

AN EXPLORATORY STUDY: BENEFICIARIES' PERCEPTIONS OF HEALTH
INFORMATION EXCHANGES IN CENTRAL TEXAS

by

Kimberly Chen, B.S.

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Committee Members:

Cristian Lieneck, Chair

Clemens Kruse

Eileen Morrison

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CHAPTER I

Introduction and Background Information

As the healthcare industry continues to move towards improving access and quality of care, it experiences greater levels of adoption and development of advanced health information technology. As demonstrated by the Patient Protection and Affordable Care Act (2010) initiatives, there is acknowledgement of areas that need continuous quality improvement and better quality outcomes. Therefore, it is important that healthcare organizations implement ways to measure specific service lines of care, such as the emergency department, and data related to emergency department readmissions and non-emergent, preventative care utilization rates. Moreover, measures implemented to enhance delivery of care and reduce readmissions for health facilities, in conjunction with effective health information technology utilization, will overall help the healthcare organization in achieving quality improvement efforts (Ben-Assuli, Shabtai, & Leshno, 2013). Furthermore, identifying and measuring improved quality care is a central focus in the present healthcare industry (Shapiro, Mostashari, Hripcsak, Soulaskis, & Kuperman, 2011).

Particularly, the ability to view patient medical information through interoperable networks within and between facilities or organizations is valuable. This interoperability provides the healthcare provider the ability to access complete and accurate patient information immediately during the health visit (Ben-Assuli et al., 2013). Interoperable networks and their ability to enhance the exchange of important medical information allow for more informed decision making to enhance the quality and reliability of health

care delivery (Ben-Assuli et al., 2013). Presence and effective use of an interoperable network showed the decrease in waiting time necessary to exchange paper health records and reduce repetitive tests, avoidable redundant admissions, and readmissions (Ben-Assuli et al., 2013).

Healthcare organizations also rely on technology to collect necessary data that enables higher quality of care to beneficiaries. In addition, Health Information Exchanges (HIE) provide benefits of a secure transport and storage method for patient health information. Specifically, the HIE transport method helps healthcare organizations, insurance payers, and other health departments with access to patient information and to better understand the individual's overall health status (Shapiro et al., 2011). The HIE is also becoming more popular in the healthcare industry as transitions toward improvement in healthcare delivery and public health initiatives are more emphasized (Shapiro et al., 2011). For example, the use of HIEs in public health makes it simpler to retrieve data for reporting purposes and improve public health-related activities such as public health investigation, population-level quality monitoring, and mass-casualty events (Shapiro et al., 2011).

Concerns about Health Information Exchanges

With the increase in healthcare technology, concerns are growing and focus is shifting towards how to maintain and enhance privacy, security, and consent protection measures (Carter, Lemery, Mikels, Bowen, & Hjort, 2006). As a result, it is common for beneficiaries to wonder how they can control their personal health information when HIEs continue to allow easier online access to information. There is also an initiative to

reevaluate privacy, security, and consent to ensure that these protection measures are properly addressed when an HIE is implemented in regions across the country (American Health Information Management Association/Health Information Management Systems Society, 2011). There must be “appropriate privacy and security policies established and enforced if we are to truly achieve the benefits of electronic exchange” (Goldstein, 2014, p. 803).

Texas HIE Initiatives

In particular, the Office of the National Coordinator for Health Information Technology (ONC) established the State Health Information Exchange Cooperative Agreement Program. This program awarded several states, eligible territories, and qualified State Designated Entities funds to grow HIEs to be able to exchange patient information within and across states (“State Health Information Exchange,” 2014). Texas was one of the states awarded funds to grow and expand HIEs to allow for the exchange of patient information within the state and potentially to other states that also have HIEs.

In Texas, Governor Rick Perry signed the Texas House Bill 300 (HB 300), also known as the Texas Medical Privacy Act, which was effective September 1, 2012. House Bill 300 (HB 300) was “designed to bring Texas into compliance with Federal Standards on patient privacy as enumerated by HIPAA” (“Texas Enacts New Privacy Law”, 2011, p. 8). The newly created health privacy bill formed “after an embarrassing data breach that exposed the personal information of more than 3.5 million Texans on a public server for more than one year (“Texas Enacts New Privacy Law”, 2011, p. 8). The

HB 300 focused on ensuring that employees of covered entities received proper HIPAA training and necessary consent for disclosing personal health information (PHI) (“Texas Enacts New Privacy Law”, 2011). The bill also discussed how covered entities might reveal PHI to other covered entities for the purpose of treatment and payment (“Texas Enacts New Privacy Law”, 2011).

Additionally, the Texas Health and Human Services Commission (HHSC) is heavily involved in the development and implementation of HIEs. In early 2011, HHSC signed a contract with Hewlett-Packard to build a state health information exchange for Medicaid patients in Texas (Opsahl, 2011). The exchange would allow Texas healthcare providers who provide healthcare services to Medicaid patients have quicker and easier access to patient records without waiting for other providers to mail patient records or rely on patients to remember their medical history (Opsahl, 2011).

To-date, there are 14 utilized HIEs in regions across Texas that access patient health information. The Texas Health Services Authority (THSA), a public-private partnership, is responsible for the coordination and promotion of HIEs in Texas (“About THSA,” n.d.). This organization wants to ensure that accurate patient information is available to providers when necessary as well as protecting patients’ privacy with the implementation of HIEs in Texas (“About THSA,” n.d.). In order to address privacy and consent with Texas HIEs, THSA designed a Texas HIE Consent Management System, which considers patients’ consent and authorization when having their information included and exchanged in HIEs (Moehrke, 2012). The THSA aims to be at the forefront of ensuring that patients’ health records are protected privately, securely, and with

consent as HIEs develop and are utilized throughout Texas to improve healthcare delivery overall (Moehrke, 2012).

Texas also has a region known as the “Texas White Space” which contains rural areas that currently do not have a HIE in the local area (“White Space,” n.d.). There is a “white space” strategy, which helps regions that do not have a local HIE to be able to exchange patient health information through direct email that is secure and follow HIPAA compliancy (“White Space,” n.d.). This “white space” strategy also requires internet access and helps providers meet Meaningful Use with the use of electronic health records (“White Space,” n.d.).

Central Texas HIE Initiatives

For Central Texas (Figure 1 in red), Integrated Care Collaboration (ICC) is the health information exchange utilized in this area by safety-net providers (Schiefelbein, Olson, & Moxham, 2014). The ICC consists of a combination of non-profit clinics and providers in Central Texas serving the uninsured and underinsured (“Regional Health Information Exchange,” 2009). It has developed a “repository for clinical data that allows safety net providers to build systems for sharing electronic medical records” (Robert Wood Johnson Foundation, 2009, p. 1). Additionally, the ICC also has the ICare System, which contains treatment support and research and analysis data on the uninsured (“Regional Health Information Exchange,” 2009). As a result, this particular HIE in Central Texas is now exchanging the following data and functions between participating healthcare institutions: demographic information, encounter data, medications data, and lab results, in an overall effort to further increase the quality of

care for central Texans (“Regional Health Information Exchange,” 2009). Figure 1 below is a representation of regions in Texas that have an HIE available.



Figure 1. Map of HIE Regions in Texas from HIETexas.

A second HIE in Central Texas based mainly in Austin, TX, is the Centex Systems Support Services. The Centex Systems Support Services is a “consortium of providers and other entities which have formed a regional non-profit corporation to support the implementation of common practice management/electronic health record among safety net providers” (“Regional Health Information Exchange,” 2009). The Centex Systems Support Services also allows participating providers to share patient data based on formed agreements (“Regional Health Information Exchange,” 2009). The current organizations involved with Centex Systems Support Services are members of this HIE and the Travis County Healthcare District (“Regional Health Information Exchange,” 2009). Currently, this local HIE is exchanging demographic, clinical, imaging, and lab results data among many healthcare facilities (“Regional Health Information Exchange,” 2009).

Local Concerns Over HIE Implementation and Utilization

The basis of acceptance of HIEs for beneficiaries in Central Texas is dependent upon how they perceive HIEs in relation to privacy, security, and consent. Beneficiaries expect HIEs to be private and secure without having to worry about compromised patient data or leaks into the wrong hands (Ancker, Edwards, Miller, & Kaushal, 2012). There definitely is a possibility that patient information could “travel several potential critical paths into another medical provider's hands, which might not have been the patient's preference” (Lieneck, 2013, p. 42). Research and marketing practices further demonstrate that beneficiary expectations change based on personal standards and beliefs therefore, adequate and desired expectations vary per beneficiary and per perception variable (levels of privacy, security, and consent perceptions) (Zeithaml, Bitner, & Gremler, 2013). Beneficiaries’ acceptance of HIEs based on their individual perceptions of the level of privacy, security, and consent will vary and possibly dependent upon individual expectations and ongoing perceptions of the privacy, security, and consent desires.

Beneficiary Expectations and Perceptions

Adequate and desired levels of expectations can change over time, between different individuals, and based on the type of variable (Zeithaml et al., 2013). The range between adequate and desired levels is named the zone of tolerance and refers to a range of acceptable service perceptions, of which beneficiaries find desirable (Zeithaml et al., 2013). Some beneficiaries may place more weight on privacy and security and would expect these two variables to have a higher level of expectation than consent. In addition,

the influence of adequate expectations is highly dependent upon situational factors and alternative options available while the influence of desired expectations is by personal needs and philosophy (Zeithaml et al., 2013).

A beneficiary's perception is also an impression that he or she has about something and can be different from the expectations. With beneficiary perceptions, the perception basis is from a specific perceived instance or continuous perceptions of overall experience (Zeithaml et al., 2013). Meanwhile, continuous perceptions is based on overall experiences and this is ultimately how loyalty and trust are built (Zeithaml et al., 2013). Overall, expectations and perceptions vary because each beneficiary has his or her own personal ideas and experiences (Zeithaml et al., 2013).

The ultimate goal therefore is to assess the individual beneficiary perceptions of HIE privacy, security, and consent in an overall attempt to further assess and thus close the customer gap. This information will ultimately allow for the healthcare industry and HIE professionals to further match beneficiary perceptions with their expectations. An example of such variances for a single healthcare beneficiary is depicted in Figure 2.

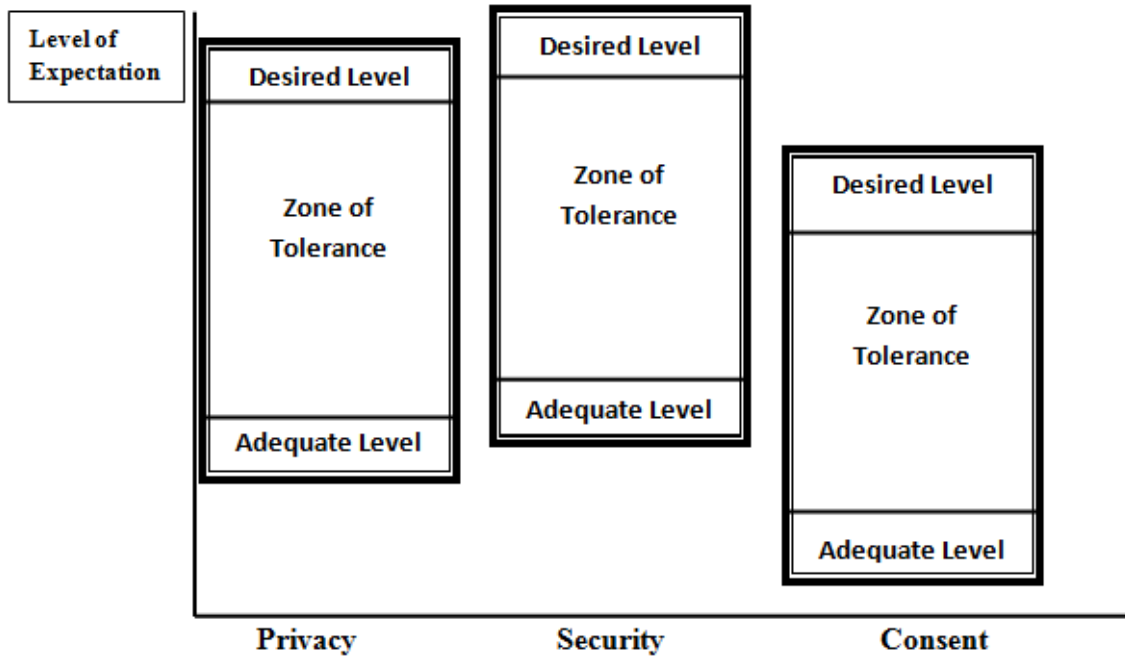


Figure 2. Depict Adequate and Desired Levels of Expectations.

With beneficiary expectations, the zone of tolerance is elastic and will continuously change based on the situation or incident at hand (Zeithaml et al., 2013). For example, a healthcare beneficiary may have a greater zone of tolerance for routine cares such as a wellness/physical exams compared to acute cares, which may be more serious and require higher levels of service delivery. In the end, the zone of tolerance varies among beneficiaries as each individual has his or her own perception of what is adequate or desired for him or herself at the point of service delivery (Zeithaml et al., 2013).

Research Sample

For this study, the target sample size will be Central Texas residents who are 18 years of age or older, and are willing to complete a short survey concerning his or her

perception of HIEs with respect to privacy, security, and consent. Beneficiaries will address their acceptance of HIEs based on the level of privacy, security, and consent present.

Key Terms

To better understand the common terminology used in this research, the terms and their definition are listed below.

1. Age. Age is the study participant's physical age at the time of the study.
2. Beneficiary. An individual who has a perception of health information exchanges in terms of privacy, security, and consent.
3. Provider. A licensed and certified healthcare professional who may utilize health information exchanges in his or her practice.
4. Computer-to-Computer. A transport method utilized to transmit personal health information between providers.
5. Healthcare organization. An entity that may utilize health information exchanges to transmit personal health information between organizations.
6. Health information exchange method. The health information exchange method is the ability for healthcare providers and beneficiaries to electronically and securely access a beneficiary's health information ("What is HIE," n.d).
7. Health information exchange organization. The health information exchange organization is the usage and accessibility of person health information for providers.

8. Meaningful use. A Medicare and Medicaid incentive program to stimulate healthcare providers to improve patient care by utilizing electronic health records (Adler-Milstein, Bates, & Jha, 2011).
9. Privacy. Privacy is the ability of an unauthorized individual to gain access and view personal health information without permission (Dimitropoulos, Patel, Scheffler, & Posnack, 2011).
10. Security. The protective measure used to keep unauthorized individuals from being able to access and review your electronic health information (Dimitropoulos et al., 2011).
11. Consent. The ability for beneficiaries to be able to control what is shared and accessed in relation to personal health information and by whom their information is visible too (Dhopeswarkar, Kern, O'Donnell, Edwards, & Kaushal, 2012).
12. Expectation. Expectation is a judged belief that serves as a standard or reference point (Zeithaml, et al., 2013).
13. Perception. Perception is a subjective assessment of actual impressions and experiences that an individual perceives (Zeithaml, et al., 2013).

Research Problem

Beneficiaries need to understand that the objectives and goals of an HIE organization is to improve quality and continuous care for patients who visit multiple providers in various locations in a secure manner. However, the acceptance of exchanges by beneficiaries is questionable because beneficiaries need proof and assurance that their personal health information is secure (Lieneck, 2013). Furthermore, HIEs require

interoperability so that access to data regardless of where a patient was seen is obtainable (Angst, 2009). There have also been problems in trying to streamline HIE usage between providers to ensure personal medical information is readily available to properly care for patients. Furthermore, information contained in HIEs is data analyzed, interpreted, and used to better communicate and treat beneficiaries seeking healthcare services.

In particular, Central Texas has experienced breached sensitive patient data, which caused compromised private and secure healthcare data. For example, a psychiatric hospital in Austin, Texas experienced patient records left unattended in an area of the hospital and another patient secured them inappropriately (Freeman, 2014). With this privacy and security issue occurring at such a local level, an immediate concern to discuss privacy and confidentiality standards to protect patient health information was necessary in order to prevent future breaches (Freeman, 2014).

Another example of compromised privacy breach occurred at a local Austin hospital. An unencrypted laptop was stolen which contained thousands of patient data records and sensitive patient information was exposed (Ouellette, 2013). The implementation of strict privacy and security measures help to prevent this situation from happening in the future (Ouellette, 2013). The local hospital staff discussed ways to prevent the incident from occurring again by implementing techniques to enhance security in all the facilities (Ouellette, 2013).

With Central Texas having experienced privacy and security breaches of patient records, it is understandable why healthcare beneficiaries may remain skeptical of the usage of HIEs that contain patient sensitive information. Gaining loyalty and acceptance

of HIEs from beneficiaries in Central Texas with regard to privacy, security, and consent requires the investigation and analysis of their perceptions and expectations. However, the industry is continuing to develop, as does its beneficiary perceptions. It is important to evaluate current healthcare stakeholder perceptions of HIEs with regard to privacy, security, and consent in order to assess levels of acceptance and permit the continued implementation of such quality outcomes in enhancing health information technology at the local level.

Research Question

To what extent do privacy, security, and consent impact beneficiaries' acceptance of HIEs as a transport method in Central Texas?

Hypotheses

H₀ – there is no significant relationship between the Central Texas beneficiaries' perception of the levels of privacy, security, and consent and acceptance of the HIE transport method in select Central Texas public areas, with respect to age.

- a. H₁ – there is a positive relationship between the beneficiaries' perception of the level of privacy and acceptance of HIEs as a transport method in select Central Texas public areas.
- b. H₂ – there is a positive relationship between the beneficiaries' perception of the level of security and acceptance of HIEs as a transport method in select Central Texas public areas.

- c. H₃ – there is a positive relationship between the beneficiaries’ perception of consent and acceptance of HIEs as a transport method in select Central Texas public areas.
- d. H₄ – there is a negative relationship between the beneficiaries’ age and perception and acceptance of HIEs as a transport method in select Central Texas public areas.

CHAPTER II

Literature Review

With the growing use of technology in healthcare, computer-to-computer health information exchanges are becoming more prevalent and frequently utilized to improve overall patient experience. The purpose of health information exchanges is to allow patient medical information to be available to various physicians regardless of where the patient seeks healthcare services. The health information exchange transport method allows physicians to access patient medical history to review specifics about a patient's history. As a result, the physician no longer has to rely on the patient to remember his or her medical history or reach out to the patient's primary physician and specialist(s) to inquire about their medical history (Lee et al., 2012). Information pertaining to the patient will be readily available through the health information exchange.

Health Information Exchanges

Technology is continuously evolving and emerging in the healthcare industry. Therefore, the healthcare industry is trying to find ways to improve patient care and reduce errors caused by not knowing a patient's medical history if health information is not interoperable. Health information exchanges are "the computer exchange of health information across health care clinicians and organizations and has the potential to improve health care quality delivered" (Dhopeswarkar et al., 2012, p. 428). Furthermore, there is need for beneficiaries to accept technology-based health information exchanges through the appropriate adoption strategies (Park et al., 2013). According to Park et al. (2013, p. 99), "education and other efforts to give the public

accurate information on benefits and adverse effects of the technology need to be tailored to the target groups' experience with the information technology" because each beneficiary views health information exchanges differently and has his or her own viewpoint. Health information exchanges as a transport method also would help with the transition towards pay for performance because the information contained in exchanges is advantageous to physicians in delivering better care to patients. Physicians, beneficiaries, and other organizations would benefit from these health information exchanges because the ultimate goal is to utilize health information exchanges to improve quality, efficiency, and safety of patient care (Dimitropoulos et al., 2011).

HIE Architectural Models. There are three types of HIE organization architectural models which are centralized, federated, and patient managed. With the centralized model, "patient health or medical-related data is collected from local sources, but stored in a central repository, and this permits local entities to maintain autonomy while cooperating to provide data at a local or regional level" (Health Information and Management Systems Society, 2009, p. 2). The HIE centralized model is beneficial because querying response to a request for personal health data is quick since health information is consolidated and maintained centrally ("Topic Series," 2009). The downside with the centralized model is that it "requires the most planning, coordination and development to be successful as well as a heavy investment in a single vendor and system integrator to build a logical central repository that makes it functional" ("Topic Series," 2009, p. 4).

The federated model “provides organization control of the healthcare record and provides the framework for data-sharing capability to enterprises, and the local entity owns their data and the Record Locator Services manages the pointers to the information” (“Topic Series,” 2009 p. 5). The advantages of the HIE federated model is that data is current, the provider owns and controls his or her own data, and data is accessed only when needed for the exchange (“Topic Series,” 2009). However, the federated model requires the “capture of beneficiary consent to opt in and opt out of the federated network thus ensuring legitimacy for data usage, need to ensure authorized access to third-party systems, and data control and availability is not guaranteed” (“Topic Series,” 2009, p. 6). Lastly, the patient-managed HIE model consists of beneficiaries managing their own personal health information. It gives the beneficiary ability to exchange data directly by using a computer-based health record bank or personal health record (Overhage, 2008). Each HIE architectural model is unique in its own way and providers must find the model that fits their needs the best.

Physicians and Other Stakeholders Perception of HIEs

Physician. Regardless of type of clinic or specialty, it is important that physicians have access to the most accurate information about any patient in order to properly evaluate and diagnosis the patient’s health. By implementing health information exchange organizations, vital patient information is available instantaneously to provide safer and more efficient quality care (Shapiro, Kannry, Kushniruk, & Kuperman, 2007). Health information exchanges would also make transition of care easier because any physician would have access to a patient’s medical record. In addition, the patient

information would not be limited to only the physician who saw and diagnosed the patient. According to O'Donnell et al. (2011), many beneficiaries support physician usage of health information exchanges especially those who care for family members or others who have chronic illnesses because it helps with coordination of care. Physicians also see the benefits of using the HIE organization as technology expands but also perceive the potential for information security concerns to arise (Lee et al., 2012).

Other Stakeholders. Several stakeholders potentially need to access patient health information for various business purposes. Health information exchange organizations not only used to improve on patient care but also used by researchers and insurance companies to better their own agendas and purposes (Angst, 2009). Meanwhile, health plans and healthcare clearinghouses considered covered entities that may transmit patient information electronically for transactions (Goldstein, 2014).

With the Privacy Rule, “covered entities may not use or disclose personal health information without patient authorization unless it is permitted or required by the Privacy Rule” (Goldstein, 2014, p. 804). As such, covered entities are able to use and disclose personal patient information with written patient permission for “treatment, payment and healthcare operations, judicial and administrative proceedings and certain law enforcement purposes (Goldstein, 2014, p. 805). The HIE organization is also beneficial to certain stakeholders such as health plans and healthcare clearinghouses because it allows access to patient information for specific transactions. However, “stakeholders have expressed concerns that privacy laws present challenges to the development of

policies and practices for electronic information sharing, particularly in the area of patient consent” (Goldstein, 2014, p. 806).

Beneficiary Perception of HIEs

Beneficiaries are usually satisfied with their medical visits when the experience was pleasurable and their needs were met (Shapiro et al., 2007). Communication between the physician and patient is also important because it builds the relationship between the two in trusting the deliverance of quality care (Jha, Orva, Zheng, and Epstein, 2008). In general, strong communication will help minimize issues of misunderstanding in the delivery of care process for the patient. It is important that there is structure in the delivery of care process in order to ensure best practices in providing optimal patient care. As discussed, technology can further assist here with better coordination of care.

In addition, health information exchange organizations are also significant in the delivery of care process because knowing what medications a patient is already taking or may be allergic to is relevant in minimizing medication errors. Information about a patient’s problems, allergies, medications, family history, etc. is useful in properly diagnosing and caring for a patient. This information can be easily retrievable through the health information exchange method and is beneficial to patients when physicians need access to medical information on the spot. Physicians can ask beneficiaries about their medical history however, not all beneficiaries can thoroughly discuss their medical history in detail. Beneficiaries may forget certain information, are not capable of providing detail due to current health conditions, or simply do not know details of their

medical history. With the health information exchange method, beneficiaries can feel confident that physicians will be able to access their most up-to-date medical information and deliver care that is most accurate. However, for health information exchange to grow and expand, beneficiaries must buy-in to the idea of patient information being accessible through the computer-to-computer exchanges (Dhopeshwarkar et al., 2012). There needs to be a level of comfort and trust that no one will easily access personal health information and is only restricted to usage by the appropriate individuals (Lieneck, 2013).

A beneficiary's perception of the HIE organization is influenced by the perceived level of security that is handled by others who can access their patient information (Wen, Kreps, Zhu, & Miller, 2010). Perhaps data segmentation of certain patient information would lead more beneficiaries toward perceiving HIEs as private and secure. The “segmentation or sequestering of sensitive health information might offer a path forward that enables electronic exchange of information and ensures its protection and compliance with privacy law for the community at large” (Goldstein, 2014, p. 806).

It may be that beneficiaries are more supportive of health information exchanges when they see the benefits and opportunities the exchanges offer to them. By building HIE privacy and security protections, it will help create beneficiary confidence and realization of HIE benefits (Wen et al., 2010). Furthermore, there is a division between beneficiaries accepting and not accepting health information exchanges with a higher percentage of beneficiaries believing that exchanges would worsen privacy and security (Ancker, Silver, Miller, & Kaushal, 2013). To address privacy and security concerns, there are established privacy laws created to “support the expression of patient

preferences and personal autonomy and encourage patient engagement” (Goldstein, 2014, p. 804). In the end, the healthcare industry must address the protection concerns in an effort to assess, measure, and build healthcare beneficiary concerns over privacy, consent, and security into their HIE implementation processes (Zeithaml et al., 2013).

For example, health information exchange organizations are a federal initiative to help with improving the delivery of patient care. However, beneficiaries are skeptical with the idea because they might be losing control of their personal health information. With personal health information “floating” in the exchanges, how can one be sure personal information is not visible to anyone? Are health information exchanges turning patient health records into public goods? (Angst, 2009).

According to Angst (2009, p. 170), “skeptics and cynics argue that creating databases of health information only further the agenda of control by various stakeholders”. Although the basis for health information exchanges is to transport patient health information/records between providers, this information is easily manipulated for usage of other purposes such as identify thief (Angst, 2009). Angst (2009) explained that health information in HIEs could create more privacy and security risks because the further utilization of data than its original purpose. For example, a patient’s social security number or date of birth might be “cross-referenced” with another database without the person’s consent, which would not have happened if information was not stored in a large, digital database (Angst, 2009). There are concerns of privacy, security, and consent because beneficiaries want control of how their health information that is used and exactly who is accessing information at any given time.

Privacy. Health information exchanges would be widely accepted if beneficiaries felt protected and strict privacy measures were set in place (Ancker et al., 2012). According to Ancker et al. (2012), patients do not necessarily feel like they must have hands-on control of the exchanges as long as there is implementation of privacy standards. Dimitropoulos et al. (2011) discussed that there is great concern on privacy of health information exchanges because of the chance that an unauthorized individual would gain access to person health records that could affect a person's life. Therefore, beneficiaries would prefer physicians be involved in determining privacy settings for HIEs and that health information is restricted mainly to the beneficiary's primary physician (Dimitropoulos et al., 2011). However, beneficiaries can see the value of health information exchanges especially with needed and pertinent patient health information to make a proper diagnosis. Beneficiaries would like to be asked permission to access health information so they have knowledge of who is about to see their personal information (Dimitropoulos et al., 2011).

Security. The implementation of health information exchanges is important to the federal government so there have been protection measures established to safeguard beneficiaries from privacy and security risks. There is a supportive effort by the National Coordinator for Health Information Technology (ONC) and Agency for Healthcare Research and Quality to address privacy and security matters regarding the establishment of health information exchanges (Dimitropoulos et al., 2011). Both of these organizations support the Health Information Security and Privacy Collaboration (HISPC) which is the "first coordinated nationwide effort established to assess and

address the effect of variations in organization-level business practices, policies, and state laws governing the privacy and security of electronic health information on nationwide electronic HIE” (Dimitropoulos et al., 2011, p. 111).

Along with HISPC, the established Health Insurance Portability and Accountability Act (HIPAA) of 1996 set standards to address the acceptable usage of protected health information. According to McDonald (2009, p. 448), “Health data exchanges have business associate agreements (BAAs) with the covered entities that provide them data so exchanges can provide clinical data to providers for treatment purposes without a BAA because the covered entity can do so”. The implementation of HIPAA set a basis of privacy protections for health information to allow beneficiaries to have protection over their personal health information (Goldstein, 2014). Security also has tightened as technology advancements grow throughout the years. In addition, beneficiaries who use the internet to pay bills, manage banking accounts, and make purchases online are more inclined to be comfortable with health information exchanges because of secure internet connections (Patel, Dhopeswarkar, Edwards, Barron, Sparenborg, & Kaushal, 2010).

Consent. Beneficiaries would more likely consent to including their information in health information exchange if the action improves their medical care because providers would have concrete patient information to help deliver proper care (Ancker et al., 2012). Consent is also important to beneficiaries because it is a way to control access to their personal health information. However, consent is very weak in terms of privacy because consent is easy to give (McGraw, Dempsey, Harris, & Goldman, 2009).

Receiving consent from beneficiaries should be tougher with the implementation of health information exchanges because beneficiaries should be able to opt-in or opt-out of having others access very specific sensitive information (McGraw et al., 2009).

According to Dimitropoulos and Rizk (2009), there are several factors contributing to the variation of consent such as understanding HIPAA requirements for patient permission and making sure to obtain patient consent to reduce liability for wrongful disclosure. Therefore, the need for consent from beneficiaries is pertinent in making them feel comfortable and accepting health information exchanges. Beneficiaries are more inclined to welcome health information exchanges if their permission is required prior to anyone accessing personal health information.

When it comes to patient consent for health information exchanges, it is important to address meaningful consent. Meaningful consent is when the patient makes an informed decision and the response is recorded (“Patient Consent,” 2014). With meaningful consent, there are six aspects: made with full transparency and education, made only after sufficient time to review educational material is provided, appropriate with circumstances for why health information is exchanged, not used for discriminatory purposes or as a condition for receiving medical treatment, consistent with patient expectations, can be withdrawn at any time (“Patient Consent,” 2014).

There are also varying degrees of informed consent when it comes to patients agreeing to allow certain individuals to access and view personal health information. The “no consent” type requires no consent nor can beneficiaries decline to participate in a health information exchange (Rupp, 2012). This type of consent does follow the HIPAA

rules for privacy protection but is worrisome because it eliminates a patient's sense of autonomy (Rupp, 2012). The global "opt-in" and "opt-out" informed consents recognize that patients can either choose to participate or decline participation in health information exchanges (Rupp, 2012). With the "opt-out" consent option, basic default patient information is already included in health information exchanges but patients can "opt-out" of having other information included in the exchanges (Rupp, 2012). These types of informed consent allow patients to have more control over their information and choices to either include or exclude from health information exchanges. Lastly, the "opt-in with restrictions" and "opt-out with exceptions" consents are granular choices structured to allow patients to be choosers of what information is included in exchanges (Rupp, 2012). Example of health information exchange consent form for New York in Appendix A.

Previous HIE Surveys on Beneficiary Perceptions

Survey development is important in moving towards gathering appropriate data to analyze how beneficiaries perceive HIEs in relation to privacy, security, and consent. Ancker et al. (2012) utilized surveys to gather data on beneficiary perceptions of health information exchanges in New York from New York residents. The survey consisted of questions about the three HIE architectural models: "directed exchange between providers, nondirected exchange in which providers access data supplied by other providers (with consent, as required in New York), and exchange through a patient-managed PHR" (Ancker et al., 2012, p. 77). There was also another study that utilized surveys to gather data on beneficiary experience with and attitudes toward health information exchange (Ancker et al., 2013). This was a nationwide random-digit-dial

telephone survey which consisted of questions pertaining to perceived effect of electronic health record and health information exchange quality, privacy, and security (Ancker et al., 2013). Overall, surveys are one way to gather data from beneficiaries that can provide personal thoughts on topics for researchers to gain further understanding on how one feels.

Statistical Methods Used to Measure Beneficiary Perceptions of HIE

To measure and analysis data on beneficiaries' perception of HIEs, statistical techniques are utilized to determine relationships and correlations between variables. A previous study utilized descriptive statistics to review the distribution of responses and also created an index to gather information on participants' perceptions of HIE (Patel et al., 2012). In the previous study conducted in New York, the researchers decided to utilize the Wilcoxon rank-sum test to analyze bivariate associations between outcomes in regards to preferences on privacy and security of HIE (Patel et al., 2012). Another study conducted by Park et al. (2013) performed a survey that used a five-point Likert scale for sample responses and also evaluated descriptive statistics to analyze the results from the survey to determine participants' perception of HIEs. Such studies provide a basic methodological framework to further assess the perceptions of privacy, security, and consent variables at the local level.

Summary

Health information exchanges impact several stakeholders such as physicians, healthcare organizations, and beneficiaries. With HIEs, privacy, security, and consent are a concern because of the exposure of personal health information to several stakeholders

and covered entities. However, the implementation of HIEs hopefully will improve delivery of care to beneficiaries and reduce misdiagnoses or redundant tests that are unnecessary. Furthermore, there have been numerous researches that conducted survey studies to better draw conclusions on how beneficiaries perceive and accept HIEs.

CHAPTER III

Research Methodology

This chapter discusses the methods used to conduct the research, collect data, and analyze the gathered data on the acceptance of health information technology in Central Texas. Therefore, exploratory in nature, it was necessary to conduct quantitative analyses of the perceptions and acceptance of HIEs in Central Texas in terms of privacy, security, and consent measures. Appropriate Texas State University Institutional Review Board (IRB) waiver approval was obtained prior to conducting the research (EXP2014V207878R).

Participants

Participants of the study were adult healthcare beneficiaries who are at least 18 years old residing in selected areas of Central Texas who voluntarily participated in the research study. There was a representative convenience sample collected for this research to answer a short survey concerning how each beneficiary perceives HIEs in relation to privacy, security, and consent. For this study, a sample size of at least 100 participants would be an adequate sample, based upon the intended descriptive and correlational assessment of variable outcomes in this study.

Data Collection and Analyses

Surveys to Participants. The participants were politely approached in a public setting and asked if they would participate in a short survey. Paper surveys were used for data collection in public settings, such as public parks, to participants. The first page of the survey listed the instructions and discussed the purpose of the survey as well as

requested consent. The survey had a total of six questions that pertained to the perception and acceptance of health information exchanges in relation to privacy, security, and consent. Each survey question required the participant to choose the best option that fits his or her individual perspective levels of privacy, security, and consent and the use of HIEs to transport private health information. The survey consent form and questionnaire are shown in Appendix B.

Privacy and security were measured by determining how private and secure the computer-to-computer transport method is when it comes to healthcare providers obtaining patient records. To strictly identify beneficiary perception of the HIE transport method, participants were asked to determine how concerned they are with health information exchanges in relation to privacy and security to transmit confidential patient medical information. For consent, participants were asked if they would agree to provide consent to healthcare providers to access their personal health information. This question analyzed if participants would even consent to healthcare providers transporting and accessing personal health information using an HIE to improve coordination of care.

In order to gather basic demographic information about the participants, the survey consisted of baseline questions on gender and age category. The survey also asked participants which zip code they currently reside in order to ensure a represented and selected area of Central Texas in the study. Survey questions listed in Appendix B.

Data Analysis. With the survey, each coded response had a number to represent the response quantitatively. The gathered surveys evaluated, analyzed, and aggregated to determine a relationship between how beneficiaries perceive and accept the

implementation and usage of HIEs. Descriptive statistics were used to identify the trend of beneficiaries who accept or do not accept HIEs in Central Texas from the survey responses. A series of bivariate correlation coefficients were calculated to assist in an initial investigation to assess any potential relationship between levels of privacy, security, and consent and the outcome variable – overall acceptance of HIEs. In addition, the Wilcoxon rank-sum test was also used to assess group differences among the acceptance of HIE within the sample consisting of ordinal data sets.

Conclusion

The Wilcoxon rank-sum test utilized measured and characterized the statistically significant relationships between levels of privacy, security, and consent and acceptance of HIEs in Central Texas. The purpose of this study was to analyze the degree that privacy, security, and consent identified if beneficiaries were more likely or unlikely to accept and perceive HIEs as acceptable and a means for improved coordination of care in healthcare delivery.

CHAPTER IV

Results

This chapter discusses the results from the survey data collected for the research question and hypotheses set forth in this research study. The collected paper survey results were handed-out to individuals at two public parks in Central Texas. In order to determine associations between privacy, security, and consent in relation to the health information exchange transport method, the collected surveys were coded in order to complete descriptive and other statistical analyses.

Survey Responses

For survey responses, recruited participants completed the surveys at two Central Texas parks. Each survey included a consent page which indicated that the participant was giving consent to be a part of the research study by completing the survey. In addition, a free bottle of water was given to participants for completing the short survey. Overall, 106 participants voluntarily participated in answering the survey. The survey collection occurred at Lady Bird Lake Hike and Bike Trail in Austin, Texas 78701 and Brushy Creek Lake Park/Brushy Creek Sports Park in Cedar Park, Texas 78613. Table 1 lists the collection of paper surveys by location and dates/times.

Table 1

Location and Date/Time of Survey Collection

Site/Location	Date	Time
Brushy Creek Lake Park /Brushy Creek Sports Park	August 30, 2014	4pm – 6:30pm
	August 31, 2014	4pm – 6:30pm
	September 6, 2014	4:30pm – 6pm
	September 13, 2014	4:30pm – 6pm
	September 28, 2014	11am – 12:30pm
	September 29, 2014	5:30pm – 7pm
Lady Bird Lake Hike and Bike Trail	September 27, 2014	11am – 12:30pm

Survey Response Directionality. The directionality of the survey responses considered for each privacy, security, and consent question. For example, questions #1 and #4 followed a “very comfortable” to not comfortable format whereas questions #2 and #3 had responses inversely related from responses for questions #1 and #4. For questions #2 and #3, an inverted response structure from “very concerned” to “not concerned” was used on purpose in the survey. The coding structure of the survey is located in Appendix C.

Data Screening

Completed surveys were screened prior to performing descriptive and statistical analyses to gather data. Upon reviewing subject zip codes, two subjects were determined as outliers and outside the research scope due to the listed zip codes being outside of the Central Texas area. Table 2 shows a representation of the number of participants from

Central Texas zip codes participating in the research study. Such data screening and subject exclusion efforts were conducted to ensure only Central Texas resident survey data were used in the study.

Table 2

Zip Codes from Surveyed Participants

Zip Codes	# of Participants
78613	19
78634	2
78641	7
78642	5
78660	2
78664	5
78665	5
78681	7
78704	2
78717	22
78726	1
78727	3
78728	1
78729	6
78741	1
78746	1
78747	2
78750	2
78753	1
78757	2
78758	1
78759	7

Privacy, security, and consent survey responses coded in order to obtain information for analyses. Each survey question, #1 - #4, as well as gender and age category had an appropriate code assigned. Additionally, entered coded surveys in Microsoft Excel imported into SPSS for analysis.

Missing Data. It was important to review all collected surveys to identify any unanswered questions. In reviewing each completed survey, there were no surveys that had missing data. All participants who completed the survey answered every survey question.

Descriptive Statistics

The Likert-scale data were evaluated as ordinal data to determine median and mode to further analyze descriptive statistics for this research study. Information pertaining to the research study’s descriptive statistics is listed in Table 3 below.

Table 3

Median and Mode for Survey Questions

	Question 1 - Privacy	Question 2 - Privacy	Question 3 - Security	Question 4 - Consent	Gender	Age Category	Zip Code
N	104	104	104	104	104	104	104
Median	3	3	3	2	2	3	N/A
Mode	2	4	4	2	2	4	78717

Table 3 shows the number of participants who answered each question and the median and mode for each question. There were 104 surveys that were included in the data collection. The median for questions #1, #2, and #3 was 3, which indicated a “neutral” response to questions in regards to privacy and security. For question #4, which pertains to consent, the median was 2, which corresponds to the response “agree”. For an ordinal level of measurement, the calculation of mean was irrelevant because it would not provide any representative statistical finding.

However, mode provides an important descriptive result for this study because it helps determine the most frequently chosen responses for each question. From the mode results, question #1 had “comfortable” as the response most frequently chosen and questions #2 and #3 had “slightly concerned” as the most popular response choice. For question #4, “agree” was the most popular response choice. The mode for the demographic questions was female and age category over 50 years old. The most common zip code listed was 78717.

The survey responses in ordinal scale provided data for central tendency calculations, especially the calculation of median and mode. Median and mode were the appropriate descriptive statistics for this study because it showed the score that is “most typical or most representative of the entire group” (Gravetter and Wallnau, p. 72, 2004). The median and mode scores indicated which responses from each question defined the distribution and common chosen responses. Figures 3 and 4 are line graphs that represent the distribution of survey responses by gender and age category for questions #1 through #4.

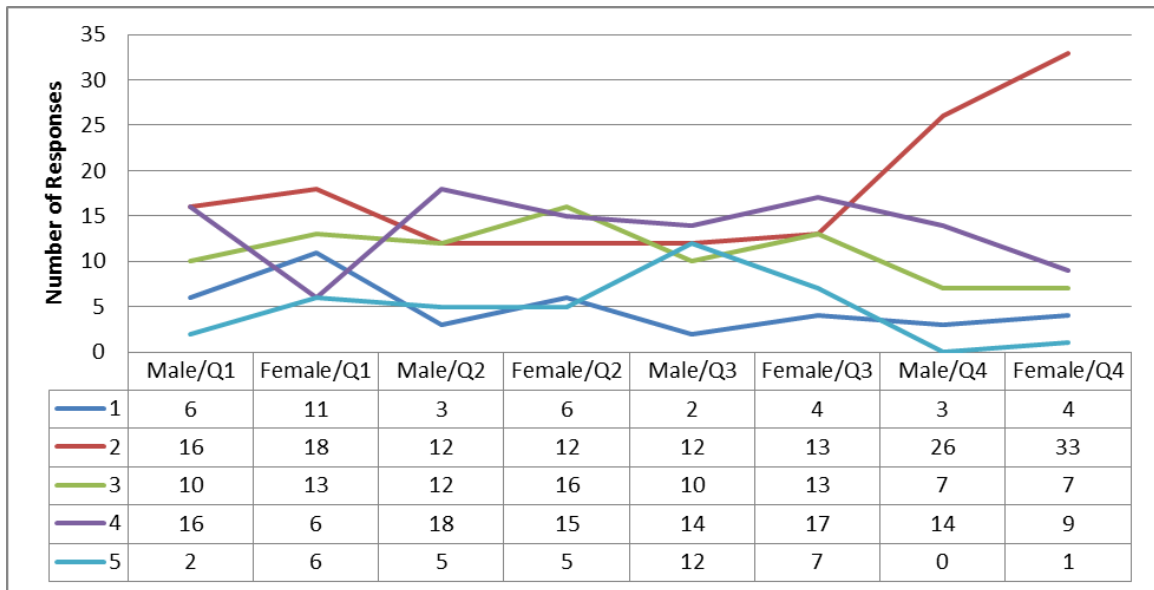


Figure 3. Privacy, Security, Consent Questions By Gender.

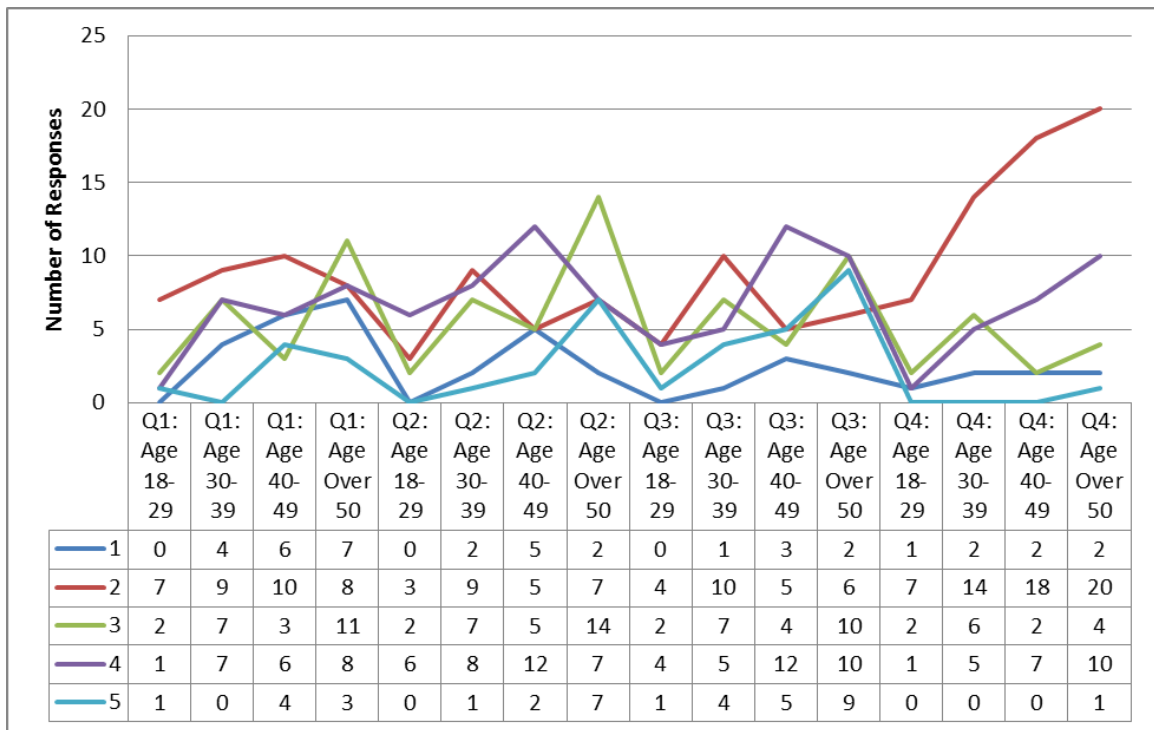


Figure 4. Privacy, Security, Consent Questions By Age Category.

The y-axis in Figure 3 is number of responses and the x-axis is question by gender. Additionally, each color on the line graph represents the coded responses, 1 through 5, for each question. Figure 3 shows that males and females mostly chose

“comfortable” for question #1, which relates to privacy of personal health information. However, there was also an equal amount of males who chose “somewhat not comfortable” compared to “comfortable”. For question #2, most males chose “somewhat not concerned” while most females answered “neutral”. For question #3, males and females mostly chose “somewhat not concerned” in regards to security of personal health information. For question #4, both males and females chose that they would “agree” if asked to sign a consent form allowing healthcare providers to utilize the health information exchange transfer method to transfer their personal health information.

On the other hand, Figure 4 outlines responses to questions #1 through #4 by age category. The y-axis is frequency of response while the x-axis is question by age category. From the initial observations, age categories 18-29, 30-39, and 40-49 years old mostly chose “comfortable” when asked if comfortable with personal health information being transferred using the “Computer to Computer” transfer method. However, age category over 50 years old mostly responded with “neutral”. For question #2, age category 18-29 and 40-49 years old mostly answered “somewhat not concerned” whereas age category 30-39 answered “slightly concerned”. For question #3 in regards to security, age category 18-29 years old had an even mix of mostly “slightly concerned” and “somewhat not concerned”. Age category 30-39 years old mostly chose “slightly concerned” to question #3. For age category 40-49 and over 50 years old, “somewhat not concerned” was a common response choice. In addition, “neutral” was also a commonly chosen response for age category over 50 years old for question #3. In regards to

question #4 pertaining to consent, all age categories overwhelming chose “agree” as the most common response.

Overall Sample Descriptive Findings

Initial observations from the mode results may indicate that beneficiaries in Central Texas are comfortable with the health information exchange transfer method but have reservations with transferring sensitive health information using this transfer method. Another thing to consider is that participants may have chosen “slightly concerned” thinking the responses for questions #1 and #2 were symmetrical but in reality the responses are inversely related. There may be a possibility that participants did not thoroughly read each question and chose a response quickly.

From the descriptive statistics calculated, participants that answered the survey were comfortable with the transferring of personal health information from Doctor A to Doctor B using the “Compute to Computer” transfer method. The participants would also agree to sign a consent form to allow healthcare providers to transfer private health information using the “Computer to Compute” method. The concern over sensitive health information being transferred using the “Computer to Computer” method is “slightly concerning” to participants. The inappropriate retrieval of personal health information using the “Computer to Computer” method is also “slightly concerning” to participants because their health information will not be safely and securely transferred using the health information exchange transfer method.

In addition, participants who mostly completed the survey were over 50 years old and resided in the 78717 zip code. The most common participants’ age category and zip

code that answered the survey may be a factor in the responses to questions #1 through #4. It is important to look at variations of the sample in order to analyze different associations and determine relationships among the sample. It is also necessary to investigate more detailed associations within the overall sample.

Bivariate Analysis

Pearson Product-Moment Correlation Coefficient outlined relationships between variables – privacy, security, and consent. Table 4 lists the Pearson correlation coefficient for each question.

Table 4

Pearson Product-Moment Correlation Coefficient for Survey Questions

	Privacy - Comfort	Privacy - Concern	Security	Consent	Gender	Age Category
Privacy - Comfort	1	.554**	.479**	.698**	-.104	.052
Privacy - Concern	.554**	1	.811**	.510**	-.081	.070
Security	.479**	.811**	1	.507**	-.107	.134
Consent	.698**	.510**	.507**	1	-.104	.116
Gender	-.104	-.081	-.107	-.104	1	-.072
Age Category	.052	.070	.134	.116	-.072	1

** . Correlation is significant at the 0.01 level

Correlations that are strong (> 0.50) resemble a stronger relationship between the two variables (Gravetter and Wallnau, 2004). For question #1 in regard to privacy comfort level in the health information exchange transport method, there is a strong positive relationship with question #2 (0.554) and question #4 (0.698) which pertain to concern

level with privacy and willingness to consent to the health information exchange transport method. Therefore, responses to question #1 reflect a similar response to question #4. Comfort level with privacy will elicit a willingness to consent to healthcare providers transferring person health information to other providers using the “Computer to Computer” method. Question #1 and #2 both pertain to privacy with the health information exchange transport method; however, question #2 looks at concern level instead of comfort level. Question #1 and #2 elicited a positive relationship (0.554) indicating that comfort level with privacy and concern level with privacy are associated. This also shows that the degree of privacy concern with the health information exchange transfer method will reflect a similar degree of security concern with the transfer method (0.811). In addition, an association between privacy concern and willingness to consent is positive (0.510).

For question #3 on security, there is a strong correlation with question #2 (0.811) which addressed concern level with personal health information being transferred through the health information exchange transport method. In addition, question #2 and #3 both addressed concern level, which shows that participants correlate the two questions and answer similarly. Consent and security also have a strong positive relationship (0.507) which indicates that these two variables associate and relate to each other.

There is a positive relationship between question #4 in regard to consent and privacy concern (0.510). There is especially a high correlation between consent and privacy comfort level (0.689) concerning personal health information being transferred

using the health information exchange transport method. Correlation results also show a strong positive relationship between consent and privacy (0.507).

In regards to age category, there is a slightly positive relationship between age category and the perception and acceptance of the health information exchange transport method in regards to privacy, security, and consent. The correlation between age category and privacy comfort level in relation to the health information exchange transport method is not significant (0.052) due to the minor correlation coefficient. The same goes with the correlation between age category and privacy concern level (0.070) which is not significant. In addition, the correlations between age category and security and age category and consent are 0.134 and 0.116 respectively, which are non-significant.

Assessment of Between-Group Ordinal Data Sets

Identifying any significance between specific population groups provided additional information on the perception of the health information exchange transport method in Central Texas. The addition of the Wilcoxon Rank-Sum Test assessed comparisons between two population groups and any differences in their perceptions of the health information exchange transport method. For this study, the Wilcoxon Rank-Sum Test used ordinal data from the survey results to determine any significance between two independent sample populations. This statistical test compared age categories and gender differences between males and females. The age category and gender populations were assessed because different age categories and genders may perceive the health information exchange transport method differently. Appendix D lists the Wilcoxon Rank-Sum Test results for each variable – privacy, security, and consent.

For gender, the Mann-Whitney U results for privacy (1170 and 1230.5) showed that there was no significant relationship between males and females when comparing perception levels of privacy in regards to the health information exchange transport method. The Mann-Whitney U results for security and consent (1190.0 and 1198.5) also showed that there was no significant relationship when comparing the perception levels of security and consent in regards to the health information exchange transport method between males and females. In addition, there is also no significant relationship in the perception level of privacy, security, and consent for the health information exchange transport method when comparing one age category with another age category. The age category 18-29/30-39 years old yielded non-significant results from the Mann-Whitney U test for each variable – privacy (143.0 and 116.5), security (137.0), and consent (126.5). For the compared age category 18-29/40-49 years old, the Mann-Whitney U test results for privacy (158.0 and 145.5), security (140.5), and consent (145.5) indicated no significant relationship between these two age categories. The 18-29/Over 50 years old results yielded the same non-significant relationship conclusion for privacy (183.5 and - .102), security (170.5), and consent (164.0) respectively. These results indicate no significant relationship between the compared age categories in relation to health information exchange transport method privacy, security, and consent perception levels when identifying relationships between two age category populations.

When comparing age categories 30-39/40-49 years old and 30-39/Over 50 years old in regard to the perception of the health information exchange transport method in relation to privacy (387.5, 356.0, 466.5, and 409.0), security (322.5 and 387.0), and

consent (373.5 and 469.0), the Mann-Whitney U test results reveal that there is no significance identified. Lastly, the population comparison for the two oldest age categories, 40-49 years old and Over 50 years old, resulted in no significant relationship in the perception levels between the two populations for variables privacy (514.5 and 497.5), security (518.5), and consent (483.0).

Conclusion

The utilization of descriptive and bivariate analyses to determine commonality in response choices and relationships between privacy, security, consent, and age category in relation to the perception of the health information exchange transport method provides results for this research study. In general, there was a strong positive relationship in regards to the perception and acceptance of the health information exchange transport method, which supports hypotheses one, two, and three. On the other hand, there was a positive relationship between age category and privacy, security, and consent in relation to the health information exchange transport method, which does not support hypothesis four. However, the correlation between age category and privacy, security, and consent was very small and in essence non-significant.

CHAPTER V

Discussion

This chapter addresses the implications from the survey findings and results. Privacy, security, consent, and age category analyzed to identify and determine relationships between privacy, security, and consent variables. Intra-associations within the sample are important to evaluate because it will help with recognizing formed relationships in the data.

Significance of the Study

For healthcare beneficiaries, the implementation of new technology that transfers personal health information to other health organizations is often frightening and unsettling because of privacy and security concerns (Ancker et al., 2012). Privacy, security, and consent raise questions on how to protect beneficiaries from their information improperly accessed or without proper authorization. The intent for HIEs as an organization and transport method needs to be justified so beneficiaries are more inclined to accept the usage of these for better coordination of care.

There also must be a certain level of privacy, security, and consent for beneficiaries to accept HIEs overall. Beneficiaries have their own perception and level of comfort when it comes to privacy, security, and consent. These issues need addressing in order to influence others to see the importance of the health information exchange transport method and its benefits and opportunities to the healthcare industry. As mentioned in a previous study, a majority of beneficiaries have expressed their concerns with the health information exchange transport method in relation to privacy and security

and would not accept this transport method unless these concerns are addressed (Ancker et al., 2012).

Review of Research Study

The purpose of the research study was to explore perception and acceptance of the health information exchange transport method in relation to privacy, security, and consent for healthcare beneficiaries residing in the Central Texas area. The results obtained in this study further supported previous literatures that indicated that beneficiaries accepted the health information exchange transfer method; however, there are still concerns over the handling of privacy, security, and consent with the transfer method. In addition, this research study had three out of four hypotheses supported by the findings.

In analyzing the line graph for question responses by gender, it shows that both males and females are “comfortable” with personal health information being transferred using the health information exchange transfer method. In regards to concern over sensitive health information being transferred using the health information exchange method, most men are “somewhat not concerned” while most females answered “neutral” to the question. For question #3 pertaining to security, both males and females mostly chose “somewhat not concerned” with inappropriate retrieval of personal health information when the health information exchange transfer method was used. Lastly in regards to consent (question #4), “agree” was overwhelming the chosen response when asked if they would provide consent to allow healthcare providers to use the health information exchange transfer method to transfer their personal health information. From

initial observations, it seems that there is no significant difference in how males and females perceive the health information exchange transfer method as it pertains to privacy, security, and consent. Age category over 50 years old again answered mostly “neutral” to question #2.

The results in this study indicated that the small sample assessed in this research study overall accept the health information exchange transport method in the Central Texas area. Beneficiaries in the Central Texas area are comfortable yet only slightly concerned with privacy and their personal health information being transferred through the HIE transport method. There was also a significant amount of beneficiaries residing in the Central Texas area who would sign a consent form to allow healthcare providers to transfer their personal health information through the HIE transport method. This information showed that the level of acceptance of the health information exchange transfer method is evolving. The healthcare beneficiaries’ perceptions of the HIE transport method in relation to privacy, security, and consent is positive and engaging. In addition, beneficiaries from this study do not seem too worried about lack of privacy and security with the health information exchange transport method. Based on this study, even age did not seem to be a significantly identifying factor on whether beneficiaries would perceive and accept the health information exchange positively or negatively.

This research study’s findings mostly coincide with perceptions of the health information exchange organization and transfer method in a nationwide view. In conclusion, individuals see the benefits and usefulness of the health information exchange transfer method; however, have some reservations about the privacy and

security of the method (Rudin, Motala, Goldzweig, & Shekelle, 2014). In addition, individuals are concerned about “how permission is given to share information” but “states that had laws requiring authorization from patients before the disclosure of health information were more likely to have operational HIEs” (Rudin et al., p. 807, 2014). This shows that individuals are likely to agree to the health information exchange transfer method if given the opportunity to provide consent, which matches with this study’s findings in regards to consent.

With regards to age, older individuals had their personal health information accessed the most, which is important for older individuals to accept and realize the benefits of the health information exchange transfer method (Campion, Edwards, Johnson, & Kaushal, 2013). The healthcare industry is trending towards more elderly individuals who need healthcare services as the baby boomer generation ages. In this research study, the individuals over 50 years old had open and positive perceptions of the health information exchange transfer method.

The healthcare industry is evolving towards advanced techniques and technology that will improve quality and efficiency of care. Various stakeholders such as providers, policymakers, and patients have noticed that the “HIE is valuable to health care particularly in terms of quality and efficiency” (Rudin et al., pg. 807, 2014) however, there are still some skepticism and barriers. Health information exchange organizations want to continuously grow the participation and usage of HIEs. Privacy, security, and consent are highly discussed when it comes to implementing the health information exchange transfer method. Indiana HIE met the challenge of addressing privacy,

security, and consent by ensuring patients first consented to healthcare providers accessing their personal health information and promoting collaboration between all stakeholders and parties involved (Morizio, 2014). This type of implementation used may expand HIEs in the nation, which will grow the acceptance of the health information exchange transfer method in futures to come.

With the Wilcoxon Rank-Sum Test, the test verified that there is no significant group difference between gender comparisons and age category comparisons when identifying relationships pertaining to the perception levels of the health information exchange transport method in relation to privacy, security, and consent. Additionally, the Wilcoxon Rank-Sum Test was used for this research study because of the ordinal data obtained from the survey results. Specifically for the age categories, the age groups for the Wilcoxon Rank-Sum Test matched the age grouping categories from the survey. Appendix D lists the Wilcoxon Rank-Sum Test results for differences between gender and age category populations. In general, there is wide-spread concern for the privacy and security of the health information exchange organization and implementation of safeguards to ensure beneficiary participation is necessary (Patel et al., 2012). Furthermore, there is a need for more beneficiaries to consent to the health information exchange organization in order to persuade others to accept this concept and its purpose (Patel et al., 2012).

The sustainability of HIEs depends on the common barriers from all stakeholders addressed such as workflow strategy, disruption, and privacy/security concerns (Morizio, 2014). This corresponds with this research study's findings that the majority of

participants are open, comfortable, and willing to accept the health information exchange transfer method. The variables of privacy, security, and consent are barriers but with the appropriate strategies, beneficiaries will more likely perceive and accept HIEs as a method to improve quality of care.

However, there is a possibility of multicollinearity between privacy, security, and consent because the variables are assumed to be quite predictive of each other in terms of perceived, overall acceptance of HIEs in Central Texas. Such correlation results assessed during the data analysis portion of the study, to include identification of potential confounding variables inherent within. Overall, there is a sense of multicollinearity between the results from questions #1 through #4 due to variables being similar in nature to healthcare beneficiaries.

Scope and Limitations. The scope of this study explored the perception and acceptance of HIEs in relation to privacy, security, and consent. The research was limited to only these three protection measures in order to isolate which one or combinations of measures were more highly weighted towards the acceptance of the HIE transport method. Privacy, security, and consent are also the most looked at concerns among beneficiaries accepting and participating in the HIE transport method (Hess, J., 2011). Since Central Texas was the focus of the study, the region's HIEs were not considered nor the development of the HIE in any particular region.

Another limitation of the study was that it only yielded a small convenient sample size (n = 104) of the Central Texas population. The location of the public parks also may have resulted in a certain demographic population segment sampled. There were more

paper surveys collected at the Brushy Creek Park compared to the Lady Bird Lake Hike and Bike Trail due to the number of park visitations. There was no consideration of reason and type of healthcare encounter or experience because the study focused on overall personal perception regardless of type of healthcare experience. Another limitation was that participants answered based on current idea, knowledge, and their personal understanding of HIEs since HIEs are not as widely used at this time. Finally, there is a strong possibility of multicollinearity between privacy, security, and consent variables, as they are assumed to be quite predictive of each other in terms of perceived, overall acceptance of HIEs in Central Texas. Based upon subject comments while taking the survey, often times such defined variables were seen as similar, even the same, as interpreted differently by the subject.

Assumptions. Several assumptions were made in this study which focused on HIE privacy, security, and consent. There are assumptions based on information from literature reviews and health information technology resources and trending articles. An assumption was that beneficiaries have had several healthcare visits/encounters throughout their lifetime and understand the deliverance of healthcare services. In order for the transference of personal health data through the health information exchange transport method, beneficiaries must see healthcare providers and share information during a visit/encounter. Another assumption was that wherever a beneficiary seeks healthcare services, there is the ability of providers to transfer and access data through HIE organizations.

There was also an assumption of the following of regulations and policies pertaining to HIE usage (Sarrico and Hauenstein, 2011). With the discussions about privacy, security, and consent, the assumption was that the health information exchange transport method has protection measures implemented that affect it directly. For example, the Health Information Security & Privacy Collaboration (HISPC) analyzes consent data in regards to intrastate and interstate policies and privacy laws for HIEs (“Federal-State Privacy,” 2013). In addition, the Health Insurance Portability and Accountability Act (HIPAA) provide regulations and policies for covered entities to follow.

Conclusion

This research study provided a reference for future studies that look at HIE organizations and the transport method as it continuously grows and advances in the healthcare industry. It is important to analyze where health information exchanges as a transport method stand at this point for beneficiaries who seek healthcare services. It is also important to analyze the health information exchange transport method through the perceptions of beneficiaries residing in the Central Texas area. There may be differences in how beneficiaries view the HIE transport method in different areas and regions. This study definitely provided a beginning outlook on where perceptions of HIEs privacy, security, and consent stand in Central Texas. The value of the study was to assess how beneficiaries in Central Texas perceive the health information exchange transfer method during times of increasing HIE usage due to healthcare reform initiatives.

From this research study, future research would provide value in further understanding the health information exchange organization and its acceptance by others. Prior to this research study, there was no study focused just on the Central Texas region. Moving forward, comparisons between Central Texas and other regions in Texas or other states would be compelling in identifying trends of perception and acceptance to the health information exchange. Additional research, perhaps from other regions/states, would be beneficial in seeing if beneficiaries from other regions/states would produce the same or different results in regards to perception of the health information exchange transport method when pertaining to privacy, security, and consent. Regions/states may have specific demographics that are unique to that area and could be telling about the perception and acceptance of the health information organization in different areas.

Another opportunity for future research would be to look at different sample populations such as education level and career field to see if the level of perception and acceptance of the health information exchange transport method in regards to privacy, security, and consent would be different. The research would identify relationships and correlations between two different populations similar to this research study which analyzed gender and age category populations. By comparing different types of populations, the data gathered would provide an insight into which type of beneficiaries are intrigued and accepting of the health information exchange and which type of beneficiaries are still uncomfortable, concerned, and not as accepting.

In addition, future research with a larger sample size would be essential in obtaining more data on the beneficiaries' perception and acceptance of the health

information exchange transport method. With continued research on this concept, the perception and acceptance may change to lesser or greater acceptance of the health information exchange. From this starting point, the research for perceptions and acceptance of the health information exchange transport method can go much further in truly identifying and analyzing what, if any, gaps that are causing beneficiaries to question the health information exchange as it pertains to privacy, security, and consent.

APPENDIX SECTION

Appendix A:

HEALTH INFORMATION EXCHANGE CONSENT FORM

In this Consent Form, you can choose whether to allow the health care providers listed on the attachment to the Consent Form ("Participating Providers") to obtain access to your medical records through a computer network operated by NYU Langone Medical Center ("NYULMC HIE") and for NYU Hospitals Center to access your medical records through a computer network operated by NYCLIX, which is part of a statewide computer network. This can help collect the medical records you have in different places where you get health care, and make them available electronically to the providers treating you.

You may use this Consent Form to decide whether or not to allow NYU Hospitals Center and the Participating Providers to see and obtain access to your electronic health records in this way. You can give consent or deny consent and this form may be filled out now or at a later date. **Your choice will not affect your ability to get medical care or health insurance coverage. Your choice to give or to deny consent may not be the basis for denial of health services.**

The NYULMC HIE and NYCLIX share information about people's health electronically and securely to improve the quality of health care services. This kind of sharing is called ehealth or health information technology (health IT). To learn more about ehealth in New York State, read the brochure, "Better Information Means Better Care." You can ask your health care provider for it, or go to the website www.ehealth4ny.org.

Please carefully read the information on the back of this form before making your decision.

Your Consent Choices. You can fill out this form now or in the future. You have the following choices:

Please check Box 1 or 2:

1. I GIVE CONSENT to ALL of the Participating Providers listed on the attachment to this Consent Form to access ALL of my electronic health information through the NYULMC HIE in connection with providing me any health care services, including emergency care and I GIVE CONSENT to NYU Hospitals Center to access ALL of my electronic health information through NYCLIX in connection with providing me any health care services, including emergency care.

2. I DENY CONSENT to ALL of the Participating Providers listed on the attachment to this Consent Form to access my electronic health information through the NYULMC HIE for any purpose, *even in a medical emergency* and I DENY CONSENT to NYU Hospitals Center to access ALL of my electronic health information through NYCLIX for any purpose, *even in a medical emergency*.

NOTE: UNLESS YOU CHECK THE “I DENY CONSENT” BOX, New York State law allows the people treating you in an emergency to get access to your medical records, including records that are available through the NYULMC HIE and NYCLIX.

Print Name of Patient

Patient Date of Birth

Signature of Patient or Patient’s Legal Representative

Date

Print Name of Legal Representative (if applicable)

Relationship of Legal Representative
to Patient (if applicable)

Appendix B:

Survey for Health Information Exchange Privacy, Security, and Consent

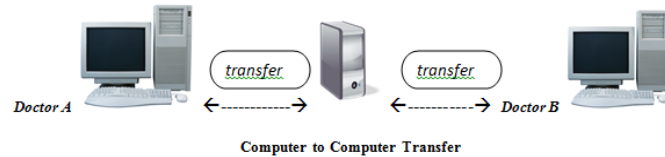
By completing this survey, you are providing consent to be a participant in this research study.

Instructions:

From the questions on this survey, please circle the best choice that represents your perception of health information exchanges. A health information exchange is a transport method for healthcare providers and beneficiaries to electronically and securely access personal health information.

Privacy

1. From the picture below, how comfortable are you with personal health information being transferred from Doctor A to Doctor B?



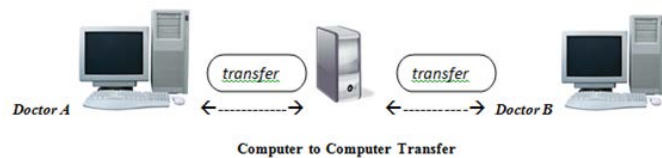
- A) Very Comfortable
- B) Comfortable
- C) Neutral
- D) Somewhat Not Comfortable
- E) Not Comfortable

2. How concerned are you with your potentially sensitive, personal health information being transferred using the “Computer to Computer” transfer method (ex: contagious diseases)?

- A) Very Concerned
- B) Slightly Concerned
- C) Neutral
- D) Somewhat Not Concerned
- E) Not Concerned

Security

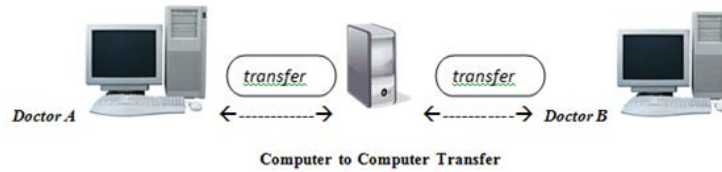
3. How concerned are you with inappropriate retrieval of your personal health history with the “Computer to Computer” transfer method?



- A) Very Concerned
- B) Slightly Concerned
- C) Neutral
- D) Somewhat Not Concerned
- E) Not Concerned

Consent

4. In general, would you agree to sign a consent form to permit healthcare providers to transfer your private health information using the transfer method below?



- A) Strongly Agree
- B) Agree
- C) Neutral
- D) Disagree
- E) Strongly Disagree

Demographic Questions (circle option that applies)

I. Gender

Male Female

II. Age Category

18-29 years old 30-39 years old 40-49 years old Over 50 years old

List your residence zip code: _____

Appendix C:

Survey for Health Information Exchange Privacy, Security, and Consent – Coding Structure

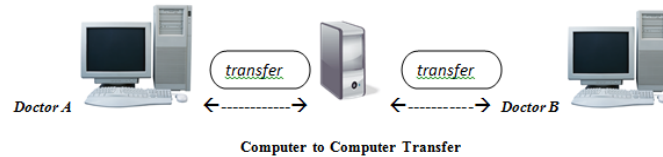
By completing this survey, you are providing consent to be a participant in this research study.

Instructions:

From the questions on this survey, please circle the best choice that represents your perception of health information exchanges. A health information exchange is a transport method for healthcare providers and beneficiaries to electronically and securely access personal health information.

Privacy

1. From the picture below, how comfortable are you with personal health information being transferred from Doctor A to Doctor B?



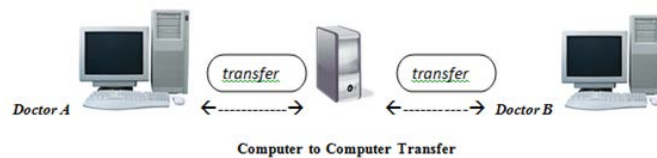
- A) Very Comfortable (1)
- B) Comfortable (2)
- C) Neutral (3)
- D) Somewhat Not Comfortable (4)
- E) Not Comfortable (5)

2. How concerned are you with your potentially sensitive, personal health information being transferred using the “Computer to Computer” transfer method (ex: contagious diseases)?

- A) Very Concerned (5)
- B) Slightly Concerned (4)
- C) Neutral (3)
- D) Somewhat Not Concerned (2)
- C) Not Concerned (1)

Security

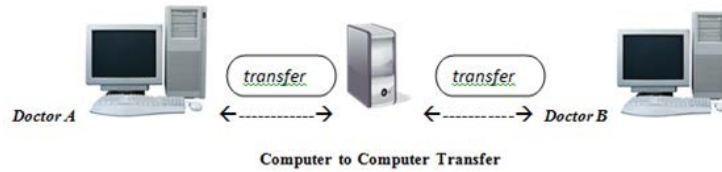
3. How concerned are you with inappropriate retrieval of your personal health history with the “Computer to Computer” transfer method?



- A) Very Concerned (5)
- B) Slightly Concerned (4)
- C) Neutral (3)
- D) Somewhat Not Concerned (2)
- C) Not Concerned (1)

Consent

4. In general, would you agree to sign a consent form to permit healthcare providers to transfer your private health information using the transfer method below?



- A) Strongly Agree (1)
- B) Agree (2)
- C) Neutral (3)
- D) Disagree (4)
- E) Strongly Disagree (5)

Demographic Questions (circle option that applies)

III. Gender

- Male (1) Female (2)

IV. Age Category

- 18-29 years old (1) 30-39 years old (2) 40-49 years old (3) Over 50 years old (4)

List your residence zip code: _____

Appendix D:

Wilcoxon Rank-Sum Test for Differences Between Gender and Age Categories

Gender

	Mann-Whitney U	Z Value	Significance (2-tailed)
Privacy - Comfort	1170.000	-1.208	.227
Privacy - Concern	1230.500	-.804	.421
Security	1190.000	-1.072	.284
Consent	1198.500	-1.099	.272

Age Category 18-29/30-39 Years Old

	Mann-Whitney U	Z Value	Significance (2-tailed)
Privacy - Comfort	143.000	-.186	.852
Privacy - Concern	116.500	-1.082	.279
Security	137.000	-.386	.700
Consent	126.500	-.783	.434

Age Category 18-29/40-49 Years Old

	Mann-Whitney U	Z Value	Significance (2-tailed)
Privacy - Comfort	158.000	-.048	.962
Privacy - Concern	145.500	-.449	.654
Security	140.500	-.601	.548
Consent	145.500	-.491	.624

Age Category 18-29/Over 50 Years Old

	Mann-Whitney U	Z Value	Significance (2-tailed)
Privacy - Comfort	183.500	-.506	.613
Privacy - Concern	199.500	-.102	.919
Security	170.500	-.834	.404
Consent	164.000	-1.078	.281

Age Category 30-39/40-49 Years Old

	Mann-Whitney U	Z Value	Significance (2-tailed)
Privacy - Comfort	387.500	-.068	.946
Privacy - Concern	356.000	-.605	.545
Security	322.500	-1.166	.243
Consent	373.500	-.330	.741

Age Category 30-39/Over 50 Years Old

	Mann-Whitney U	Z Value	Significance (2-tailed)
Privacy - Comfort	466.500	-.462	.644
Privacy - Concern	409.000	-1.273	.203
Security	387.000	-1.574	.116
Consent	469.000	-.454	.650

Age Category 40-49/Over 50 Years Old

	Mann-Whitney U	Z Value	Significance (2-tailed)
Privacy - Comfort	514.500	-.291	.771
Privacy - Concern	497.500	-.519	.604
Security	518.500	-.240	.810
Consent	483.000	-.777	.437

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