



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 mid 2011, **FairWarning®** commissioned New London Consulting to develop a survey of U.S. consumers, or patients, of care providers to determine how ***patient privacy considerations impact the actual delivery of healthcare***. 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 10,000 consumers across the United States. Invitations to participate were sent to a population that mirrors U.S. census demographics relative to race, economic class, age and gender. The survey invitation resulted in participation of 1265 respondents. The survey was live for approximately 120 days. The full survey methodology is detailed in Appendix 1.

Of special note, 59.6 percent of respondents were women. According to a U.S. Department of Labor report, women make 80 percent of the healthcare decisions for their families. Statistically, responses garnered in this survey approximate an accurate picture of what influences the decision making process relative to healthcare and where and from whom medical treatment is delivered to the household.

Purpose of the Survey

A series of 29 questions were posed that sought to reveal how privacy concerns impact patients' healthcare decisions and more specifically measure to what degree:

- ***Privacy considerations influence who patients seek care from***
- ***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***

This research documents how privacy concerns influence the healthcare decisions of U.S. 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, who 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.

85.2 percent of participants indicated that if they had a sensitive medical condition, a care provider's reputation for protecting privacy would influence their choice to seek care from that provider. 27.1 percent of patients stated they would withhold information from their care provider based on privacy concerns. 27.6 percent stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns. More than 1 out of 2 patients indicated they would seek care outside of their community due to privacy concerns with 35 percent indicating they would travel more than 50 miles. By withholding medical information, patients are impacting the care received and hence the outcome. More specific industry and academic research and study is 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 1 out of 4 patients stated that if they had a sensitive medical condition, they would withhold information from their care provider or postpone seeking care out of privacy concerns.

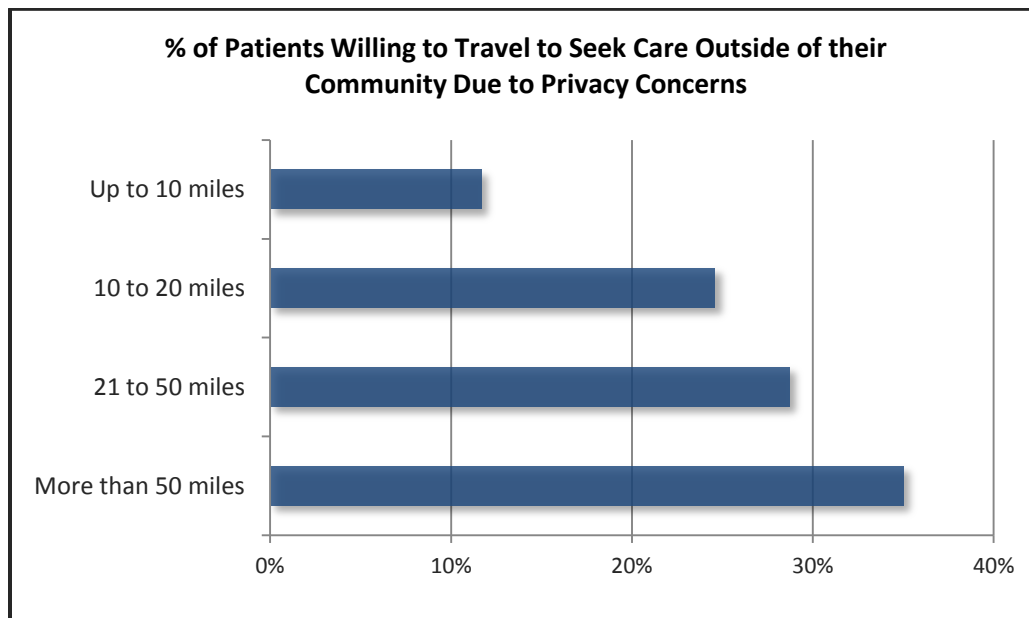


Figure 1. Patients Willingness to Travel to Avoid Privacy Concerns

Consumers have a significant negative response when a privacy violation occurs. This break in trust results in patient attrition and damage to the provider’s reputation.

When privacy violations occur within their care provider, patients have a significant negative response and report that their initial reaction was intent to stop seeking care ranging from 19.1 percent to 61.4 percent. Intent to stop seeking care is three times greater, 64.1 percent versus 19.1 percent when the patient learns of the breach through the media rather than the provider.

84.8 percent of patients that a care provider’s reputation is a significant consideration when choosing a provider. When a care provider suffers a major privacy breach or a series of privacy breaches, 74.2 percent of survey respondents state it damages or severely damages the provider’s reputation, while 21.8 percent note it mildly damages the provider’s reputation. The damage to the provider’s reputation will have a negative impact on the growth of the medical practice and likely result in loss of patients.

60 percent of patients who were victims of a privacy breach no longer seek care from that care provider.

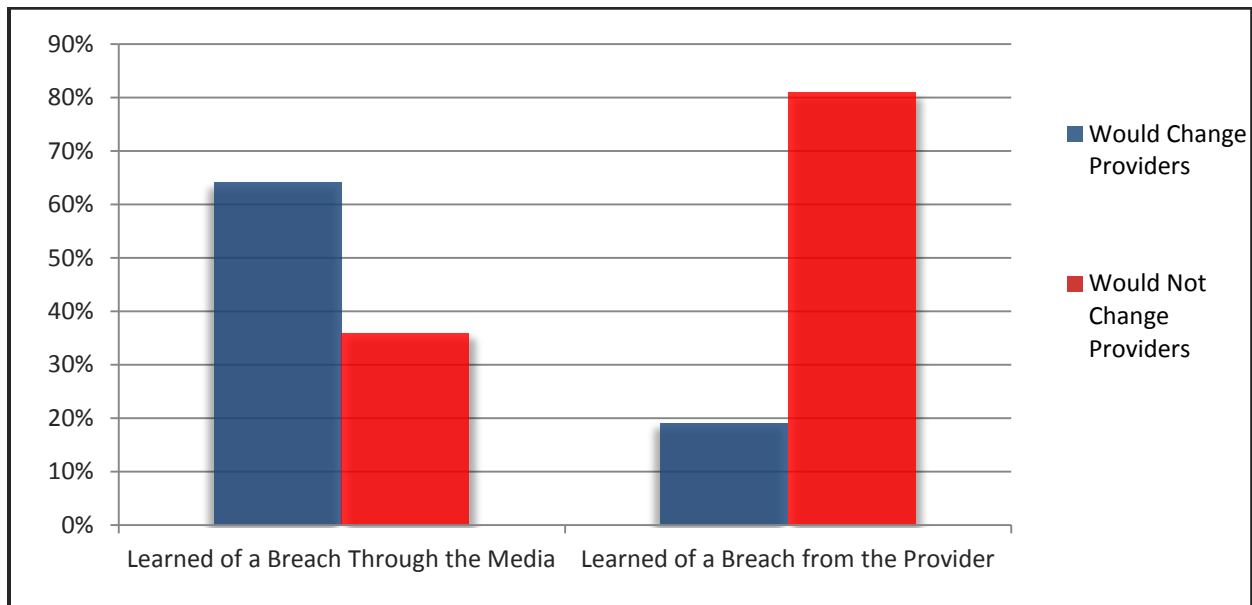


Figure 2. Intention to Change Providers over Source of Breach Notification

Patients who had experienced a breach of their private medical information validated the attitudes and anticipated actions of non-breached respondents. The consequences of the breach they experienced also validates industry studies on the patient impact of a privacy breach.

6 percent of patient respondents indicated they had been alerted their medical records had been compromised. As a result of the breach, 60 percent indicated they no longer seek care from that provider. These respondents note that when alerted initially, the top three consequences of concern included: identity theft, leaking of sensitive medical/personal information and medical identity theft.

The top three consequences of the breach most commonly reported included:

- A sensitive medical issue was no longer private
- The patient required credit monitoring to ensure their identity was not compromised
- The patient became the victim of identity and/or medical identity theft.

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.

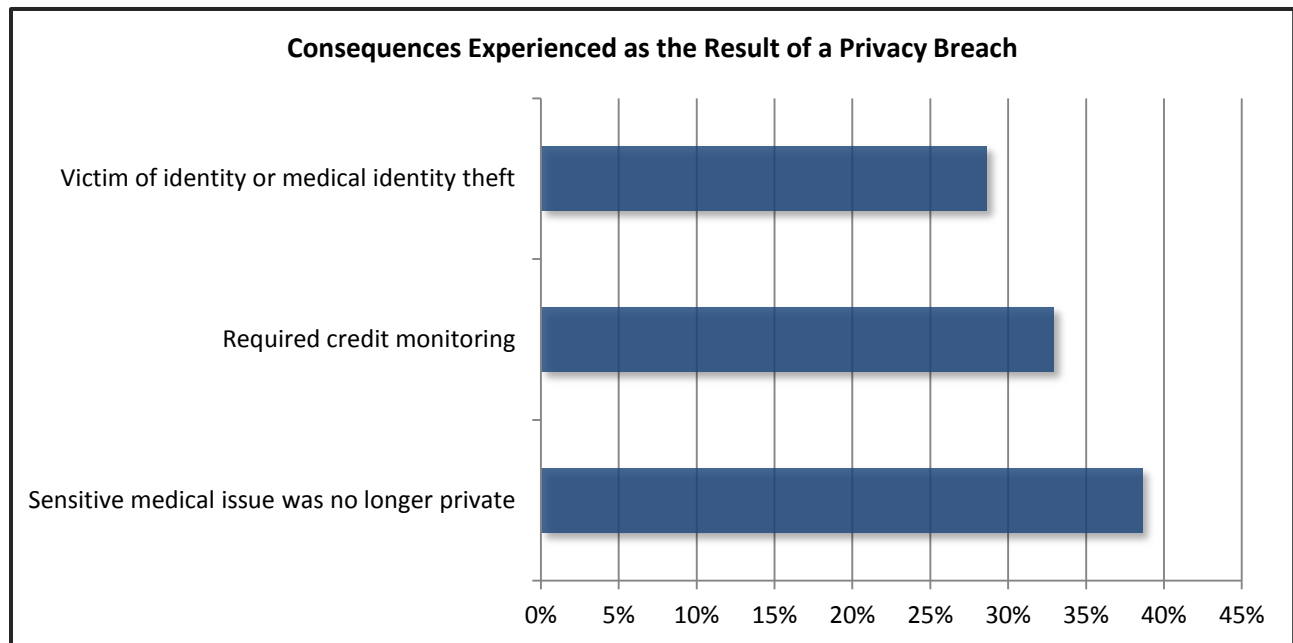


Figure 3. Patient Consequences Resulting from Privacy Breach

Breach victims reported that in 21.4 percent of cases a family member breached their records and in 20 percent of cases, it was an employee of the care provider.

Survey results suggest that providers who embrace a culture of privacy have an opportunity to positively influence choice of provider by patients with sensitive medical conditions.

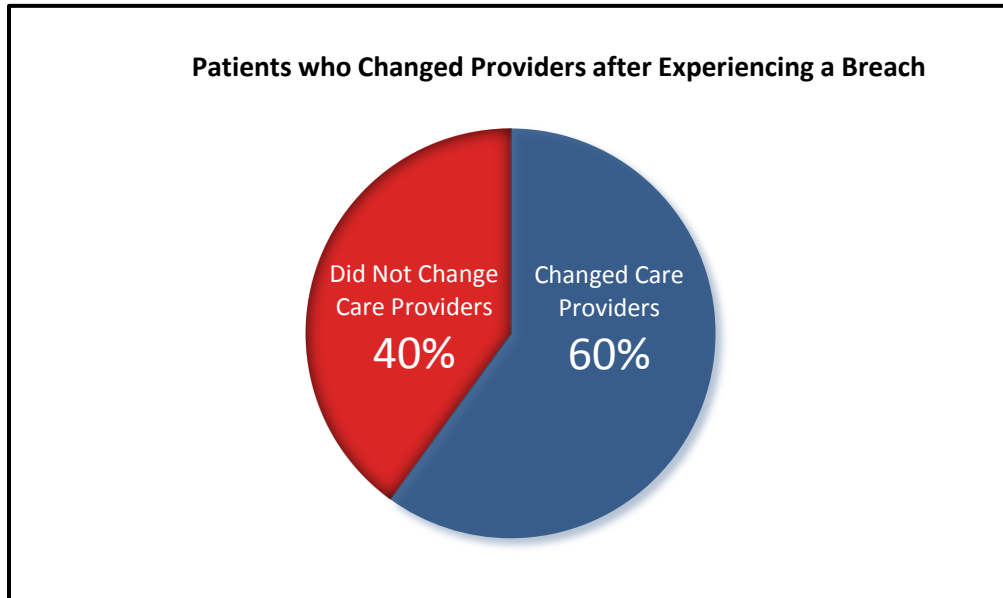


Figure 4. Patients Who Actually Changed Providers

Complete Survey Findings

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

- 85.2 percent of participants indicated that if they had a sensitive medical condition, a care provider's reputation for protecting privacy would influence their choice to seek care from that provider.
- 27.1 percent of patients stated they would withhold information from their care provider based on privacy concerns
- 27.6 percent stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns.
- More than 1 out of 2 patients indicated they would seek care outside of their community due to privacy concerns with 35 percent indicating they would travel more than 50 miles. An additional 28.7 percent of patients noted they would travel between 20 and 50 miles.
- 58.8 percent of patients report that their belief that their care provider keeps their information private influences their choice to seek care from that provider.
- The reputation of a care provider ranked as the most consistent influencer, with 84 percent of patients noting a provider's reputation influences their choice to seek care from that provider.
- 74.2 percent of patients assert that if a care provider suffers a major privacy breach or series of privacy breaches, the provider's reputation will be damaged or severely damaged.

When privacy violations occur, patients have a strongly negative response to the care provider particularly when they learn of the breach through the media.

- When privacy violations occur within their care provider, patients have a significant negative response and report high levels of attrition ranging from 19.1 percent to 61.4 percent.
- 64.1 percent of patients indicated that if their care provider suffered a privacy breach and the patient learned of the breach in the media, they would no longer seek care from this provider.
- 19.1 percent of patients indicated that if their care provider suffered a privacy breach and the patient learned of the breach from the provider first, they would no longer seek care from this provider.

Patients are 3 times more likely to stop seeking care from a provider when they learn of a breach through the media, further demonstrating the importance of timely communication from the provider to the patient regarding breaches.

- Patients are 3 times more likely to stop seeking care from the provider when they are surprised through media, further demonstrating the importance of timely communication from the provider to the patient regarding breaches as documented in this report.
- When a care provider suffers a major privacy breach or a series of privacy breaches, 74.2 percent of survey respondents state it damages or severely damages the reputation of the care provider, while 21.8 percent note it mildly damages the provider's reputation.

Patients who had experienced a breach of their private medical information validated the attitudes and anticipated actions of non-breached respondents. The consequences of the breach they experienced also validates industry studies on the patient impact of a privacy breach.

- 6 percent of patient respondents indicated they had been alerted their medical records had been compromised. As a result of the breach, 60 percent indicated they no longer seek care from that provider.
- Breach victims state that when alerted initially, the top three consequences of concern included: identity theft, leaking of sensitive medical/personal information and medical identity theft.
- The top three consequences of the breach most commonly reported included: a sensitive medical issue was no longer private, the patient required credit monitoring to ensure their identity was not compromised and they became the victim of identity and/or medical identity theft.
- 62.8 percent of the victims were alerted by care provider of the breach within 60 days. 5.7 percent of victims discovered the breach on their own.
- 52.9 percent of the victims stated they were satisfied with the care provider's resolution of the breach.
- Breach victims reported that in 21.4 percent of cases a family member breached their records and in 20 percent of cases, it was an employee of the care provider. The remaining breaches were committed by friends, co-workers, a stranger, or unknown. These numbers are consistent with industry studies on healthcare privacy breaches ([Best Practices & Breach Findings Report](#)).

Nearly 2 out of 3 patients have high expectations with regard to care providers' confidential treatment of their medical records.

- 66.4 percent of patients report when a privacy breach occurs, their trust in electronic health records is affected.
- 61.4 percent of patients expect their care provider to comply with Federal privacy regulations.
- 58.5 percent of patients expect care provider to foster a culture of trust.
- 59.7 percent of patients expect to be alerted in a timely manner if their medical record inappropriately accessed.
- 60.8 percent of patients expect to have inappropriate access resolved in a timely manner.
- 59.5 percent of patients expect care provider to respond quickly as to who assessed their records.

- 58.8 percent of patients report that their belief that their care providers keep their information private influences their choice to seek care from them.
- 61.4 percent indicate that knowledge regarding technology and processes which protect the confidentiality of their medical records would influence their decision to seek care from that provider.

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.

- 80 percent of respondents believe that their care providers have safeguards in place to protect private medical information however, only 48.4 percent of patients believe their care provider is committed to protecting their privacy.
- 58.5 percent of patients expect their care provider to foster a culture of patient privacy.
- Nearly 2 out of 3 patients expect their care provider to proactively detect unauthorized access to their private record and respond quickly to the patient’s inquiry as to who has accessed their record.
- 53.7 percent of patients stated that open communication with patient regarding privacy efforts would make them feel that their care provider takes patient privacy seriously.
- 61.4 percent of patients state that if they knew that a care provider had invested in technologies and processes that detect and prevent privacy breaches, that they would be more likely to seek care from this provider.

61 percent of patients indicated that they would be more likely to seek care from a provider that invested in technologies and processes to detect and prevent privacy breaches.

Patients believe care providers are ethically and legally obligated to protect privacy and indicated consistent and strong responses regarding breach protection expectations.

Survey responses illustrate that patients have high expectations with regard to the confidential treatment of their medical records by care providers. When survey questions became more specific to privacy violations and expectations associated with protection against privacy violations, patients were more assertive in their responses. This suggests there a segment of the respondents fundamentally trust care providers to “do the right things” with regard to privacy, but react quite emotionally when surprised by a privacy violation.

- 97.2 percent of patients believe care providers have a legal and ethical responsibility to protect patients’ medical records and privacy information
- Patients note that they expect the following from their care provider relative to the protection of their privacy:
 - 74.4 percent state they expect their care provider to deliver clear and consistent communication to staff regarding what constitutes inappropriate access to patient records

- 73.9 percent state they expect consistent training of staff on privacy laws and the care provider's privacy policies
- 73.3 percent expect clearly defined penalties for unauthorized access to patient records
- When care provider staff members inspect patient records out of curiosity, patients indicated suspension (15.6 percent), termination (24.7 percent), and report offense to authorities (16.3 percent) were all appropriate punishments.
- When care provider staff members inspect patient records with intent to do harm, patients indicated suspension (5.9 percent), termination (30.6 percent), and reporting offense to authorities (51.7 percent) were all appropriate punishments.

Patients are optimistic about electronic health records, but demonstrate very little substantive knowledge of the risks of paper versus electronic health records.

- 74.2 percent of patients believe that moving from medical records to electronic health records will help healthcare professionals to deliver better care.
- Patients ranked the following respectively as the top three benefits of electronic health records and reasons for optimism:
 - The ability of doctors to share my medical information freely with other medical professional who need it for my treatment
 - Up to date/real time medical information
 - Easy access to my medical records
- 32 percent of patients feel that providers are more equipped to protect the privacy of electronic records, 39.7 percent responded neutrally, and 28 percent feel that providers are more equipped to protect the privacy of paper records than electronic records.
- 48.4 percent believe their care provider is currently committed to protecting their privacy, 25.5 percent responded neutral and 26.1 percent of patients responded their provider is not committed to protecting their privacy.

Survey data indicates that the majority of patients feel that privacy laws, government enforcement and sanctions for privacy breaches have a neutral or no effect on the motivation of care providers to protect patient privacy.

- 61.4 percent of patients expect their care provider to comply with Federal privacy regulations.
- 64.6 percent of patients believe that there are adequate laws in place which mandate the protection of patient privacy however 72.2 percent of patients believe that the passing of additional laws would have a neutral or no impact on the number of privacy breaches among care providers.
- 48.9 percent of respondents believe the government adequately enforces healthcare privacy laws.
- Nearly 1 in 2 patients state that stronger enforcement of current privacy laws would have a neutral or no effect in reducing the number of privacy breaches.

- A slight majority, 50.9 percent of consumers believe that the government should impose heavy fines against care providers for privacy breaches.
- 31.4 percent of patients believe that passing additional privacy laws would distract care providers from delivering quality care.

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 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 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
- Privacy is not top of mind to patients. However, the survey demonstrated that when asked specific questions about privacy, patients expressed concerns regarding privacy and noted privacy as an influencer in their decision to seek care from a specific provider. Although most patients have high expectations with regard to the confidential treatment of their medical records by care provider, more consistent responses were received as survey question became more specific to privacy violations and expectations associated with protecting against privacy violations. This suggests 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
- The relatively uniform or even random responses by patients suggest a lack of substantive knowledge of privacy risks associated with electronic health records versus paper records. Privacy advocates as well as electronic health record vendors seeking to promote their positions on privacy should focus on sober consumer education rather than emotional histrionics, threats and defensive behavior when it comes to privacy
- Many consumers may not have an adequate understanding of privacy laws. They know they exist however, answers demonstrate that although 3 out of 4 want quick responses from their providers regarding access they may be unaware of disclosure laws. Additionally, nearly 30 percent of respondents note that they don't expect their provider to comply with Federal privacy regulations

Appendix 1

In February 2011, FairWarning® commissioned New London Consulting to develop a survey of US consumers, or patients of care providers to determine how **patient privacy considerations impact the actual delivery of healthcare**. The survey was designed 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.

New London Consulting and FairWarning® developed a survey consisting of 29 questions. The survey was conducted using an online platform. Survey invitations were sent to more than 10,000 consumers across the US. Invitations to participate were sent to a population that mirrors US census demographics relative to race, economic class, age and gender. The survey invitation resulted in participation of 1265 individuals. The survey was live for approximately 120 days.

Gender

Female*	59.6 percent
Male	40.4 percent

* Of note, the majority of respondents were women. According to a U.S. Department of Labor report, women make 80 percent of the healthcare decisions for their families. Statistically, responses garnered in this survey represent a more actual picture of what influences the decision making process relative to healthcare and where and from whom medical treatment is delivered to the household.

Ethnicity

White, not Hispanic	68.9 percent
Hispanic/ Latino	16.1 percent
African American	10.7 percent
Asian American	5.1 percent
Other	3.7 percent
Prefer not disclose	1.9 percent

Highest Level of Education Completed

Less than high school	2.2 percent
High school graduate	18.0 percent
Some college	33.1 percent
College graduate	32.9 percent
Graduate or professional degree	13.8 percent

U.S. States Represented

Survey participants represented 49 US States.

14 There were no survey participants from Wyoming.

