



Canada: 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 October 2011, FairWarning® commissioned New London Consulting to develop a survey of Canadian 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 results of the survey provide baseline measurements of attitudes and actions of Canadian patients. These findings will be retested within 12 months to provide benchmarks for changes in attitudes. It is expected that patient responses will change as a result of any or all of the following factors:

- Media coverage of privacy breaches
- Institution of additional healthcare privacy laws
- Increased enforcement or lax enforcement of privacy laws
- Patient awareness and education around individual privacy rights
- Widespread adoption of Electronic Health Records (EHRs)

The results will also be used for a global comparison of attitudes and actions of patients in multiple countries including the United States, throughout the United Kingdom, France and Australia.

The Canadian survey was conducted using an online platform. Survey invitations were sent to 20,937 patients across Canada. Invitations to participate were sent to residents of all provinces in Canada 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 1002 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 Canadian patients' healthcare decisions and, more specifically, to 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 Canadian patients. These concerns and expectations impact when, where and from which care providers patients seek medical treatment as well as their truthfulness with their providers 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 in Canada. These privacy concerns affect the flow of information to providers to use in the diagnosis and care of their patients.

43.2 percent of Canadian patients stated they have withheld or would withhold information from their care provider based on privacy concerns. 31.3 percent stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns. More than 2 out of 5 Canadian patients, 42.9 percent indicated they would seek care outside of their community due to privacy concerns, with 33.7 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, Canadian patients are impacting the care received and hence the outcome.

Nearly half of Canadian patients surveyed stated that if they had a sensitive medical condition, they would withhold information from their care provider. 2 out of 5 stated they would postpone seeking care out of privacy concerns.

Patient treatment in modern healthcare is entirely information-based. Any friction in the free flow of information between care providers and patients, such as that caused by privacy concerns, prevents the patient from receiving the best possible care. Canadian responses indicate that there is more work to be done to enable the free flow of pertinent medical information, and thus the best patient care outcomes.

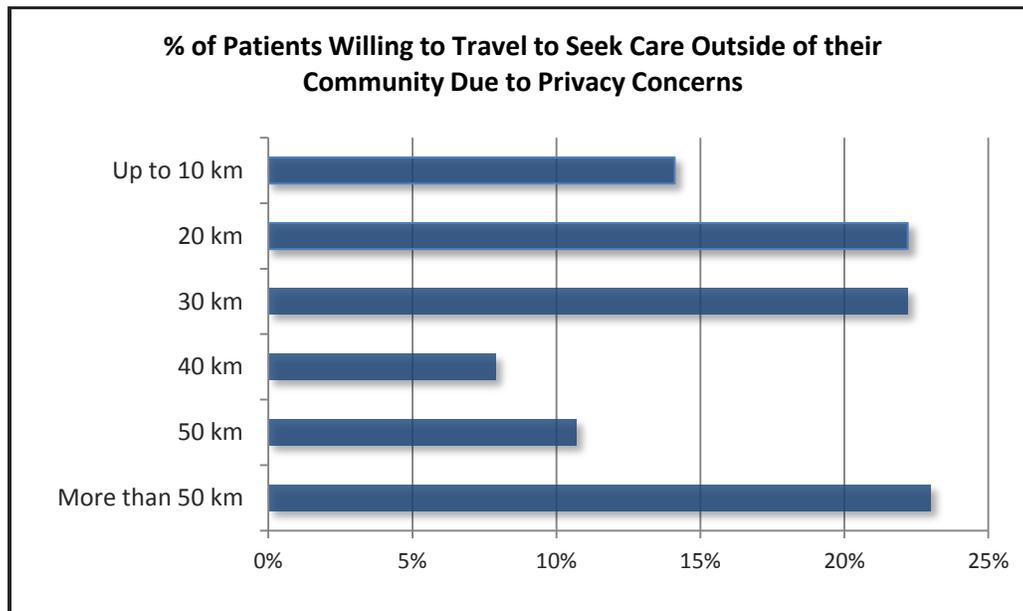


Figure 1. Patients' Willingness to Travel to Avoid Privacy Concerns

61.9 percent of Canadian 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.

Canadian 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.

98.0 percent of Canadian 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. 83.5 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 90.6 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. 77.1 percent of respondents stated that chief executives and top managers need to do more to stop unauthorized access to medical records, while 89.5 percent stated that healthcare providers should currently monitor who looks at medical records and detect unauthorized access to personal information.

83.9 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 (*see Figure 2 on following page*). 69.5 percent of Canadian respondents stated that there should be a public listing hosted by the Canadian government that lists which hospitals have had breaches of patient health records.

More than 4 out of 5 Canadian 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.

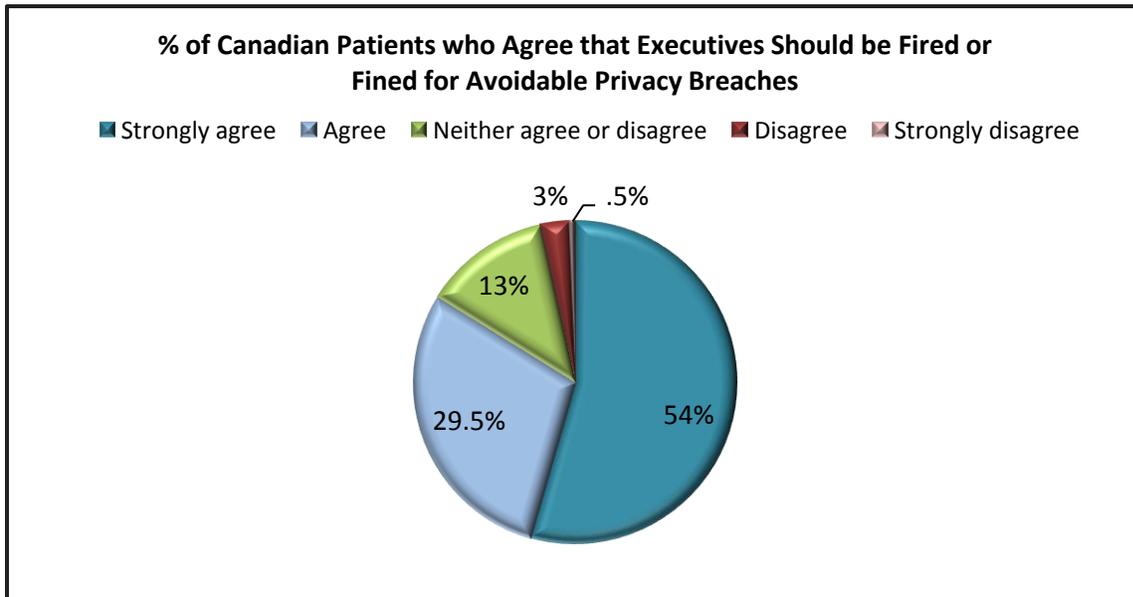


Figure 2. Canadian patients call for executive accountability for privacy breaches

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

73.6 percent of Canadian patients agreed that healthcare providers are committed to protecting their privacy and 83.6 percent noted they have never been worried about the security of their personal information at a hospital or healthcare provider where they sought care. 68.5 percent overall noted they believe healthcare providers are good at stopping patient information from being lost, stolen or accessed by unauthorized people. However, 20.8 percent of Canadian 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. 75.4 percent of patients stated that a healthcare provider’s reputation influences their choice to seek care from that provider. 77.4 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. 61.9 percent of patients stated that, if there were breaches of patients’ personal information at a hospital, it would make them think the hospital was poorly managed.

More than 3 out of 4 Canadian patients surveyed stated that a breach of patients’ personal information would cause considerable to severe damage to the Canadian health provider’s reputation.

41.2 percent stated that serious or repeated privacy breaches would reduce their confidence in the quality of care provided by a hospital, while 50.6 percent stated that if they were going to a hospital for treatment and discovered there had been breaches of personal information about patients, they would choose to be treated at another hospital.

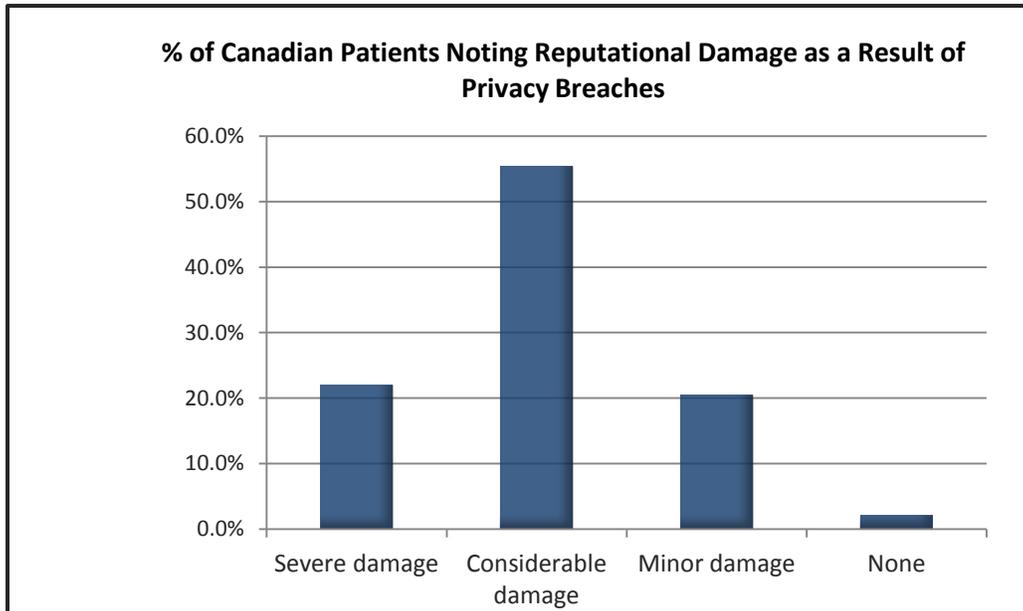


Figure 3. Patient perception of reputational damage as a result of privacy breaches

Survey data reveals that Canadian patients have a strong belief that additional privacy laws and greater enforcement of privacy laws would provide a greater impetus for healthcare providers to take privacy more seriously.

A majority, 59.2 percent of Canadian patients stated that new and stronger laws are needed to guarantee the privacy of patient information. 74.7 percent of patients agreed that stronger enforcement of existing data protection laws would result in fewer privacy breaches. The majority of Canadian patients, 52.2 percent stated that they do not believe the laws to protect patient privacy are properly enforced. Canadian patients noted that healthcare providers and hospitals should be held responsible for following the law. 89.8 percent agreed that healthcare providers and hospitals must uphold the data protection laws currently in place.

3 out of 4 Canadian patients surveyed believe stronger enforcement of existing privacy protection laws would reduce the number of privacy breaches.

Canadian 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.

3.7 percent of Canadian 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 in Canada reported that in 18.9 percent of cases, it was an unknown employee of the hospital or healthcare provider where the patient sought care, in 10.8 percent of cases it was a family member that breached their records, in 10.8 percent of cases it was a friend, in 5.4 percent of cases it was a member of a crime ring or criminal, and in 2.7 percent of cases it was a co-worker. In 43.2 percent of cases the perpetrator is still unknown.

56.8 percent of respondents noted they suffered negative consequences as a result of the breach. The most common consequences they experienced as a result of the breach were respectively:

- Victim became the subject of gossip in their social circle and/or workplace (24.3 percent)
- Sensitive medical issue was no longer private (13.5 percent)
- Required significant amount of personal time to correct the situation (13.5 percent)
- Private information was used against me in a lawsuit (13.5 percent)
- Victim of identity theft (10.8 percent)
- Inaccurate medical information added to my record (10.8 percent)

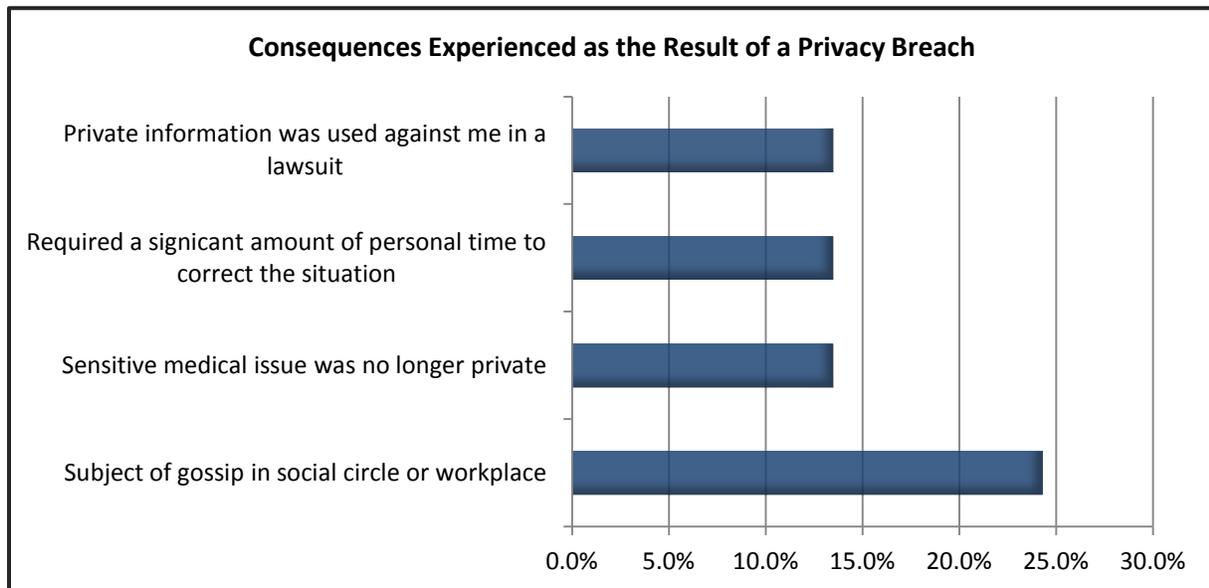


Figure 4. Canadian Patient Consequences Resulting from Privacy Breach

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.

Complete Survey Findings

Trust in the confidentiality of medical records is influencing when, where, who and what kind of medical treatment is delivered to Canadian patients. Canadian 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 Canadian providers can diagnose medical conditions and deliver appropriate care.

- 43.2 percent of Canadian patients stated they would withhold information from their care provider based on privacy concerns
- 31.3 percent stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns.
- More than 2 out of 5 Canadian patients indicated they would seek care outside of their community due to privacy concerns with 33.7 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.
- 61.9 percent of Canadian 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.

Canadian 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.

- 98.0 percent of Canadian 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.
- 83.5 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.
- 90.6 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.
- 77.1 percent of Canadian respondents stated that chief executives and top managers need to do more to stop unauthorized access to medical records.
- 89.5 percent stated that healthcare providers should currently monitor who looks at medical records and detect unauthorized access to personal information.

- 83.9 percent of Canadian 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.
- 69.5 percent of Canadian poll respondents stated that there should be a public listing hosted by the Canadian government of which Canadian hospitals have the most breaches of patient health records.

The majority of Canadian 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.

- 73.6 percent of patients agreed that healthcare providers are committed to protecting their privacy and 83.6 percent note they have never been worried about the security of their personal information at a hospital or healthcare provider where they sought care.
- 68.5 percent overall noted they believe healthcare providers are good at stopping patient information from being lost, stolen or accessed by unauthorized people. However, 20.8 percent of Canadian patients, when specifically asked about privacy safeguards, stated they do not believe their hospital/healthcare provider has proper privacy safeguards.
- 75.4 percent of Canadian patients stated that a healthcare provider’s reputation influences their choice to seek care from that provider.
- When a care provider suffers a major privacy breach or a series of privacy breaches, 77.4 percent of Canadian patients stated the effect on the Canadian care provider’s reputation would be considerable to severe, while an additional 20.5 noted that the hospital would sustain minor reputational damage.
- 61.9 percent of Canadian patients stated that if there were breaches of patients’ personal information at a hospital, it would make them think the hospital was poorly managed.
- 41.2 percent stated that serious or repeated privacy breaches would reduce their confidence in the quality of care provided by a Canadian hospital while 50.6 percent stated that if they were going to a hospital for treatment and discovered there had been breaches of personal information about patients, they would choose to be treated at another hospital.

Survey data reveals that Canadian patients have a strong belief that additional privacy laws and greater enforcement of privacy laws would provide a greater impetus for healthcare providers to take privacy more seriously.

- 59.2 percent of Canadian patients stated that new and stronger laws are needed to guarantee the privacy of patient information.
- 74.7 percent of Canadian patients agreed that stronger enforcement of existing data protection laws would result in fewer privacy breaches.
- The majority of Canadian patients, 52.2 percent stated that they do not believe the laws to protect patient privacy are properly enforced.
- Canadian patients noted that healthcare providers and hospitals should be held responsible for following the law. 89.8 percent agreed that healthcare providers and hospitals must uphold the data protection laws currently in place.

Canadian 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.

- 3.7 percent of Canadian patient respondents indicated they had been alerted their medical records had been compromised.
- The most common consequences of the breach most commonly reported included: the victim became the subject of gossip in their social circle and/or workplace; a sensitive medical issue was no longer private; it required a significant amount of personal time to correct the situation; and private information was used against the victim in a lawsuit.
- 43.2 percent of respondents noted they did not experience any negative consequences as a result of the breach.
- 16.2 percent of victims were notified immediately by the healthcare provider, 18.9 percent were notified within 30 days. 16.2 percent of victims reported they were alerted between 30 and 60 days. 24.3 percent of breach victims reported they were not alerted, but rather discovered the breach on their own.
- Canadian polled patient victims of privacy breaches reported that in 18.9 percent of cases, it was an unknown employee of the hospital or healthcare provider where the patient sought care, in 10.8 percent of cases it was a family member that breached their records, in 10.8 percent of cases it was a friend, in 5.4 percent of cases it was a member of a crime ring or criminal, and in 2.7 percent of cases it was a co-worker. In 43.2 percent of cases the perpetrator is still unknown. These numbers are consistent with industry studies on healthcare privacy breaches ([Best Practices & Breach Findings Report](#)).

- Less than half, 35.1 percent of the victims stated they were satisfied with the Canadian care provider's resolution of the breach.

Survey responses reveal Canadian patients are aware of the benefits of electronic records and are most aware and worried of the negative consequences of breached records, relative to criminal use.

- 96 percent of patients noted there are significant benefits to electronic health records. The top four benefits noted are respectively:
 - Doctors can freely share patients' medical information with other medical professionals who need it for patient treatment, 85.9 percent
 - A patient's records can always be kept up to date, 76.2 percent
 - It is easy for people involved in my care to access patient records, 68.7 percent
 - Healthcare providers can prevent people from seeing a patient's record without expressed permission from the patient, 24.2 percent
- Nearly 1 out of 2 Canadian 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.
- When asked about some possible negative consequences in patient records being breached, 59.6 percent of patients noted they were worried their identity could be stolen and used to commit fraud while 56 percent noted they were worried criminals could use their name, address and other details to target the patient, their family or their home.

Canadian 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 utilizing best practices for protecting patient privacy and initiating a dialog with patients regarding how they proactively protect patient privacy.

The majority of Canadian 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, 90.9 percent of patients
- Monitor who looks at medical records to detect unauthorized access to personal patient information, 89.8 percent of patients

- Communicate to patients regarding inappropriately accessed records, 89.5 percent
- Effectively resolve a privacy breach in a timely manner, 91.3 percent
- Quickly tell me who has accessed my records if I ask, 88.6 percent

Patients noted that the top four actions that health providers can take to make them feel as though they take patient privacy seriously are, respectively:

- 76.8 percent indicated if healthcare providers were to ensure electronic records systems are monitored to identify and stop privacy breaches
- 75.0 percent of Canadian patients stated that if patient data is encrypted so stolen information cannot be used
- 70.6 percent of patients stated that if there is good staff training on data protection laws
- 67.7 percent stated that if there are swift investigations into unauthorized accessing of patient records
- 53.4 percent of Canadian patients stated that open communication with patients regarding privacy efforts would make them feel that their care provider takes patient privacy seriously.
- 60.6 percent of Canadian patients noted that if their healthcare provider experienced a privacy breach and they learned of it through the media, they would no longer seek care from that provider whereas, if the provider was the first to notify the patient, only 10.6 percent indicated they would no longer seek care from that provider.

Nearly 4 out of 5 Canadian patients noted that they would feel as though their care provider took patient privacy seriously if they were to ensure electronic records systems were monitored to identify and stop privacy breaches.

Survey Observations, Analysis and Further Research

- Further research and discussion are needed regarding how privacy concerns are changing the course of care, including exploration of the concept that 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 Canadian 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 and within the healthcare provider.
- Further benchmark research is needed to assess the impact of Canadian governmental enforcement on privacy protections on the attitudes of patients relative to their beliefs that their personal data is safe and secure.
- Further recommendations are needed for how Canadian 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 note significant reputational damage to the care provider when a breach occurs.

Appendix 1

In October 2011, FairWarning® commissioned New London Consulting to develop a survey of Canadian 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.

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Gender

Female	49.5 percent
Male	50.5 percent

Education Level

Graduate education	7.6 percent
University education	7.3 percent
College education	26.8 percent
Trade certificate or diploma	12.3 percent
High school education	25.0 percent
Less than a high school education	3.5 percent

Regions Represented

Alberta	11.7 percent
British Columbia	17.0 percent
Manitoba	4.0 percent
New Brunswick	2.4 percent
Newfoundland and Labrador	1.8 percent
Nova Scotia	2.5 percent
Ontario	42.7 percent
Prince Edward Island	0.4 percent
Quebec	14.3 percent
Saskatchewan	3.0 percent
Northwest Territories	0 percent
Nunavut	0 percent
Yukon	0.1 percent