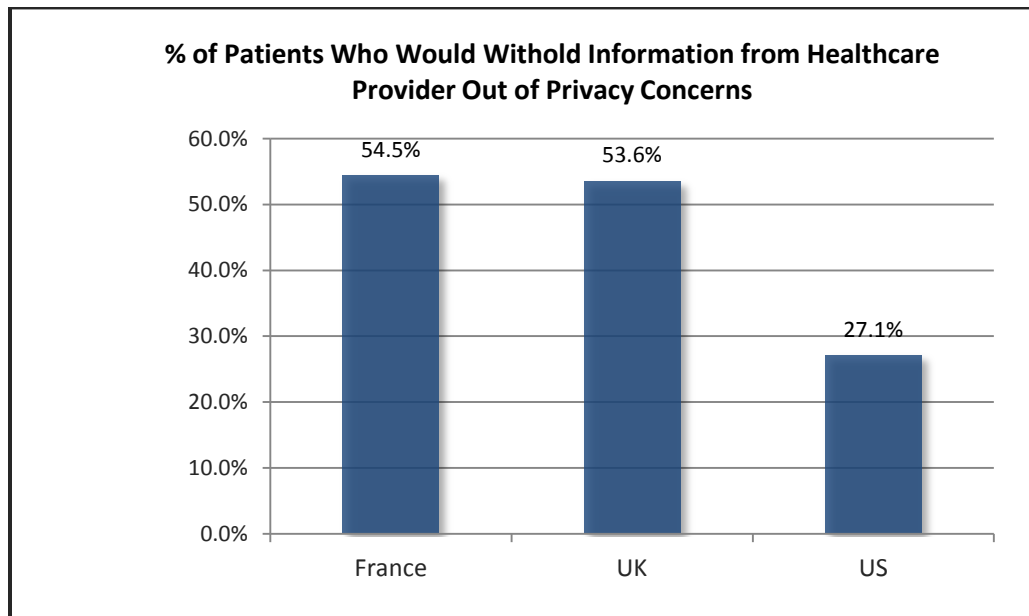
- 67 percent of French patients stated they are confident that their healthcare providers are protecting their medical records and patient privacy.
- 76.1 percent of respondents stated they believe that their care providers have safeguards in place to protect private medical information and 62.8 percent of patients believe that healthcare providers are committed to protecting patient privacy.
- 89.6 percent of patients agreed that chief executives and top managers need to do more to stop unauthorized access to medical records.
- However, the majority of poll respondents agreed healthcare providers should deliver the following in an effort to meet the high patient expectations to ensure confidentiality:
 - Make staff aware of the importance of patient privacy, 88.4 percent of patients
 - Monitor who looks at medical records to detect unauthorized access to personal patient information, 89.7 percent of patients
 - Communicate to patients regarding inappropriately accessed records, 89.3 percent
 - Effectively resolve a privacy breach in a timely manner, 90.9 percent
- Patients noted that the top three actions that health providers can take to make them feel as though they take patient privacy seriously are respectively:
 - 77.2 percent of patients indicated that a clear and consistent communication to staff regarding what constitutes inappropriate access to patient records, quick resolution of any privacy incident
 - 47.3 percent indicated they would feel that healthcare providers take privacy seriously if they were to make sure electronic records systems are monitored to identify and stop privacy breaches.
 - 41.2 percent of patients stated that open communication with patients regarding privacy efforts would make them feel that their care provider takes patient privacy seriously.

Survey data indicates that patients have a strong belief in the rule of law relative to ensuring healthcare privacy. A substantial majority of respondents also indicated that greater enforcement and sanctioning would provide a greater impetus for healthcare providers to take privacy more seriously.

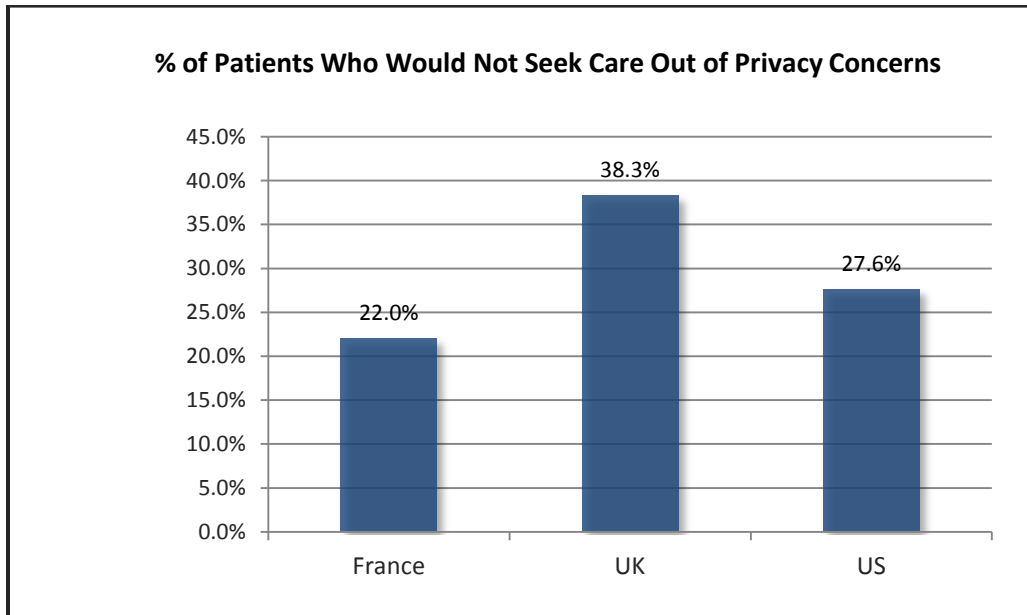
- 71.1 percent of patients agreed that existing laws are enough to ensure that healthcare providers protect the patient however 80.4 percent of patients agreed or strongly agreed that new and stronger laws are needed to *guarantee* the privacy of patient information.
- 85.1 percent of patients stated that stronger enforcement of existing data protection laws would result in fewer privacy breaches.
- 92.2 percent of patients believe healthcare providers and hospitals must make sure they uphold data protection laws.

France, US and UK Comparative Data and Findings Highlights

A universal finding in the France, US and UK surveys is that trust in the confidentiality of medical records is influencing when, where, from whom and what kind of medical treatment is delivered to patients regardless of geographies. However, the extent to which these privacy concerns affect the flow of information to providers to use in the diagnosis and care of their patients varies. French and UK patients are almost twice as likely as US patients to withhold information from their care provider about a sensitive personal medical matter if they had as poor a record of protecting patient privacy as their American counterparts.



Additionally, patients were asked if they have or would put off seeking care for a sensitive medical issue. In France, 2 out of 10 French patients indicated postponing care, in the US, 3 out of 10 and in the UK nearly 4 out 10. This finding suggests that French patients and US patients believe obtaining medical care is more important than the risks associated with privacy violations however, it still has substantial impact on the population and medical outcomes if even one patient fails to seek the care they need.



A significant finding across the France, UK and US surveys is that patients believe care providers are ethically and legally obligated to protect privacy however, in France and the UK, patients indicated that they feel more strongly than US citizens about the degree to which executives and top managers should be held accountable for protecting patient privacy in the case of a breach.

92.8 percent of French patients, 97.1 percent of UK patients and 97.2 percent of US patients stated that chief executives and healthcare providers have a legal and ethical responsibility to protect patients' medical records and private information from being breached. 90.8 percent of French patients and 87.1 percent of UK patients agreed that, if a chief executive and senior management were made aware of risks but failed to act and there is a serious breach, they should be fined or lose their job. Comparatively, only 27 percent of US patients noted that termination was an appropriate sanction for inappropriate access to the patient record for curiosity purposes versus 32.4 percent who stated it was an appropriate sanction if the intent was to do harm or use the record for personal gain.

Survey Observations, Analysis and Further Research

- Further research and discussion regarding how privacy concerns are changing the course of care, including exploration of the concept that French patients are withholding medical information, traveling outside of their community and delaying care based on privacy concerns. This is the key finding of the report.
- Further discussion should explore to what degree French patients feel executives should be held accountable for privacy breaches. The discussion should address law making, formalized fines and sanctions and explore how these laws/rules will be enforced both at a governmental level at within the healthcare provider.
- Further research and discussion of how care providers can leverage the privacy work they have already initiated and integrated to demonstrate to patients their level of commitment to privacy.
- The survey demonstrated that a segment of respondents fundamentally trust care providers to do the right things with regard to privacy, but react quite emotionally when surprised by a privacy violation.

Appendix 1

In September 2011, **FairWarning®** commissioned Vanguard Software and New London Consulting to develop a survey of French patients of care providers to determine how ***patient privacy considerations impact the actual delivery of healthcare and to what degree patients believed healthcare executives and managers should be held accountable for healthcare privacy protections and breaches.*** The survey was designed to garner a baseline understanding of patient beliefs relative to a care providers' legal, ethical and moral responsibility to protect patient privacy. More importantly, the survey sought to measure how privacy considerations affect patient behaviors and decisions and influence patient care outcomes.

The survey was conducted using an online platform. Survey invitations were sent to more than 1,500 patients across France including metropolitan and rural regions. The survey resulted in responses from participants of varying educational level, economic class, age and gender. The survey invitation resulted in participation of 1,002 respondents. The survey was live for 6 days.

Gender

Female	61.3 percent
Male	38.7 percent

Education Level

Sans diplôme	3.0 percent
Brevet des colleges	7.3 percent
CAP/BEP (autres diplômes techniques)	23.0 percent
Bac (général, pro et technologique)	25.6 percent
Bac+2 (BTS ou autre)	20.6 percent
Bac+3/4 (Licence, Maîtrise)	14.9 percent
Bac+5 (Master, écoles d'ingénieur, écoles de commerce.)	5.1 percent
Bac+7 et plus (Doctorat, post-doc, thèse)	0.6 percent