



UK: 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, October 6, 2011

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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 United Kingdom 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 behaviours and decisions and influence patient care outcomes.**

The survey was conducted using an online platform. Survey invitations were sent to more than 9,349 patients across the United Kingdom. Invitations to participate were sent to residents of England, Scotland, Wales, and Northern Ireland. The survey resulted in responses from participants of varying race, educational level, economic class, age and gender. The survey invitation resulted in participation of 1001 respondents. The survey was live for approximately 9 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 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***
- ***To what degree 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 UK 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.

53.6 percent of patients stated they would withhold information from their care provider based on privacy concerns. 38.3 percent stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns. Nearly 1 out of 2 patients, 45.1 percent indicated they would seek care outside of their community due to privacy concerns with 37 percent indicating they would travel substantial distances, 30 miles or more, to avoid being treated at a hospital they did not trust, in order to keep sensitive information confidential. By withholding medical information, patients are impacting the care received and hence the outcome. 72.9 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 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 half of patients stated that if they had a sensitive medical condition, they would withhold information from their care provider. Nearly 2 out of 5 stated they would postpone seeking care out of privacy concerns.

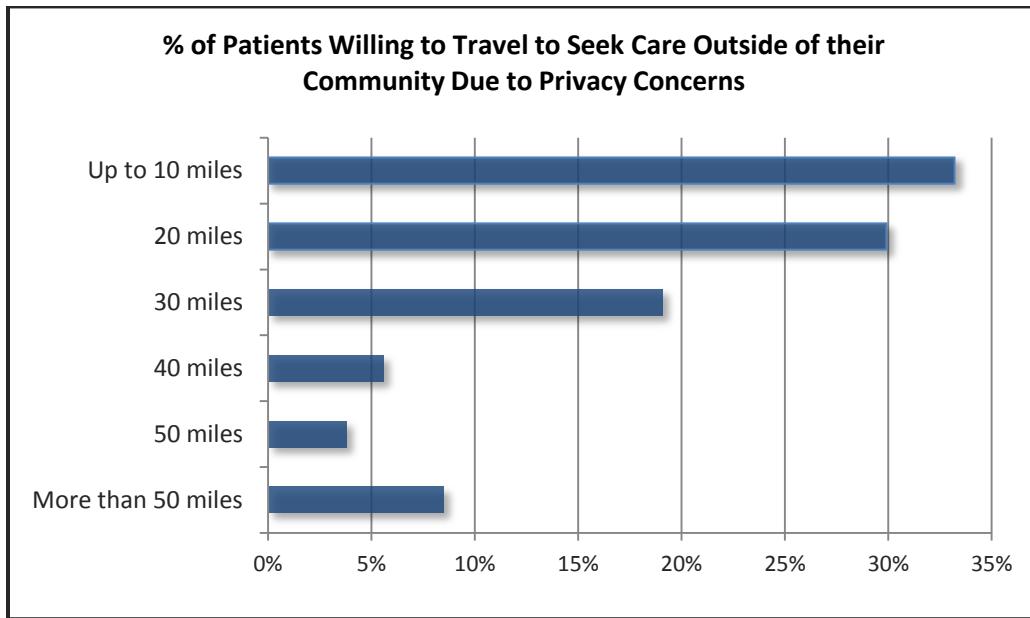


Figure 1. Patients Willingness to Travel to Avoid Privacy Concerns

Patients expect the NHS and healthcare 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.

97.1 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. 86.2 percent of patients agree 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 90.3 percent agree 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 percent of respondents stated that chief executives and top managers need to do more to stop unauthorised access to medical records while 87.2 percent stated that healthcare providers should currently monitor who looks at medical records and detect unauthorised access to personal information. 87.1 percent of patients agree 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. 62.1 percent of poll respondents state that there should be a national league table showing which hospitals have the most breaches of patient health records.

Nearly 9 out of 10 patients state 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.

% of Patients that Agree that Executives Should be Fired or Fined for Avoidable Privacy Breaches

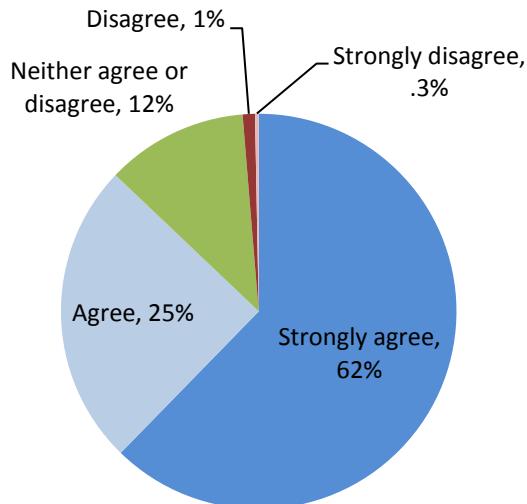


Figure 2. Patients call for executive accountability for privacy breaches

A majority of patients believe the NHS is committed to protecting their personal data however, patients report privacy breaches result in a break of trust and significant damage to the NHS' reputation.

63.2 percent of patients agree that the NHS is committed to protecting their privacy and 80.9 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. Rather, 29.4 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 huge damage to the reputation of the health service. 52.7 percent of patients stated that privacy breaches in health services reduce their trust significantly in healthcare providers and hospitals. Of significant note, this question was not specific to breaches within their own provider but within health care overall. 87.3 percent of patients state that if there were breaches of patients' personal information at a specific hospital, it would make them think the hospital was poorly managed, while 86.5 percent think that a serious breach of personal data would do severe or considerable damage to a hospital's reputation. 72.9 percent stated that serious or repeated privacy breaches would reduce their confidence in the quality of care provided by a hospital while 61.5 percent stated that personal information breaches would make them want to seek treatment at another hospital.

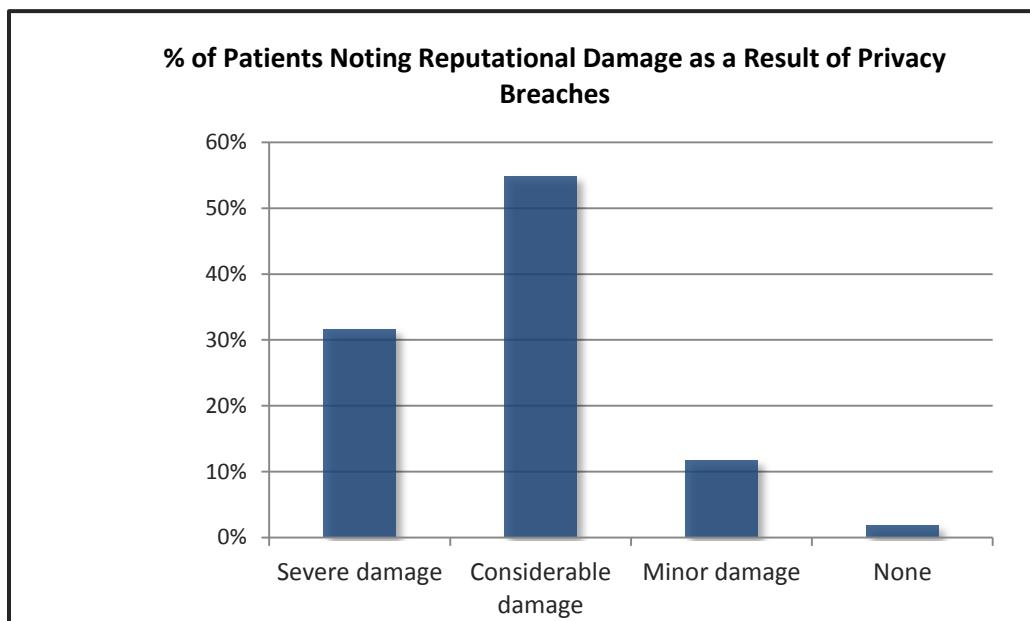


Figure 3. Patient perception of reputational damage as a result of privacy breaches

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.

4.1 percent of 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 22 percent of cases it was a family member that breached their records, in 14.6 percent of cases it was a co-worker and in 14.6 percent of cases it was an unknown employee of the hospital or healthcare provider where the patient sought care. In 9.8 percent of cases it was a friend, in 7.3 percent of cases it was a neighbour and in 31.7 percent of cases, it was unknown who breached the record.

These respondents noted that 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
- Also became a victim of identity theft
- The victim required credit 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.

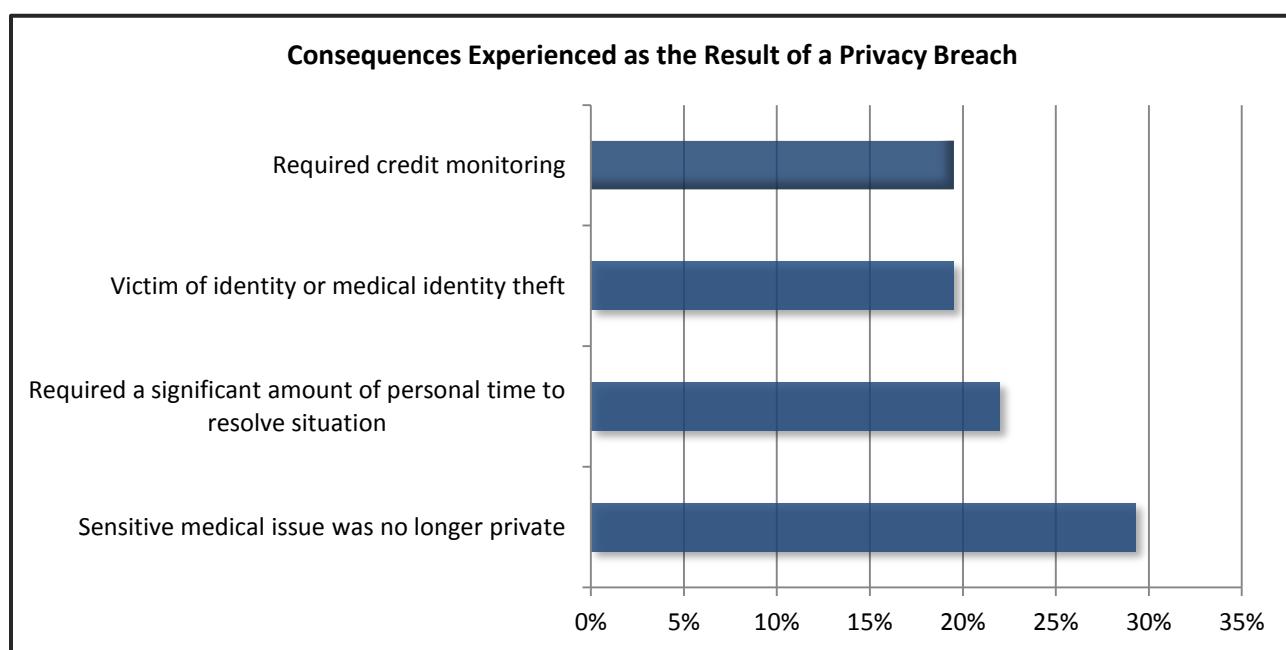


Figure 4. Patient Consequences Resulting from Privacy Breach

UK Regionalised data and an overview of US and UK comparative data is detailed in the Complete Survey Findings Section.

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.

- 53.6 percent of patients stated they would withhold information from their care provider based on privacy concerns
- 38.3 percent stated they have or would postpone seeking care for a sensitive medical condition due to privacy concerns.
- Nearly 1 out of 2 patients indicated they would seek care outside of their community due to privacy concerns with 37 percent indicating they would travel a substantial distance, 30 miles or more to avoid being treated at a hospital they did not trust in order to keep sensitive information private.
- 72.9 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 the NHS and healthcare 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.

- 97.1 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.
- 86.2 percent of patients agree 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.
- 90.3 percent agree 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 percent of respondents stated that chief executives and top managers need to do more to stop unauthorised access to medical records.
- 87.2 percent stated that healthcare providers should currently monitor who looks at medical records and detect unauthorised access to personal information.
- 87.1 percent of patients agree that the chief executive and senior management were made aware of risks but failed to act and if there is a serious breach, they should be fined or lose their jobs.
- 62.1 percent of poll respondents state 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, 86.5 percent of survey respondents state it damages or severely damages the reputation of the care provider, while 11.7 percent note it mildly damages the provider's reputation.

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.

- 4.1 percent of patient respondents indicated they had been alerted their medical records had been compromised.
- The top three consequences of the breach most commonly reported included: a sensitive medical issue was no longer private, it required a significant amount of personal time to resolve the situation, the patient became a victim of identity theft and the patient required credit monitoring to ensure their identity was not compromised.
- 41.5 percent of victims were notified immediately by the healthcare provider, 26.8 percent were notified within 30 days. 9.8 percent of victims reported they were not alerted but rather discovered the breach on their own.
- Polled patient victims of privacy breaches reported that in 22 percent of cases it was a family member that breached their records, in 14.6 percent of cases it was a co-worker and in 14.6 percent of cases it was an unknown employee of the hospital or healthcare provider where the patient sought care. In 9.8 percent of cases it was a friend, in 7.3 percent of cases it was a neighbour and in 31.7 percent of cases, it was unknown who breached the record. These numbers are consistent with industry studies on healthcare privacy breaches ([Best Practices & Breach Findings Report](#)).
- 70.7 percent of the victims stated they were satisfied with the care provider's resolution of the breach.

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.

- 57.7 percent of patients believe the UK health services is good or very good at stopping patient information from being lost, stolen or accessed by unauthorised people.
- 70.6 percent of respondents believe that their care providers have safeguards in place to protect private medical information and 68.2 percent of patients believe that the NHS is committed to protecting their privacy.

- However, the majority of poll respondents agree the NHS 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 percent of patients
 - Monitor who looks at medical records to detect unauthorised access to personal patient information, 87.2 percent of patients
 - Communicate to patients regarding inappropriately accessed records, 85.1 percent
 - Effectively resolve a privacy breach in a timely manner, 87.6 percent
- Patients noted that the top three actions that health service managers can take to make them feel as though they take patient privacy seriously are respectively: Ensure electronic records systems are monitored to identify and stop privacy breaches, encrypt patient data so stolen information cannot be used, train staff on data protection laws.
- 86.3 percent of patients expect healthcare providers and hospitals to uphold data protection laws.
- 69.8 percent indicate 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.
- 43.6 percent of patients stated that open communication with patients regarding privacy efforts would make them feel that their care provider takes patient privacy seriously.

The vast majority of UK patients believe electronic health records provide significant value.

- 92.8 percent of patients note there are significant benefits to electronic health records.
- The top three benefits noted are respectively:
 - Doctors can freely share patients' medical information with other medical professionals who need it for patient treatment
 - A patient's records can always be kept up to date
 - Healthcare providers can prevent people from seeing a patient's record without expressed permission from the patient

Survey data indicates that a slight majority of patients believe that new and stronger privacy laws are needed to motivate healthcare providers to proactively protect privacy. The majority of respondents also indicated that greater enforcement and sanctioning would provide a greater impetus for healthcare providers to take privacy more seriously.

- 56.7 percent of patients agree or strongly agree that new and stronger laws are needed to guarantee the privacy of patient information.
- More than 3 out of 4, 73.3 percent of patients stated that stronger enforcement of existing data protection laws would result in fewer privacy breaches.

- 86.3 percent of patients believe healthcare providers and hospitals must make sure they uphold data protection laws.

Regionalised Poll Results

The survey included significant numbers of respondents from Scotland (102, or 10.3%), Wales (100, or 10.1%) and from many English regions. For example 253 respondents (32.4%) were from London and the south east, and 103 (13.2%) from the North West. Comparisons between the UK nations and English regions reveal significant variations in attitudes and opinions – though people in all areas strongly agree with the survey's main findings.

Scots were even more in favour of national league tables showing the best and worst hospitals for data security (66.6%) than the UK as a whole (62.1%). As Scotland is making the fastest progress in this area it is likely that some Scottish hospitals would fare very well in any UK-wide tables. Scots (90.1% compared to UK 87.2%) were also very much in favour of the idea of effective NHS monitoring of who accesses their personal files. The Welsh had even stronger views with 91% wanting access to their records monitored. Indeed, Welsh attitudes were among the strongest in many areas, for example 42% (compared to 35.3% in the UK as a whole) were worried that security breaches could result in sensitive information reaching people who knew them.

In London and the south east there were especially high levels of concern about how personal information could be misused with, for example, 40.3% (34.1% UK-wide) concerned that details could be leaked to their employer. Respondents from across the UK also showed great, but varying, levels of confidence in the potential effectiveness of laws and regulations. For example in the West Midlands 77% of people (73.3% for the UK) said that better enforcement of the rules would cut security breaches.

US and UK Comparative Data and Findings Highlights

A universal finding in the US and UK surveys is that trust in the confidentiality of medical records is influencing when, where, who 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. UK patients are almost twice as likely to withhold information from their care provider about a sensitive personal medical matter if they had a poor record of protecting patient privacy as their American counterparts.

UK patients		US patients	
Yes	53.6 percent	Yes	27.1 percent
No	46.4 percent	No	72.9 percent

Additionally, nearly 4 out of 10 UK patients versus nearly 3 out of 10 US patients noted they have or would put off seeking care for a sensitive medical condition due to privacy concerns.

UK patients		US patients	
Yes	38.3 percent	Yes	27.6 percent
No	61.7 percent	No	72.4 percent

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

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. 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 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 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 UK patients feel executives should be held accountable for privacy breaches. The discussion should address law making, formalised fines and sanctions and explore how these laws/rules will be enforced both at a governmental level and by 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.
- The survey showed clear variations in views and opinions between respondents in England, Scotland and Wales and within different English regions. With the devolved nature of the NHS between the home nations, and the increasing autonomy of English healthcare providers, further research would be beneficial in most geographical areas in order to identify concerns and to ensure confidence in local hospitals.

Appendix 1

In September 2011, **FairWarning®** commissioned Vanguard Software and New London Consulting to develop a survey of United Kingdom 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*	50.7 percent
Male	49.3 percent

Ethnicity

White, British	87.9 percent
White, Other	5.0 percent
Black	1.8 percent
Asian	3.0 percent
Other	1.4 percent
Prefer not disclose	0.8 percent

Highest Level of Education Completed

GCSEs or equivalent	33.9 percent
A Levels or equivalent	26.2 percent
Degree	23.7 percent
Post graduate qualification	8.7 percent
No academic qualifications	7.4 percent