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Emerging technological innovations such as personal health records (PHRs), electronic health records (EHRs) and the nationwide health information network (NHIN) provide the ability to increase the sharing of medical records among healthcare stakeholders. The goal of these innovations is to improve the quality of human healthcare by accessing medical information at the point of care and decreasing medical errors. Technology allows for widespread access to patient medical information, giving providers a comprehensive view of a patient's medical history so that they can make better decisions. The capability to use technology to electronically exchange medical records is called Healthcare Information Exchange (HIE).

Recent studies have shown that patients want more control over their medical records. HIE technology can allow patients to control their medical records. Because patients often have chronic illnesses and can be transient when using different providers for care, HIE technology can support patient access and control over the sharing of their medical information between doctors. Therefore, the concern for patient empowerment has emerged within the healthcare community's discussions on HIE technology and policy efforts.

A careful review of the literature shows that there is no existing theory of consumer empowerment in HIE, therefore a qualitative approach was utilized. There are two phases to this study: the first reveals the dimensions of consumer empowerment through discussions of United States federal and state empowerment groups as well as individual everyday consumers who do not work in healthcare or information technology fields. Through this investigation of the quest for consumer empowerment in HIE, it was found that Consumer Confidence in HIE, Fairness in HIE, and Consumer Commitment and Engagement in HIE are three dimensions that support consumer empowerment in HIE. These dimensions foundational to the second phase, which describes ways that consumer empowerment may be achieved in HIE. A theory is generated which can aid practitioners in developing and implementing appropriate HIE policy and technology. Academicians can build upon this theory for future research in areas such as incorporating consumer input into HIE technology systems analysis and design and examining the success of initiatives to achieve consumer empowerment in HIE.

CONSUMER EMPOWERMENT IN HEALTHCARE INFORMATION EXCHANGE: AN INVESTIGATION USING THE GROUNDED THEORY APPROACH

by

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To my family who provided me with invaluable support which allowed me to pursue a project which became my passion (and sometimes obsession). To Jim for his encouragement during a challenging journey; to Annabel and Tristan, who inspire me with their spirit of excitement and exploration; and to my parents, who gave much of themselves to help me persevere through my many years of education.

APPROVAL PAGE

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INTRODUCTION

Background

> Twenty-first century health care means untethering care from the doctor's office to weave health care and disease management into people's lives. It's empowering consumers to be active participants in their care rather than passive recipients.
>
> ----U.S. Representative Patrick Kennedy (HIMSS, 2007)

The United States healthcare industry is currently experiencing a transformation. Due to recent technological advances in the field such as electronic health records (EHRs; a list of acronyms is available in Appendix E) and the nationwide health information network (NHIN), patient information can be shared among many healthcare providers towards the goal of reduced medical errors and increased quality of care. It has been estimated that as many as 400 people may have access to one's personal medical information throughout the typical care process (Mercuri, 2004). This increased availability for healthcare partners to access sensitive medical information, while pursuing positive goals,

also has negative effects. There have been instances where employees have sought medical care and their personal health information (PHI) has been disclosed, without patient consent, to their employers, ex-spouses, and insurance companies, resulting in higher premiums and other unintended consequences (Ferris, 2006; Rindfleisch, 1997).

Patients are more aware now of these negative consequences of using technology to store and transmit information, primarily through news stories of unauthorized disclosures in financial institutions and medical institutions. However, patients lack empowerment to control the disclosure of their sensitive health information through new technological innovations. States such as North Carolina have found that their citizens' consumer protection worries include not receiving copies of their medical records when requested from the physician's office (North Carolina Attorney General's Office, 2006). A survey by the California HealthCare Foundation (Broder, 2006) found that most U.S. consumers want to have control over who accesses their medical information and that only three percent used an online medical record service (personal health record). However, in a study conducted by Price Waterhouse Cooper (2006) that asked "Do you believe that having an electronic health record would improve the quality of care you would receive?" 42% of respondents said that they were unsure, because they would need more information.

Of the 800 people surveyed by the California HealthCare Foundation, 264 suggested that they were not comfortable with their insurance company sharing medical information with hospitals and almost half shared a fear of information being accessible through the Internet without their control (Broder, 2006). Some also responded that they did not trust healthcare entities to protect the privacy of their information. Also, it has been suggested that specialized populations such as minority groups or patients with specific 'stigmatizing' conditions such as HIV or mental illness may have different levels of trust to share information than other populations (Hall, et al, 2001). Many state privacy laws have been enacted for the purpose of addressing mental health and HIV/AIDS confidentiality issues to "encourage people to seek appropriate care, without fearing harmful reprisals. . . .In order to encourage people to seek testing, counseling, treatment, and other health services, many states have established heightened protection for people with mental illness HIV/AIDS, drug and alcohol dependence, and other circumstances where people face stigma, discrimination, and embarrassment." (Congress, May 1999). If patients do not trust that their sensitive medical information will be kept private, they may not share information with the physician or, worse, may not seek treatment (Rindfleisch, 1997).

A patient's trust in the security and privacy of their medical data may affect how they share their information. Currently what is not clear is patients'

awareness of the “trade-offs between legitimate concerns about their privacy and the benefits of making more complete information available to the providers” so that they can provide optimal care based on more comprehensive information (Tang & Lansky, 2005, p. 1292). The patient is the person with the most at stake and is in the best position to provide information to providers (Markle, 2006). This suggests that a patient currently places trust in providing information to physicians since physicians control access to medical records to provide treatment, resulting in a power disparity in the doctor/patient relationship. Providers, therefore, are perceived to hold control over access to medical records and how such sensitive information is shared.

In another study (Lake Research, 2006), Americans expressed concern that their PHI would be shared and utilized for non-medical purposes such as identity theft, fraud, and marketing purposes (such as target marketing for specific medications or health-related products). Outside of the entities who utilize medical information for patient care purposes, secondary users of healthcare data are researchers, marketing departments and businesses, public health organizations, insurance companies, and hospital accreditation companies. Many patients may not realize the extent that data mining techniques are used on databases that store medical information, and the electronic health record is prime for such examinations.

The state and federal government, as well as other healthcare-related research endeavors, find that vital healthcare statistics are found more easily in larger databases. There are logical reasons for this, especially to find healthcare patterns and trends (such as flu pandemics or patterns in heart disease throughout the country) and to determine what policies and funding are needed. This data mining extends mainly to information that is de-identified and aggregated—meaning that any patient identifiers such as social security numbers are disguised. However, Dr. Barry Hieb, a health care research director at Gartner Research states that:

> . . .the really difficult thing is a thing called inferencing. You look at a set of data and you say, 'Gee, this is a patient in the Cincinnati area. I don't have the name, but I do have her birth date and can go find some other piece of information,' such as they had an appendectomy on July 14, and then you tag some other source, and before you know it, you know who the person is (Ferris, 2006, Government Health IT Website).

"The lack of coherent policies and practices for the secondary use of health data presents a significant impediment to the goal of strengthening the US healthcare system" (American Medical Informatics Association (AMIA), 2006, AMIA Website).

The Need for Health Information Exchange

Primary stakeholders in health information exchange (HIE) include the physicians, hospitals, pharmacies, insurance companies, legislators, government organizations, and patients/consumers. Henceforth, the term 'consumer' is used to include both patients and their caregivers, if the patients themselves may not be capable of taking on a decision-making role in their healthcare. An example is a caregiver of an elderly parent or child. Many reasons have been given for the necessity to share medical information across entities. One is that the goal of health information exchange is to improve the quality of healthcare, thus the quality of human health. HIE it utilizing information systems and technology for electronic storage, retrieval, and sharing of healthcare information among participants in the healthcare system so that information is accessible at the point of care. For example, the mission of the Indiana Health Information Exchange is to provide "services that streamline the healthcare industry by delivering information at the most critical time: the point-of-care. The organization's Quality Health FirstSM service provides clinicians with a summary of various aspects of care across all of their patients, along with peer comparisons to help improve

overall patient health."[1] If healthcare information can be stored and exchanged in a way that a comprehensive medical history is available to the provider at the point-of-care, it is logical to assume that better healthcare decisions can be made. Healthcare information exchange may allow consumers to access their medical records and manage their own healthcare. Quality of health is critical, as emphasized by the following statement by U.S. Senator Kennedy (HIMSS, 2007, website):

> One out of every 7 primary care visits is affected by missing medical information. More than 40 percent of Americans have been affected by a medical error, either personally or through a friend or relative . . . [Health information technology] places control over health care in the individual's own hands, through personalized electronic health records. . . .

In a study by California HealthCare Foundation, about 40% of the responding Californian physicians stated that within the past year, their patients had experienced problems because coordination of care did not occur across multiple healthcare providers' sites (2007). In the same study, 21% of the responding physicians stated that, because the necessary health information wasn't available at the point-of-care, there were patients who had repeated tests.

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[1] Indiana Health Information Exchange. *Mission*. Retrieved May 2008 from http://www.ihie.com/mission.htm.

And, due to the many silos of health information at different providers' offices, 57% of the physicians felt that it was difficult to compile a comprehensive list of patient medications, therefore understanding which medications could put the patient at risk for interactions. Because there are an increasing number of patients with chronic illnesses or patients who are transient (moving from one doctor to another, perhaps due to changes in employment and insurance coverage), it will be critical to improve the management of information so that it is accessible at the point of care and will improve health outcomes. Ultimately, the goal is to catch illnesses before the conditions become chronic.

What is of concern to many patient privacy advocacy groups such as the Health Privacy Project is that patients currently do not have a knowledge of HIE technologies such that they will be able to make informed decisions as to disclosure of their medical information.[2] In the Lake Research 2006 study, it was found that Americans felt that personal health records would allow them more control over their health so they could track symptoms and the status of their healthcare through the Internet. This was the feeling of 82% of parents who wanted access to track their children's health records for information such as immunization dates. The majority of respondents (80%) also felt that an

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[2] From Health Privacy Project (2007) Retrieved February 2008 at www.healthprivacy.org.

advantage of accessing their records is to be able to manage the financial aspects of their healthcare. Approximately 84% of those surveyed by Lake Research were interested in checking the accuracy of their electronic records, of which African Americans and Latinos expressed the greatest concern. Respondents also felt that having this access would improve the communication with their physicians.

Although a concern of consumers is the unauthorized sharing of their information, many Americans also felt it necessary to share information under certain circumstances. These included (Joch, 2007): 73% of the respondents would be comfortable sharing information for public health purposes (detecting outbreaks) and 58% for information collection on bio-terrorist attacks, while 72% were willing to share information for improvement of care through clinical research, and 71% felt that sharing information for detection of medical fraud was appropriate. These responses were based on the assumption that appropriate safeguards and identity protection would be enforced. The capability to provide audit trails of data access by individuals or organizations is an advantage of HIE (Joch, 2007).

In his article on Health-e Connections, Slone (2007) discusses the primary advantages of sharing medical information electronically. Slone (2007) states that electronic records can serve as a permanent, timely, comprehensive health

record which can be accessed from anywhere, and in case of disaster, such as Hurricane Katrina. Electronic health records also allow the personalization and standardization of care, typed records which are legible and easily interpreted, and less duplicated paperwork. The risk of drug interactions, complications, missed tests or duplicate tests can be decreased with health information exchange (HIE) between healthcare providers (HIMSS, 2007). Fortunately, HIE technology enables medication errors to be decreased (Slone, 2007). Also, the capability to monitor public health is now available to detect trends or disease through shared and aggregated health information (Ferris, 2006). All of these advantages add up to two primary benefits: less cost for providing healthcare and improved human health. Information technology (IT) innovations may enable these advantages of HIE and are discussed next.

Technological Innovations for HIE

HIE is the process of utilizing information systems and technology for electronic storage, retrieval, and sharing of healthcare information among participants in the healthcare system so that information is accessible at the point of care. There are generally three different types of technology which support HIE and are used to store patient health information— Electronic Medical Records (EMR), Electronic Health Records (EHR), and Personal Health Records (PHR). The EMR is the electronic equivalent of the existing paper medical

record, typically used in one organization (Larsen, 2006). The Electronic Health Record EHR is a “secure, real-time, point-of-care, patient-centric information resource for clinicians” (Handler et al., 2003, website), which allows the sharing of patient information between organizations for improved quality of care. President Bush has mandated that healthcare providers adopt an EHR by 2014 (Slone, 2007). The PHR is “an electronic application through which individuals can maintain and manage their health information. . .in a private, secure, and confidential environment” (U.S. DHHS, website). “Since this [PHR] approach empowers individuals to control all access to their own health information, it gives each consumer the freedom to establish their own personalized privacy policy” (Enrado, 2006, website) and decide how it will be shared across organizations such as the Regional Health Information Organization (RHIO) and U.S. Nationwide Health Information Network (NHIN). Both RHIOs and the NHIN will enable an infrastructure for sharing patient information across organizations such as hospitals, providers’ offices, insurance companies, and government agencies for public health surveillance.

Due to privacy and security concerns, there is a rising concern to address how patients can become more involved in how their medical information may be shared through HIE technology. Access via smart cards or the Internet by either the patient, healthcare partners, or patients results in vulnerable PHI unless a

secure technical infrastructure is in place. Janlori Goldman, privacy advocate and member of the Health Privacy Project (1999) calls for a "reversal of the technological status quo by demanding that technology be designed to empower individuals." This can be achieved by shifting the balance of power between "the individual and those seeking personal information," for example, through giving control of medical information to the patients. With the advent of EHR and PHR technology, some patients have become savvier and want not only access, but the ability to control their information, for example, by annotate information in the medical record and carrying a smart card or flash drive containing the data (Chan et al, 2001).

Concerns In Disclosing Personal Health Information

> Anything you do to make information more accessible for good, laudable purposes will simultaneously make it more accessible for evil, nefarious purposes. People intuitively understand that, and they are worried.
>
> --Dr. William Yasnoff (Pear, 2007, p. 1.22)

A RHIO, the California Care Data Exchange, which was the longest-running U.S. RHIO effort, has closed due to privacy concerns and costs (Robinson, 2007). The primary issue was not the interoperability or security of the technology, but legal concerns of the involved entities regarding the

possibility of the data being accessed by an unauthorized source (Robinson, 2007). However, due to these hurdles, healthcare entities contemplate whether to share information and, if so, how to implement such a hefty task to avoid unauthorized disclosures.

Most unauthorized disclosures of medical information are from within the organization (Gue, 2004), whether intentional or not. This has major implications for the healthcare provider. It has been suggested that culture of the organization affects how policy can be implemented and enforced (Gordon, 1991). If the culture values communication and training of policy and enforces policy, the organization will become more deeply compliant to these policies (Trevino, 1986). People "are the heart and soul of secure systems . . .and require awareness, literacy, training, and education in sound security practices for system to be secured" (Maconachy, 2001, p. 308). There may be policies in place to regulate security of medical information through employee behavior, but if employees do not comply with such policies, healthcare information is at risk of improper disclosure.

Another hurdle is the potential conflict in state and federal privacy laws. There are variations in state and federal privacy regulations (Slone, 2007; North Carolina Healthcare Information Security and Privacy Collaboration (HISPC), 2007), which create barriers to health information exchange. For example, North

Carolina has two statutes, NCGS 8-53 (North Carolina General Statute) and NCGS 122C-55(i) which conflict with federal Health Information Portability and Accountability Act of 1996 (HIPAA) regulation in regards to how information may be shared (NC HISPC, 2007).

The interpretation of these two laws varies among physicians as discovered by a federally-funded study to examine the barriers and solutions to healthcare information exchange through a project called HISPC (Health Information Security and Privacy Collaboration). HISPC was funded for 32 state projects so that a comprehensive view of sharing medical information within the U.S. states could be investigated. North Carolina was one of the states to be awarded such a project through North Carolina Healthcare Information and Communications Alliance (NCHICA). NCGS 8-53 "establishes the physician-patient privilege, which protects information patients share with their physicians from release to third parties without the patient's consent or a court order" (NC HISPC, 2007, p. 37). This means that confidential medical information should be "furnished only on the authorization of the patient" or caregiver" (p. 37). This conflicts with HIPAA which states "A covered healthcare provider may, without consent, use or disclose protected health information to carry out treatment, payment, or healthcare operations" (45 CFR 164.506 (2) (Code of Federal

Regulations). The second North Carolina statute NCGS 122C-55(i), which conflicts with HIPAA's disclosure for treatment feature, and:

> allows for release of mental health and substance abuse information without patient authorization to the physician or psychologist who referred a patient to the facility, but it fails to provide for the release of this information without authorization to any other physician who currently is treating the patient. (NC HISPC, 2007, p. 38).

Other reasons stated as challenges for sharing medical information include:

1. *Unauthorized disclosure of sensitive information* (Clemens and Hitt, 2004; Botkin, 2001; Ferris, 2006; AMIA, 2006)—These include disclosures of information to unauthorized entities or individuals such as employers, marketing agencies, or clinical researchers. It also includes disclosure from theft, accidental release, or purposeful (but unauthorized) release.

2. *Lack of security and policy standardization across entities* (NC HISPC, 2007)—This is a concern because some privacy and security regulations are not standardized across state and federal government policies. Also, organizations involved in healthcare information exchange (HIE) may have diverse policies regarding the sharing of information.

3. *Accurately matching patient search to the correct patient* (Ferris, 2007)—When organizations involved in HIE share information, employees often need to search for a particular patient's medical record through the computer systems. When doing so, the employee should be sure that the correct patient's record has been chosen. The example given by Ferris (2007) is that of the boxer George Foreman, who named his five sons after himself. There need to be technological algorithms developed to suggest how accurate the patient match is, based on patient name, birthdate,

address, or other unique factors. Otherwise, the use of HIE would be damaging to human health.

4. *Quality of the data and liability for 'dirty data'* (Ferris, 2007)—Another issue is who should have the capability to populate the data in the medical records, and whether providers can contribute information to one another's medical record systems. If the information contributed is inaccurate, who would be liable for medical errors resulting from 'dirty data?'

5. *Confusion as to ownership of and access privileges to the information* (American Medical Association website)—Since there is no law referring to who owns the medical record, access and control lies within the power of the provider. When sharing information across organizations, consistent access privileges need to be determined so that unauthorized disclosure is prevented.

6. *Lack of definition for consumer empowerment in HIE and how to include it in system design* (NC HISPC, 2007)—Although consumer empowerment has been a recent topic of interest among healthcare stakeholders, there has been no definition for consumer empowerment or the facets involved to achieve it. One suggestion for enabling the achievement of consumer empowerment in HIE is to include it in the design of HIE technology. People often believe that either someone is empowered, or is not. Perhaps empowerment lies on a continuum instead.

7. *Lack of consumer understanding and awareness of HIE technology; therefore less consumer input* (Broder, 2005; Broder, 2006; NC HISPC, 2007)—As discussed previously, there is a lack of consumer awareness of HIE technology and its impacts for HIE. Although consumers have expressed an interest in using HIE for controlling and sharing their medical information, they also aren't sure of the technological features and how it can be accomplished. This is understandable, because the technology is often developed by other healthcare stakeholders. However, including consumer representative input in the design of policy and technology has been suggested as an important aspect of consumer empowerment in HIE.

Next, the current government and grassroots efforts in the United States will be investigated.

Government and Grassroots Efforts

To examine these issues, there are a handful of U.S. government efforts, and many bills have been introduced in an attempt to remedy problems as well as to enable HIE. However, there are also a number of grassroots organizations across the United States which are aimed at advocating for healthcare IT and consumer protection and empowerment. Sociological research such as Berger and Luckman (1966) suggest that security and privacy perceptions may be socially constructed by the interaction and power of certain stakeholders, as suggested by Swanson's notion (2004) of organizing visions (those organizations which influence the adoption and use of technology). Therefore, it is important to examine which stakeholders and organizations are currently working to change the healthcare IT landscape, either through laws, policy, advocacy, or education. The two groups to be examined are the U.S. government and federally-sponsored initiatives and grassroots efforts, which are those efforts typically organized by one or more people and which organically grow to become voices for consumers of health IT.

Federal Government

As stated previously, few people in the United States would trust the federal or state government to deliver information to them about secure electronic health information exchange (e-Health Initiative, May 1, 2007). Perhaps the words of Pierre-Joseph Proudhon (1923, p. 293) from his essay on '*What Is Government?'* relay the feelings of U.S. citizens:

> To be GOVERNED is to be watched, inspected, spied upon, directed, law-driven, numbered, regulated, enrolled, indoctrinated, preached at, controlled, checked, estimated, valued, censured, commanded, by creatures who have neither the right nor the wisdom nor the virtue to do so. To be GOVERNED is to be at every operation, at every transaction noted, registered, counted, taxed, stamped, measured, numbered, assessed, licensed, authorized, admonished, prevented, forbidden, reformed, corrected, punished.

In essence, Proudhon's statement can be applied to individuals' feelings of the U.S. government regarding the disclosure of medical information. It seems that people do not trust the government because they feel that the government will utilize the medical information in inappropriate ways to regulate them, perhaps even to reform or punish them if they have stigmatizing conditions. An example is an alleged case of the Justice Department, in response to litigation against health care providers, issuing subpoenas of medical records for women who have obtained abortions in New York (Delia, 2004). U.S. Representative Towns issued a letter to Attorney General John Ashcroft regarding this case

because “this Administration has no problem violating people’s civil liberties . . . [and] the actions taken by the Justice Department undermine people’s fundamental right to privacy of their own medical records.” The Justice Department claims that the federal laws do not protect the doctor-patient privilege in these cases.

A brief history of major legislation on the state and federal will allow for a better understanding of healthcare information technology and privacy issues in the context of regulations. Table 1 is a list of recent major legislation and initiatives which relate to healthcare information technology and privacy, security, and sharing of medical information.[3] Additional information about HIPAA and its advantages and disadvantages is in Appendix F.

Beyond legislation, government efforts also entail forming initiatives which examine health IT issues on a larger scale. Such efforts include the NHIN (Nationwide Health Information Network) Project, Agency for Healthcare Research and Quality (AHRQ), American Health Information Community (AHIC), the National Governors Association Center for Best Practices (NGA) the State Alliance for e-Health, and the HISPC (Health Information Security and Privacy Collaboration) project.

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[3] From http://www.govhealthit.com/resources/bills.asp.

Table 1. Recent Major Healthcare IT Legislation and Initiatives

Law	Purpose
PL 104-191--Health Insurance Portability and Accountability Act (HIPAA)	To cover insurance reform for ensuring preexisting coverage when changing jobs and also to provide rules for ensuring the privacy and security of healthcare information. The two rules of HIPAA are the Security Rule and Privacy Rule. The **Security Rule** requires that PHI be protected specifically in electronic storage and transmissions. In essence the Security Rule can be thought of as the technological aspects that can support the protection of PHI. The **Privacy Rule** focuses on the use and disclosure of medical information, specifically that which is personally identifiable--PHI (Protected Health Information. It requires the patient to fill out the "Notice of Privacy Practices Patient Acknowledgement" form, which suggests that the patient has read the HIPAA privacy information and allows the patient to determine the people to which one's PHI can be disclosed.
H.R. 568 — Patient Empowerment and Education Act of 2005.	To authorize the Secretary of Health and Human Services and the Secretary of Education, acting jointly, to make grants for community outreach programs to empower patients and health care consumers, and for other purposes.
HR 676 — United States National Health Insurance Act (or the Expanded and Improved Medicare for All Act)	To provide for comprehensive health insurance coverage for all United States residents, and for other purposes. Includes electronic patient record system
HR 1653 (S 810) — The Safeguarding Americans from Exporting Identification Data Act	To prohibit the transfer of personal information to any person outside the United States, without notice and consent, and for other purposes.
HR 4157 — Health Information Technology Promotion Act of 2005	To amend the Social Security Act to encourage the dissemination, security, confidentiality, and usefulness of health information technology.
S 810 (HB 1653) — The Safeguarding Americans from Exporting Identification Data Act, or the SAFE-ID Act.	To regulate the transmission of personally identifiable information to foreign affiliates and subcontractors.
S. 1262 — Health TEQ Act of 2005	To reduce healthcare costs, improve efficiency, and improve healthcare quality through the development of a nation-wide interoperable health information technology system, and for other purposes.
S. 1418 — Wired for Health Care Quality Act	To enhance the adoption of a nationwide interoperable health information technology system and to improve the quality and reduce the costs of health care in the United States.

The NHIN was developed to:

> . . . .provide a secure, nationwide, interoperable health information infrastructure that will connect providers, consumers, and others involved in supporting health and healthcare. The NHIN will enable health information to follow the consumer, be available for clinical decision making, and support appropriate use of healthcare information beyond direct patient care so as to improve health.[4]

The NHIN is similar to the Internet, since it is basically a 'network of networks' upon which healthcare providers transmit health information to each other to improve coordination at the point-of-care. The features of this infrastructure will be ensuring security of the health information, providing interoperability and standards for data to be transmitted among disparate systems, and providing capabilities for consumers to manage and control their own health records. The NHIN project involves trial implementations in which healthcare providers will incorporate these features into a pilot system to transmit health information. One of the Use Cases which helped to shape the scope of the NHIN was that of Consumer Empowerment and Consumer Access to Clinical Information. Other Use Cases included: Emergency Responder Access to the EHRs, Public Health Case Reporting, and Medication Management. Through

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[4] United States Department of Health and Human Services. *Nationwide Health Information Network (NHIN) Background.* Retrieved February 2008 at http://www.hhs.gov/healthit/healthnetwork/background/.

these use cases to guide the trial implementation, the goal is to utilize these Use Cases to guide a trial implementation of the NHIN. This will enable providers throughout the United States to share information efficiently and effectively, while also allowing access for consumers to their medical records. Nine contracts were awarded by Research Triangle Institute (RTI) for a total of $22.5 million to begin trial implementations. The awardees will be critical to the development of a secure foundation of health information exchange. One of these awardees is North Carolina Healthcare Information and Communications Alliance (NCHICA), which was involved in this research study. The NHIN trial implementations will leverage the work of other government agencies, including: the Healthcare Information Technology Standards Panel (HITSP; to create standards for interoperability), the Certification Commission for Healthcare Information Technology (CCHIT; to certify electronic medical record products), and the Health Information Security and Privacy Collaboration (HISPC; to examine barriers to HIE).[5]

AHRQ (Agency for Healthcare Research and Quality) is a federal agency which performs research on healthcare outcomes, quality, costs, and patient

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[5] United States Department of Health and Human Services. *HHS Awards Contracts for Trial Implementations for the Nationwide Health Information Network*. Retrieved February 2008 at http://www.hhs.gov/news/press/2007pres/10/pr20071005a.html.

safety.[6] AHRQ's goals are to help consumers, providers, and policymakers by providing education based on the results of their research. AHRQ has provided federal research funding for projects such as the HISPC Project, which investigated barriers to HIE.

The AHIC (American Health Information Community) is a federal advisory board which recommends to the Secretary of the Department of Health and Human Services (DHHS) ways that health IT adoption and development can be accelerated. Although the first phase of the AHIC was to report to the DHHS, in 2008, plans are being made to convert AHIC's efforts into that of a public-private partnership. AHIC has identified areas for possible advancement of HIE.[7] To examine these areas, AHIC formed workgroups for each focus: Biosurveillance; Consumer Empowerment; Chronic Care; Electronic Health Records; Confidentiality, Privacy & Security; Quality; and Personalized Healthcare. Consumer Empowerment was identified as one of the four initial areas that was ripe for breakthrough development. These groups meet individually and discuss the objectives for the particular area, such as developing a medication history

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[6] United States Department of Health and Human Services. Agency for Healthcare Research and Quality. *What is AHRQ?* Retrieved February 2008 at http://www.ahrq.gov/about/whatis.htm.

[7] United States Department of Health and Human Services. *American Health Information Community.* Retrieved February 2008 at http://www.hhs.gov/healthit/community/background/.

record for personal health records, and then report their findings back to AHIC. AHIC coordinates the work between these areas so that the work is synergistic.

The National Governors Association Center for Best Practices "was awarded a contract from the Office of the National Coordinator for Health Information Technology (ONC) to establish and manage the State Alliance for e-Health, a consensus-based, executive-level body of state elected (and appointed) officials to collectively address state-level health information technology (health IT) issues and challenges to interoperable electronic health information exchange."[8] The State Alliance for e-Health has been active in collaborative efforts between states to examine the barriers to health information exchange and how policy issues among and between state and federal laws should be reconciled to provide the best possible security and privacy protection of health information. Another similar initiative is the HISPC Project, which is discussed next.

The NC HISPC (Health Information Security and Privacy Collaboration) project has been significant in examining security and privacy aspects of HIE. Therefore, some background on the NC HISPC project is necessary because it

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[8] National Governors Association Center for Best Practices. *State Alliance for e-Health Background Information*. Retrieved February 2008 at http://www.nga.org/portal/site/nga/menuitem.1f41d49be2d3d33eacdcbeeb501010a0/?vgnextoid=5066b5bd2b991110VgnVCM1000001a01010aRCRD#overview.

became an integral component of this study. The NC HISPC project was funded initially by the federal agency, AHRQ (Agency for Healthcare Research and Quality) in which RTI (Research Triangle Institute), the contractor, awarded one of thirty-three contracts in the United States to NCHICA to "assess and develop plans to address variations in organization-level business policies and state laws that affect privacy and security practices-including those related to HIPAA-and may pose challenges to interoperable health information exchange."[9] From the findings of each of the state projects, the National HISPC Project Manager aggregated the results so that a national view of the privacy and security barriers to the sharing of health information was generated. This allowed the states to collaborate in areas where there was overlap; for example, many states found that interpretation of HIPAA was a problem and they were able to work together to propose solutions. National HISPC Meetings were held during each phase so that members of the state HISPC groups presented their findings to the other state representatives.

Two of the findings from the NC HISPC project which were disclosed in the Final Implementation report were (2007, pg. 10):

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[9] North Carolina Healthcare Information and Communications Alliance. North Carolina Health Information Privacy and Security Collaboration. *NC HISPC Phase 1.* http://www.nchica.org/NCHISPC/intro.htm.

BR_8a. Lack of consumer understanding or awareness of the benefits of health information technology which results in lack of consumer input into the underlying policy and technology to support health information exchange

BR_8b. Lack of definition of consumer empowerment and lack of methodology for including it in policy and systems design

The NC HISPC project was completed in two parts: the first phase was the previously mentioned contract to address variations in policies and laws and also funded the establishment of the CACHI website. The second phase of the project for the North Carolina HISPC group was to examine the North Carolina laws related to privacy and security of health information and also to develop a Consumer Toolkit "to provide avenues to engage and involve the consumer in the discussions of healthcare information exchange (HIE) and technology (HIT) so that consumers can make informed decisions about sharing their health information" (NC HISPC Consumer Empowerment Toolkit, 2007, pg. 11). The NC HISPC Project Manager attended most of the CACHI meetings to incorporate the Council's efforts for consumer engagement and participation into the NC HISPC project efforts. While I worked with the Project Manager during the first phase of the NC HISPC project efforts on one of the Variations Workgroups in which the lack of consumer input into policy and technological innovations

emerged, the second phase of the project included more participation and engagement from the CACHI group.

As part of this second phase, the NC HISPC Project Manager collaborated with the CACHI members to also gather input from them regarding the NCHICA Annual Conference. The purpose was to send CACHI members to the NCHICA Annual Conference to attend presentations given by healthcare vendors, providers, and government officials to uncover the council members' feelings about the information presented as well as the manner in which it was presented. The council members gave their reactions to the presentations both in oral debriefing sessions at the conferences, as well as in writing after the conference was complete (See APPENDIX G. Important CACHI Activities) .

To apply the findings of the first phase of the HISPC project, the Project Manager asked the CACHI group if she could utilize their documentation of sample minutes, agendas, and other procedures as the basis for a Consumer Empowerment Toolkit. The idea for the Consumer Empowerment Toolkit was to generate a toolkit which other states could employ to engage consumers by starting a similar type of council. Therefore, the procedures, minutes, agendas, and other documentation produced by the CACHI group were used as foundation to create generic documentation for others to put into practice. The lessons learned throughout organizing, recruiting, and helping the CACHI group to

become established were also incorporated into the Consumer Empowerment Toolkit.

Because the work of the NC HISPC project so closely aligned with the CACHI goals in some aspects, the NC HISPC project ultimately did affect the emerging establishment of the CACHI group. Without the NC HISPC Project Manager's efforts to incorporate and engage the CACHI group, the CACHI group may ultimately have materialized differently. Through participating in the NC HISPC projects, the CACHI group began to see more opportunities to become involved and have a voice in the emergence and creation of HIE technology, policy, and law.

State and Other Grassroots Efforts

There are two primary types of grassroots efforts. The first is through organizational efforts, either those involved with patient groups who may advocate for specific groups of people (such as senior citizens or people with mental illness). The second type of grassroots effort involves RHIOS (Regional Health Information Organization) and Health Information Exchanges that are formed in different states.

It is important that patient advocacy groups such as AARP (Association for the Advocacy of Retired People[10]) and NAMI (National Alliance on Mental Illness[11]) understand HIE so that they can help their members to make informed disclosure and consent choices. NCHICA is a prominent figure in the national arena of healthcare IT and is currently leading projects such as the Consumer Advisory Council and NHIN Project to enable the advancement of healthcare IT in an appropriate and meaningful way.

There are many groups which are on the cusp of examining these emerging issues of patient empowerment in healthcare. The main goal so far of these groups has been to educate patients on their privacy rights. The largest of the grassroots efforts includes Markle Foundation and the California HealthCare Foundation. The Markle Foundation "works to realize [the potential of information and communication technologies] and to accelerate the use of these technologies to address public needs, particularly in the areas of Health and National Security."[12] The mission statement for CHCF[13] is to "expand access to affordable, quality health care for underserved individuals and communities and to promote fundamental improvements in the health status of the people of

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[10] Association for the Advocacy of Retired People. Retrieved May 2008 at www.aarp.org.
[11] National Alliance on Mental Illness. Retrieved May 2008 at www.nami.org.
[12] Markle Foundation. Retrieved November 2007 at www.markle.org.
[13] California HealthCare Foundation. Retrieved September 2007 at www.chcf.org/aboutchcf.

California" Both Markle and CHCF have performed important surveys regarding how IT adoption has affected the ability to provide services and share information in the healthcare industry.[14] The Privacy Rights Clearinghouse[15] contains many documents to educate people in general privacy issues such as identity theft, but also includes a page dedicated to privacy issues and medical records. The Health Privacy Project is one advocacy group which strongly encourages the collaboration of providers, healthcare stakeholders, legislators, and patients to educate those involved in the issues related to healthcare privacy so that patients are empowered to make informed consent decisions. Their web site[16] contains a plethora of information to educate the consumer as well as other healthcare privacy stakeholders in areas such as knowing consumer privacy rights, understanding how to file a complaint, facts about the HIPAA regulation, and how to protect their privacy. The organization that seems to be the fiercest advocate of patients is Patient Privacy Rights[17], founded by Dr. Deborah Peel. The focus of this group is to both educate consumers and also motivate patients to be

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[14] Markle Foundation. *Reports and Publications*. Retrieved May 2008 at www.markle.org/resources/reports_and_publications/healthcare/index.php and California HealthCare Foundation. *Reports and Initiatives* Retrieved May 2008 at www.chcf.org/topics/index.cfm?topic=CL108.

[15] Privacy Rights Clearinghouse. Retrieved September 2007 at www.privacyrights.org.

[16] Health Privacy Project. Retrieved November 2007 at www.healthprivacy.org.

[17] Patient Privacy Rights Organization. Retrieved September 2007 at www.patientprivacyrights.org.

active in healthcare IT initiatives, policy-formation, and advocacy. The emphasis is on advocacy through contacting legislators regarding IT legislation. Besides educating the patient, these advocacy groups provide a forum of consumer coalitions to bring together the providers, stakeholders, legislators, and patients to discuss these issues and to determine where gaps and misconceptions exist.

Marc Holland, program director of provider research for Health Industry Insights (HII), suggests that 15% of hospitals responding to his 2008 survey are actively participating in HIE, while 35% of hospitals are in discussions to form HIEs. He predicts that there will be 'organic growth' of HIEs and RHIOs, but it will be slow due to lack of funding and government participation. The key challenges of HIEs and RHIOs entail complex and disparate processes, along with concerns for privacy and security. Holland also suggested that many HIEs in operation are successful, because they are formed as "grassroots effort(s), driven by strong, commonly held community goals, or the dominance of a single provider."[18] However, one well-known RHIO was shut-down because of privacy and security concerns (Robinson, 2007). Table 2 displays examples of RHIOs that are currently sharing data in healthcare information exchange.

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[18] From Enrado, Patty (April 15, 2008) NHIN Watch. *Perspective: The Future Looks Good for Information Exchanges*. Retrieved April 2008 at http://www.nhinwatch.com/news.cms?newsId=3381.

Table 2. RHIOs That Actively Share Data in a Live Environment
(Adapted from: Dullabh, et al, 2007)

RHIOs that are actively sharing data in a live environment	
HIE Name	**Location**
Indiana Health Information Exchange	Indianapolis, IN
MidSouth eHealth Alliance	Nashville, TN
Utah Health Information Network	Murray, UT
Marin Medical Practice Concepts Inc.	California
Santa Cruz - RHIO	California
Taconic IPA/MedAllies Regional Health Information Exchange	New York
Inland Northwest Health Services	Spokane, WA
Healthbridge	Cincinnati, OH
MIE - Medical Informatics Engineering	Fort Wayne, IN
Michiana Health Information Network	South Bend, IN
MA eHealth Collaborative	MA
South Florida Health Information Exchange	Miami Shore, FL
MA-SHARE Clinical Data Exchange	Waltham, MA
New England Healthcare EDI Network(NEHEN)	Waltham, MA
Adirondack Medical Center	Saranac Lake, NY
Rocky Mountain RHIO	Colorado

The current economic slowdown in the United States could have an effect on health IT funding. However, Robinson (2008) suggests that states often recognize health IT efforts in their budgetary allocations because it improves the care for their citizens. In March, 2008, Pennsylvania Governor Rendell signed an executive order establishing the Pennsylvania Health Information Exchange to improve citizen health and decrease the cost of healthcare through fewer duplicate tests and increased accessibility to health records. The “number of governors who mentioned health IT in their state-of-the-state speeches almost

doubled this year compared to 2007" (Robinson, 2008, website). Funding is minimal from the states to form RHIOs and HIEs; the two states which allocated the most are: Minnesota and Missouri at $18.5 million and $15 million, respectively; and other states allocate much less, such as Arizona at $275,000 (Robinson, 2008). One obstacle to gaining state funding is explaining how the HIE works to state legislators. It is critical for healthcare stakeholders to communicate with legislators the importance of HIE to cost savings in healthcare and, ultimately, for improvement of human health. Effective lobbying is vital (Ferris, 2008), and part of the persuasion is in showing ways that the improvement from IT can be measured. These issues make it difficult to form and maintain RHIOs and HIEs, putting the burden on the healthcare providers who are determined to begin such initiatives, to put up their own money or to find government funding.

What is important to understand from both the federal and state/grassroots initiatives, is that there are a number of groups working on HIE initiatives and educating consumers on HIE issues. While these initiatives are formed at different levels, with different interests in mind, there are often opportunities for collaboration and networking. There are opportunities in which the federal arm has reached out to the state/grassroots level to collaborate, which should provide a more comprehensive effort for HIE development. The

work of these groups is critical to HIE initiatives, and to understand how the concept of consumer empowerment may be intertwined within these efforts.

Significance of the Study

Due to emerging technologies in the healthcare field, the possibilities for sharing medical information have increased drastically. Information can be shared electronically between health care stakeholders such as patients/consumers, doctors, pharmacies, insurance companies, hospitals, research organizations, and government agencies. The purpose of sharing such information is to improve the quality of human health through better healthcare. The recent concerns among healthcare stakeholders in sharing sensitive medical records have been the access, control, and disclosure of information across entities. The protection of medical record information is critical, and in his testimony before the U.S. House Committee on Commerce, Chris Koyanagi of the Consumer Coalition for Health Privacy, stated that "without trust that the personal sensitive information that they share with their doctors will be handled with some degree of confidentiality, patients will not fully participate in their own healthcare" (Congress, May 1999). As stated by Congressman Dennis Moore, "putting patients at the center of this transformation is not only the right thing to do; it's the smart thing to do" (HIMSS, 2007). Consumer empowerment, in this

context, would enable self-determination of how and what medical information the patient feels the need to share.

There is an emerging “transience” nature to a consumer’s healthcare, with patients often moving from one family doctor to different physicians, and utilizing different physicians due to the managed care system as they change jobs. Because of this, it will be important to involve consumers in the management of their own records so that physicians have a comprehensive knowledge of their health history (Roth, 1994) and that chronic illnesses can be managed.

Research is needed to examine the variety of perspectives involved in the disparate communities for healthcare stakeholders such as providers, legislators, providers, and other organizations regarding consumer empowerment in healthcare in the U.S. The goal of this study is to investigate the concept of consumer empowerment in HIE so that an understanding of consumer empowerment dimensions in HIE will aid in implementing appropriate policy and technology to ultimately improve human health. This research will provide theory which can facilitate development of information management and technology policy incorporating consumer concerns; and improve understanding of the intersection among information technology, policy, and social context related to consumers in the healthcare system. It also provides a foundation for

further research using positivist or interpretive approaches to further understand consumer empowerment in HIE

Research Questions

Examining consumer empowerment in HIE is necessary since the technological innovations allow for the sharing of a person's medical information between people in organizations. Because the technology enables new relationships between people and entities, the sociological aspects and technology intermingle to create a phenomenon of consumer empowerment in HIE. In order to investigate the phenomenon of consumer empowerment dimensions in HIE, the research questions will be broad since this area is emerging. Lee (2001, p. iii) states that "research in the information systems field examines more than just the technological system, or just the social system, or even the two side by side; in addition, it investigates the phenomena that emerge when the two interact." Figure 1 shows that technology and empowerment interact to produce a phenomenon of consumer empowerment in HIE. The research of this phenomenon will begin with what Gregor (2006) calls "socio-political research" questions. These are questions which study the context of a phenomenon through examining the stakeholders, history, sociology, application (the technology, in this case), practicality, ethical, and political issues. She

suggests that socio-political research questions seek to bring about "improvements in the human condition" (p. 612).

Based on the preliminary analysis of consumer empowerment literature and the recent interest in the issues of consumer empowerment in societal venues, the following research questions are posed for this study.

1. What are the dimensions of consumer empowerment in Health Information Exchange?
2. How can consumer empowerment be achieved in Health Information Exchange?

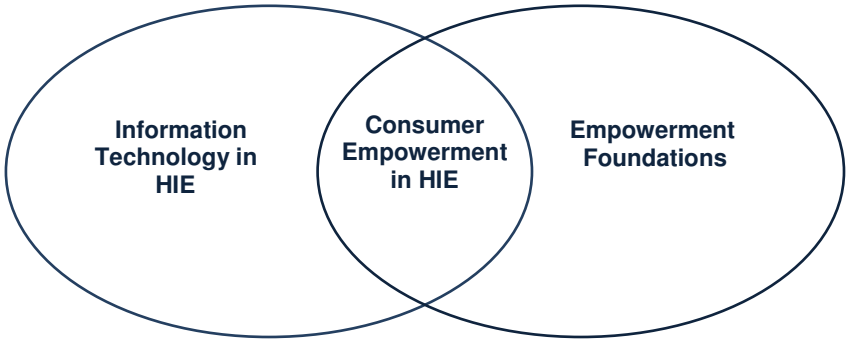

Figure 1. Interaction of Technology and Empowerment in HIE

This study will investigate the phenomenon that occurs when information technology in HIE interacts with consumer empowerment foundational issues. No prior theory exists to explain consumer empowerment in HIE. The first

question examines the dimensions and facets of consumer empowerment in HIE contexts, which will be discovered through the grounded theory methodology, and the second question synthesizes what has emerged from the grounded theory methodology to generate recommendations for ways that consumer empowerment may be achieved in HIE.

For grounded theory studies, the purpose is to discover theory from concepts in data analysis. Because there should not be an in-depth preconceived notion of consumer empowerment and other dimensions assumed to be related (such as security, privacy, and education), the literature review revolves around the concept of empowerment, the power of information and the factors which may affect the physician/patient relationship. For this study, a preliminary literature review will be conducted as a first step. The data analysis will be then conducted, and, based on the concepts which emerge from the data, previous literature in other streams of related research topics will be utilized to help support or disconfirm the results of this study.

CHAPTER II

LITERATURE REVIEW

"Empowerment is a construct that links individual strengths and competencies, natural helping systems, and proactive behaviors to social policy and change" (Perkins & Zimmerman, 1995, p. 569). There are numerous definitions of empowerment, and most research implies that empowerment is more than just self-esteem, self-efficacy, competency, or locus of control (Perkins & Zimmerman, 1995). Given that empowerment is the central focus, a review of the literature from empowerment in healthcare, management, information systems (IS), marketing and sociology research streams will provide a context for this research study. Additional literature regarding the power of patient information and trust in provider/patient relationships will also be investigated.

Empowerment in Marketing

Inherent in the function of the empowerment and its benefit to those involved is the aspect of power. The aspect of empowerment in the marketing literature which focuses primarily on the concept that consumers can enforce their power through marketplace economics (Shaw, Newholm, & Dickson, 2006;

Wathieu et al, 2002). This suggests that the more choices consumers have in their purchases, the more they are able to exercise power through consumption choices (Shaw et al, 2006). The purchases consumers make in the marketplace reflect their preferred choices in an attempt to influence the suppliers to meet their consumption needs.

According to Shaw and colleagues (2006), this type of influential purchasing is very similar to citizens casting votes in elections. This political comparison is of interest to note that consumers also may consciously make a choice to purchase or not purchase based on the ethical choices of the company. For example, if the company pursues strategies using child labor or sweatshop practices, a consumer may boycott those practices through the non-purchase of that company's products. However, this premise presumes two things: that everyone has the same capacity to make the same types of choices, and that consumers are aware of the "re-configuration of power relationships that are emerging between consumers and producers" (Shaw, et al, 2006, p. 1062). Shankar and colleagues (2006) state that the lay view of consumer empowerment assumes that the power is shifted from producers to consumers and, since consumers know what they want, empowerment is beneficial to consumers. According to Shankar et al (2006), this also assumes that consumers are rational utility maximizers in making choices. Such a marketplace

and consumption situation discussed by Shaw and colleagues (2006) therefore creates a further gap in the disparity between those who can afford to purposely choose another vendor, even if their product is more expensive, than someone who cannot afford to make that choice.

The marketing research assumes rational utility decision makers (Shankar, et al, 2006) and that there are institutional factors which can create unequal resources and unequal power (Shankar, et al, 2006). Empowerment in the marketing literature is based on how consumers make choices based on the resources that they have available. There has been no consistent model for government or organizations to provide funding and resources for consumer empowerment in HIE, either through the availability of technology or money for PHRs (Personal Health Records). Although insurance companies and employers have been the target stakeholder to provide PHRs to patients, this increases the disparity of those patients who are unemployed or uninsured. A study of consumer empowerment in HIE is needed to examine whether these weaknesses are experienced in the quest for consumer empowerment in HIE and how they may be handled.

Empowerment in Management and Information Systems (IS)

Wilkinson (1997) suggests that although empowerment has been studied in management literature, it has not been studied in a historical context. From a

managerial and IS perspective, the emphasis on modern empowerment began in the late 1980s through the management of organizational culture, creation of teamwork and employee involvement in innovation efforts to ensure that the company was profitable. For example, in IS research, participatory design in information systems and knowledge management were to empower employees while also creating a more efficient and profitable firm (Sjoberg et al, 1998).

The primary question which stems from the management and IS research is who benefits from the employee being empowered? Seemingly, there should be benefits for both, through improved corporate profits or increased worker satisfaction. In the HIE context, the lessons for participatory design and knowledge sharing for innovation can be utilized to provide feasible and user-friendly PHRs by conducting an examination of what features and capabilities the patients want from PHR technology. However, patients and physicians do not hold the same amount of power, and this power disparity creates different motives for allowing patient to be empowered. The primary motive for physicians to share medical information has been through government mandates to adopt electronic health records and to share information to decrease the cost of healthcare, while also improving human health. Examining the dimensions of consumer empowerment in HIE will be important to investigate power issues and how they affect the adoption and implementation of HIE technology and policy.

Empowerment in Sociology

Empowerment in sociology has been examined by Rose (1999), Foucault (White, 2002), Parsons (White, 2002), and Marx (Kamenka, 1983) as being perspectives of disparity in power, class, and control through surveillance. One way that the government and organizations can enact social control is through the control of information. Foucault perceives institutional medicine as a form of social control rather than healing. He states that surveillance of citizens is the "organization of information that can be stored by agencies and used to monitor the activities of an administered population. . . .[and that] modern medicine is a manifestation of an administered society in which the centralization of information about citizens is essential for social planning" (White, 2002, p. 118-119) such as biosurveillance. Ultimately, empowerment is socially constructed (Berger & Luckman, 1966) and is "an outcome of changes in fundamental structures and relations of power" (Anderson, 1996, p. 698), whether instigated by those in control or those being controlled.

The primary weakness discussed in the sociological literature is the inherent difference in power due to institutional structures and power relations. Most organizations flourish within the socially constructed realms of power differences, and transferring power from those in charge to those who are not is very difficult. Historically, the healthcare provider has controlled access to

patient information, and this shift of control and access to the patient through PHRs also signifies a drastic shift in power from the provider to the patient. Not every stakeholder in the healthcare industry holds the same amount of power, and this disparity results in patients often being deferent to the other stakeholders such as providers and insurance companies. This is also emphasized by U.S. Representative Edolphus Towns, who feels that "progress towards eliminating . . . health disparities has been slow. . .now we must tackle the implementation of health information technology (HIT). My fear is that we will create further divisions in service delivery for medically underserved communities if we don't include these communities in both the national dialogue and in the implementation of HIT" (HIMSS, 2007, website). Because of this inherent difference in power in institutional structures; patients have not been able to seek empowerment through HIE technology.

Empowerment in HIE

Literature suggests that empowerment is self-determination over one's own life (Geller et al, 1998) as a result of having access to information and resources to enable an informed choice (Wowra et al, 1999). However, most healthcare-related literature discusses consumer empowerment in four different contexts:

1. of HIE web sites and the availability of patients to access treatment on the web regarding their treatments, diagnoses, and support group options (Luo & Najdawi, 2004)

2. of specific areas such as mental health and enabling patients to recover with a sense of self-determination (Wowra et al, 1999)

3. of sharing information to organizations outside of the healthcare providers for secondary purposes such as genetic research (Botkin, 2001)

4. of health disparities and giving consumers more choices, power, and resources to reduce disparities (Anderson, 1996).

Empowerment in healthcare literature focuses primarily on consumers reading information from a website to educate themselves on a variety of treatments, medications, procedures, and quality of healthcare providers (such as that provided through LeapFrog) (HON, 2002[19]). Healthcare empowerment, therefore, is being able to successfully navigate the healthcare system and understand the processes involved in seeking treatment. HIE empowerment focuses on understanding the processes, technology, and policies in the collection, storage, and sharing of health information. For HIE, this involves analyzing patient access and control of their own medical records for self-

[19]Commission of the Euorpean Communities. *Purposes of Implementation of Quality Criteria for Health Related Websites.* Retrieved November 2007 at http://www.hon.ch/HONcode/HON_CCE_en.htm.

determination of who the information will be shared with and for what purpose, based on the technology utilized.

Power of Patient Information

Traditionally, records in the healthcare industry have been paper-based, enabling strict accessibility to records. Due to advances in technology, managing the large amount of information involved in patient care has become much more important. Therefore, information has, in essence, become the "key organizational currency" for which companies need to manage and control to "harness the power of the politics" which comes from such control (Davenport, et al, 1992). Davenport suggests that as information becomes the "basis for organizational structure and functions, politics will increasingly come into play" (p. 54). Politics have become more important in the control and access of healthcare information, both internal and external to the organization.

Review of existing privacy regulations shows that there is no law that governs who actually owns the patient medical record. Because the control of either the paper-based medical record or electronic medical record is in the provider's hands, traditionally, the question has been that of patient access to the record rather than ownership. Ownership of medical information may become a more sensitive issue due increased access through technology, and the AMA (American Medical Association) does provide guidelines on how to provide

patient access to medical information, but not specifically a statement as to who owns the data. There is no consistent law as to the definition of a medical record (NC HISPC, 2007). For example, what if a primary physician refers a patient to a cardiologist and sends the patient's primary medical record to the cardiologist. Does that primary record then also belong to the medical record of the cardiologist? Can the cardiologist then claim to have consent to disclose that information to any other entity? At what point does that information become outdated and unreliable to pass on to another physician? Who would be held liable for inappropriate healthcare provided based on outdated records?

The AMA and state medical boards address the access issue only and advise that "medical records are confidential documents and should only be released when permitted by law or with proper written authorization of the patient.. . . .physicians are responsible for safeguarding and protecting the medical record and for providing adequate security measures" (AMA and North Carolina Medical Board[20]). This implies that the healthcare provider will genuinely give "access" to the patient when requested, typically through giving a photocopy of the medical record to the patient. Also addressed is the fact that

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[20] American Medical Association. *Patient Confidentiality*. Retrieved July 2007 at http://www.ama-assn.org/ama/pub/category/4610.html and the North Carolina Medical Board. Retrieved July 2007 at www.ncmedboard.org.

"physicians should not relinquish control over their patients' medical records to third parties unless there is an enforceable agreement that includes adequate provisions to protect patient confidentiality and to ensure access to those records."[21]

There are concerns which have risen to question how PHI (Personal Health Information) will be shared. Currently, the patient gives a "blanket statement" for a single entity, but patients may not want to give such generic access across healthcare entities. Patients have a fear that information will be used by someone outside of the healthcare entity for unethical purposes, such as identity theft. Because outsourcing has become a more common practice, HIPAA (Healthcare Insurance Portability and Accountability Act of 1996) now requires that contracts with third parties (such as billing clearinghouses and collection agencies) state that the PHI will not be shared for purposes outside of performing contractual duties (Gue, 2004). Clemen's (2004) research on information poaching reveals the need for transactional governance and firm contracts which provide incentive to avoid poaching and unauthorized sharing of PHI. (For more information on HIPAA, see the Appendix F.)

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[21]North Carolina Medical Board. Retrieved July 2007 at www.ncmedboard.org.

HIPAA privacy policies will need to be edited to allow for different types of opt in/out procedures when more than one entity is involved. Technology must also be in place so that PHI is not shared electronically with other entities when the patient opts out of sharing information with specific entities. U.S. Representative Patrick Kennedy is interested in creating legislation which will provide opt-out clauses for patients and restore the right of patient consent, along with better audit trails for patient knowledge of how their information is disclosed along with improved enforcement of the law (Hayes, 2006). This gives the patient an increased sense of privacy as well as a feeling of control of the information. A recent bill was passed by the US House Committee on Government Reform that would require federal employee insurers to provide enrollees with PHRs by 2010. The PHR will include data of the member's choosing at no increased cost to the enrollee (Beaudoin, 2006). Technology such as the PHR gives a feeling of empowerment to the patient for control of their information as well as increased participation in the healthcare process.

Doctor/Patient Relationships

"As an instrumental value, trust is widely believed to be essential to effective therapeutic encounters. It has been hypothesized or shown to affect a host of important behaviors and attitudes, including patients' willingness to seek care, reveal sensitive information, submit to treatment, participate in research,

adhere to treatment regimens, remain with a physician, and recommend physicians to others" (Hall et al, 2001, p. 614). If a patient does not trust the security and privacy of HIE, specifically the patient information kept in electronic medical records, the patient may not seek care, or may withhold information from the healthcare provider (Rindfleisch, 1997). "Trust is the essential factor for everyone. . . If patients are going to trust their personal information to a system, they have to trust who will hold it and how it will be used" (Reese, 2006, website). The implications of these patient security and privacy concerns will ultimately be in whether patients trust healthcare entities with their information.

In their analysis of doctor/patient meanings of trust in a meta-analysis of the literature, Hall and colleagues (2001), suggest that common themes of definitions of trust include the "optimistic acceptance of a vulnerable situation in which the truster believes the trustee will care for the truster's interests" (Hall et al, 2001, p. 615); specifically through the notions of fidelity, competence, honesty, confidentiality, and global trust (see Table 3 for definitions). Of the examples of studies from previous research examined in Hall's analysis, there was no study of the patient's perceptions of the dimension of confidentiality.

Table 3. Dimensions of Trust
(Hall et al, 2001)

Dimensions of Trust	
Fidelity	Protecting patient's best interests and vulnerability
Competence	Avoiding mistakes to achieve quality of care
Honesty	Physician telling the truth
Confidentiality	Protection of sensitive and private information
Global Trust	'soul of trust'

Examining trust in doctor/patient relationships is important because the structure of healthcare delivery and policy can be changed in a manner that supports trust, for example, through increased provider/patient communication (Hall et al, 2001). In accordance with Hall's findings, a recent study by the e-Health Initiative Foundation (2007) of patients in five U.S. Gulf States revealed that 67% of consumers trust doctors to deliver information to them about secure electronic health information exchange. Hospitals was second, with only 8%, followed by the federal government with 7%, health insurance companies with 5%, and employers and state government with 3% each. Patient trust in the relationship can be affected by the competence displayed by the provider to best protect the patient's information and to be honest in the privacy policies to maintain confidentiality of medical information. It is important to note that the amount of power differential in the doctor/patient relationship results in the patient's need to place more trust in the doctor's competency to protect medical

records and to communicate with the patient since the doctor controls the medical records.

Implications from Literature

The implication of the consumer empowerment literature in healthcare, marketing, management, information systems, and sociology for this study is important. Most definitions in literature view empowerment as "an intentional ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment Group, 1989). As Shaw (2006) and Shankar et al (2006) suggest, power is often seen as being transferred from the producer to the consumer. To examine power and how it is held and transferred is important in HIE because traditionally the healthcare provider has held power, especially in the doctor/patient relationship.

With the advent of new technologies such as the PHR, primary control of the medical record could be transferred from the healthcare provider to the patient. For a transfer of power to take place, the perspectives of the doctor, patient, and other stakeholders such as insurance companies, legislators, and pharmacies need to be examined.

One assumption from these empowerment research streams suggests that empowerment is positive for the consumer and the economy. However, it is important to ask who benefits from empowerment? Those who hold the power typically determine how empowerment will be allowed, usually for the benefit of the institution in power. Because of these power issues, one challenge of empowerment is that of the possible widening disparity between those who can exercise choice and those who don't have the resources (such as technology and literacy level) to do so. In HIE, it has not been determined how the technology and access to EHRs would be provided and who would be responsible for the costs, maintenance, and education to implement such technology. Some PHRs are offered at a monthly fee, and this may affect who can have the opportunity to control their own medical records. If control is a dimension of empowerment, this means that these disparities can negatively affect consumer empowerment.

It is anticipated that existing literature outside of consumer empowerment may be utilized in two ways. They may identify concepts that are relevant to the current study so that the theory generated is encompassed in previous research. Also, these areas may be utilized after data analysis to either provider supporting or disconfirming evidence found in the data collection and analysis. Such potential areas of interest are: security, privacy, policy, conflict theory, socio-

organizational aspects (such as culture, change, training, enforcement), information (such as social life cycles of information and information as an asset), healthcare supply chain, and business processes.

Because there is no existing theory for consumer empowerment in HIE, data that are rich and detailed in description are needed to be the source and foundation for such a theory. "We need consumers as part of the equation" as well as providers, legislators, advocacy organizations, and other healthcare stakeholders to create a more comprehensive view of consumer empowerment (Hayes, 2007, p. 32). Since grounded theory research methodology allows one to develop new theories where none exist, from data that is rich and detailed in description, this methodology will be utilized. Using grounded theory, this research examines consumer empowerment in the context of HIE primarily by analyzing three different data sources from the federal, state, and individual level.

CHAPTER III

GROUNDED THEORY METHODOLOGY

The grounded theory approach will be utilized to propose a theory for consumer empowerment in HIE since no such theory currently exists. It is an appropriate approach to use because it provides rigor and relevance (Fernandez & Lehmann, 2005) through its systematic methods using data from the field. The grounded theory approach will allow the research questions to be answered within the rich context of the setting. The grounded theory approach is an "initial, systematic discovery of the theory from the data. . .and since the categories are discovered by examination of the data , laymen involved in the area to which the theory applies will usually be able to understand" (Glaser and Strauss, 1967, p. 3).

The Qualitative Research Approach

Qualitative research approaches have been in use in the social sciences for over sixty years (Fernandez & Lehmann, 2005), and have become accepted in IS research (See Table 4 for grounded theory references in IS research). Qualitative research approaches are utilized when the nature of the research

question is “how”, “what”, or “why”, and the topic has not previously been explored such that theories are available to explain the phenomena in question (Creswell, 1998). If the research question will require a detailed view of the topic and a study of a natural setting, qualitative approaches are appropriate.

Qualitative research has been defined in a variety of ways, and historically has been utilized in the social sciences fields such as sociology, anthropology, political science, philosophy, and history (Creswell, 1998). Creswell’s (1998, p. 15) definition of qualitative research is “an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting”. Creswell also offers a definition of qualitative research given by Denzin and Lincoln (1994, p. 2) as “multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials—case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts—that describe routine and problematic moments and meaning in individuals’ lives.”

Planning Qualitative Research Studies

In qualitative research, it is often difficult to generate a detailed design and plan for study because of the emerging nature of qualitative research (Creswell, 1998, p. 18). A general approach to the study is developed, including how the literature review will be approached. Investigating prior research is important to understand the nature of the field and if the research study in question has been performed before. However, the question of how much prior research to examine depends on the researcher, the topic in question, and to what extent prior theory is needed to conduct the study at hand. Many qualitative research approaches rely on development of theory from the concepts which emerge from the data collection, and do not require much, if any prior literature review.

Conducting and Writing Qualitative Research

The nature of much qualitative research is “emotion laden, close to people, and practical” (Creswell, 1998, p. 19). Due to this and the exploratory and emerging essence of qualitative research, it is important to be open and flexible when conducting data collection, especially in asking open-ended questions. Data can be collected in a multitude of ways—through interviews, focus groups, photographs, observations, and other documentation and interactions with the natural setting. Analysis methods depend upon the nature of the qualitative tradition chosen (Fernandez & Lehmann, 2005), but are

conducted thoroughly to present the researcher's interpretation of the data. When writing any qualitative research results, the analysis and discussion of the findings should be rich and thick with descriptions from the natural setting.

There are many different types of qualitative research, such as phenomenology, ethnography, narrative, biography, and grounded theory. Each approach is chosen for a specific purpose, depending on how the phenomenon of interest can be answered, and, therefore, each approach has its own techniques for data sources, analysis, and writing up the results. For this study, the grounded theory approach will be utilized to investigate the quest for consumer empowerment in HIE.

Grounded Theory Approach

The grounded theory approach is a well-established and systematic way to develop theory founded in qualitative data. Grounded theory is appropriate to use when there is no theory or if a phenomenon is not clearly understood, and such an approach seeks to better understand human behavior and experience (Bogdan & Biklen, 2003). Glaser and Strauss (1967) suggest that the grounded theory approach is the purposeful "discovery of theory from data systematically obtained" (p. 2).

History of Grounded Theory

Grounded theory was first articulated by sociologists Barney Glaser and Anselm Strauss in 1967. In their book "The Discovery of Grounded Theory: Strategies for Qualitative Research" (1967) they propose that theories should be grounded in data from the field and documented thoroughly through interactions with the natural setting. Various aspects of the Grounded Theory approach have been developed, such as the concepts of open, axial, and selective coding, and how to verify and judge the rigor of the results. Glaser and Strauss (1967) suggest that quantitative and qualitative methods are equally of value and should be utilized appropriately depending on the research question. However, many researchers have attempted to create ways to analyze qualitative data in comparison to quantitative data to justify the usage of qualitative methods. Glaser (2004) feels that this is inappropriate and that the "classic GT" approach has been eroded by such efforts to "scientize" the approach. Glaser writes "The goal of grounded theory is to generate a conceptual theory that accounts for a pattern of behavior which is relevant and problematic for those involved. The goal is not voluminous description, nor clever verification" (1978, p. 93).

Generating Theory in Information Systems Research

Gregor (2006) proposes that there are research questions that arise within bodies of knowledge. These questions include domain questions (boundaries of

the discipline); structural questions (questions about theory and its structure); epistemological questions (questions about constructing and testing theory); and socio-political questions (historical and sociological aspects of knowledge in a discipline). In examining these types of questions, there are multiple views of theory existing in IS literature, according to Gregor (2006). According to the Encarta Dictionary, a theory is a "set of facts, propositions, or principles analyzed in their relation to one another and used to explain phenomena."[22] The IS field has relied upon other fields for theoretical foundations, and each field has a different view of theory. For example, scientific theories are those which provide explanations, predictions, and are testable. The interpretivist tradition of building theory is used in several disciplines, and views theory as understanding the socially-constructed situation in the context of those who live it. In areas such as management, it is important to identify constructs, their relationships, and be able to test those relationships to build theory. Theory in Information Systems research has been examined as (Gregor, p. 613):

1. Statements that say how something should be done in practice
2. Statements providing a lens for viewing or explaining the world
3. Statements of relationships among constructs that can be tested.

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[22] Encarta Dictionary. Retrieved May 2008 at http://encarta.msn.com/dictionary_/theory.html.

Each of these types of theories can be valuable, especially in a discipline such as IS, which intersects object, such as the IT artifact, with the knowledge of human behavior (Gregor, 2006). Each type of theory is valuable and can be interrelated. Gregor (2006) further classifies theory in IS as being either theory for analyzing, explaining, predicting, for explaining and predicting, or for design and action (p. 634). The critical factor in determining what type of theory to utilize is to begin with the phenomenon of interest and "determine which type of theory is appropriate for the problem, given the current state of knowledge in the area" (Gregor, p. 634).

The importance of building theory is that it contributes to knowledge, provides new insights, and provides credibility to the arguments made (Gregor, 2006). Because the IS field has been concerned with rigor and relevance issues, there is a need to achieve synergy between academic research contributions and practice. Because variables such as politics and culture are difficult to replicate in experimental or survey-based research, rich sources of data allow variables such as politics and culture to be examined in context so that they are relevant to practitioners.

Both case studies and grounded theory research allow the study of new complex phenomenon in a natural setting (Fernandez & Lehmann, 2005). However, there are some differences in the approaches. Case study research

involves a priori selection of the cases to be examined, whereas grounded theory data sources are chosen by theoretical sampling, based on the emergence of theory (this will be discussed later). One of the basic tenets of case study research, as described by Yin (1994) is that a priori theory development is essential for case studies. While grounded theory research may rely on a brief literature review, it is critical that a priori biases are minimized. Lastly, case study research has often followed positivist methods by utilizing hypothesis formation and verification or falsification, resulting in a quasi-experimental situation. Grounded theory studies have different methods to examine credibility than verification or falsification, as in positivist traditions. However, Fernandez and Lehmann (2005) state that studies can utilize the grounded theory approach as an overarching methodology which builds theory from case study data. This will allow for the generation of theory from rich data sources, while also following the systematic methods of the grounded theory tradition.

Grounded theory research is appropriate to use in IS studies when the "focus is on emerging socio-technical IS phenomena because it [grounded theory approach] avoids the risk of transferring incorrect theoretical assumptions to emerging phenomena" (Fernandez & Lehmann, 2005). In the study of emerging phenomena, one should seek to generate theory by examining the environment in context "to discover what is going on, rather than assuming what should go on"

(Fernandez & Lehmann, 2005, p. 83). Table 4 references some of the relevant articles from IS research in which grounded theory approach is used in different contexts.

Table 4. Examples of Grounded Theory Approach in IS-Related Studies

Source	Concepts Studied
De Vreede et al, 1998-1999	Acceptance of GSS
Orlikowski, 1993	CASE Tools and Organizational Change
Crook & Kumar, 1998	EDI Use in Multiple Industries
Sjoberg et al, 1998	IS Participatory Design in Healthcare
Scott, 2000	Interorganizational Learning
Galal, 2001	Operationalizing Contingent Process Models
Sarker et al, 2001	Virtual Team Development
Pauleen, 2003	Virtual Team Leader Relationship Building
Zahedi et al, 2006	Cultural Aspects of Web Documentation

Perhaps the best example of the application of grounded theory in and IS study is that of Orlikowski's MIS Quarterly paper, which won the Best Paper award for 1993. She examined how CASE Tools were utilized within the context of organizational change, focusing on the process and behavior of actors in the organizations studied. Due to her work, other IS researchers have successfully applied grounded theory to other contexts, such as Sjoberg's (2001) study on participatory design and Sarker's (2001) and Pauleen's (2003) studies on virtual

team development and member behaviors. Each of these researchers investigated the intersection of technology and human behavior within the context of rich data sources to produce theory using grounded theory methods.

Grounded Theory Methods

One “fundamental tenant” (Glaser, 2004, p. 5) of grounded theory is to begin with no preconceived theory. In fact, Glaser (2004, p. 13) states that the Grounded Theory methodology “treats the literature as another source of data to be integrated” into the study once the basic conceptual development has advanced. It is typical that the literature review will be brief in a grounded theory study. Entering into a study with a minimal amount of preconceived notions as possible will also enhance the researcher’s theoretical sensitivity, the awareness of the researcher of the correspondence of the data to the research questions posed (Glaser, 2004). The grounded theory methodology is systematic through theoretical sampling, the constant comparative method, developing and examining documentation and immersing oneself in a setting, will enable one to generate a theory (Glaser & Strauss, 1967).

Selecting a grounded theory study is challenging to researchers. Challenges include (Creswell, 1998, p. 58):

1. The researcher avoiding preconceived notions, assumptions, and biases as much as possible.

2. The researcher should understand that the Grounded Theory approach is flexible, but does follow systematic methods to discover theory.

3. The researcher trusting herself to know when the coding is saturated and the theory is parsimonious.

4. The researcher recognizing that the purpose of the Grounded Theory approach is to generate a theory which includes: a core variable, causal conditions, strategies, conditions, context, and consequences.

However, using the systematic methods of grounded theory traditions, these challenges can be overcome to successfully produce a contribution to theory.

Data Sources

According to Glaser and Strauss (1967), the notion of theoretical sampling should be utilized to determine which data sources are appropriate for the study. Theoretical sampling is "the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges" (Glaser & Strauss, 1967, p. 45). In essence, emerging theory controls the data collection since the researcher does not know the next steps until gaps in theory and research questions have been revealed. While collecting data, the concepts of theoretical sampling and single versus aggregate units of analysis should be considered as the theory emerges. Glaser and Strauss (1967, p. 47) suggest that the research could include "aggregates or single

people as the equivalents of groups, with respect to the strategies of comparative analysis."

There are two goals that could be used for theoretical sampling: finding similarities between groups and finding differences between groups. Initially, the researcher may plan to minimize differences in the groups to establish basic categories. Next, the researcher may decide to use these categories and strategically find additional data sources to maximize differences between the groups. The maximization of differences approach was used for this study. This increases the probability that data sources will be varied while also attempting to discover the similarities among the groups in a strategic manner. This results in elaboration of theory (Glaser & Strauss, 1967, p. 57).

Determination for when to cease data collection was based on the concept of saturation. Initially, it was estimated that the data collection would involve approximately a year of time. The data sources for this study were determined based on theoretical sampling and the theoretical relevance of those sources (Glaser & Strauss, 1967, p. 49). From these emerging sources and based on saturation of each data source, the length of data collection ranged from a few months to one and one half years.

The grounded theory approach allows the researcher to listen to the participants openly discuss issues rather than encouraging them to talk by asking

specific interview questions. The critical task is to listen to the voice of the participant without preconceived notions of literature or researcher bias (Glaser, 2004). In listening to the voice of the participants, either through spoken or written word, Glaser and Strauss (1967) consider "all as data." In essence, any type of data can be utilized, including documents, interviews, and observations, and the researcher should treat all of the data as if it could hold vital information to contribute to generating theory.

Analysis—Using the Constant Comparative Method

The constant comparative method which is unique to Grounded Theory methodology allows for theory to be generated through jointly and systematically coding the data and analyzing the data for content. If analyzing documents or transcription for similar content, each instance of similar content is considered an incident. For example, each incident of the terms empowerment or power that appears in the data would be aggregated to form a concept of empowerment. The comparisons take three forms: 1) incidents are compared to other incidents to develop concepts; 2) concepts are compared to incidents to determine if the particular incident should be aggregated with the concept; and 3) concepts are compared to concepts to determine parsimony of the concepts (Glaser, 2004). The comparisons should be performed until the concepts are saturated and begin to repeat in the data. When the researcher begins to ponder ways to

interpret the codes, theoretical notations or memos should be made for future reference (Glaser & Strauss, 1967). Glaser (2004) suggests that a primary core variable will emerge which accounts for the central focus of the research questions. This core variable can be any kind of code and should recur frequently and relate easily to the other concepts.

The constant comparative method is one in which, "both implicitly and explicitly, the analyst continually checks out his theory as the data pour in" (Glaser & Strauss, 1967, p. 26). In essence, the researcher performs joint coding and analysis at the same time by using systematic coding and analysis procedures (Glaser & Strauss, 1967, p. 102). "This approach requires that data and theory be constantly compared and contrasted throughout the data collection and analysis process. Evolving theory directs attention to previously established important dimensions while the actual data simultaneously focus attention on the theory's suitability as a frame for the most recent data being collected. The result of this fluid movement between theory and data is a reconceptualization, often based on a creative leap" (Isabella, 1990, p. 12). Open coding is the first step in this approach.

Open (Conceptual) Coding

In open coding, the researcher analyzes each line of transcript of data to discover the substantive concepts which arise in the data. Patterns in the

incidents of codes are recognized and as many codes as possible are generated (Glaser, 2004). These codes are also referred to as categories by some researchers (Creswell, 1998, p. 57). As the data is analyzed, patterns of incidents are identified as either new codes or associated with existing codes. When new incidents are detected, the researcher then understands the direction to take and can then conduct theoretical sampling. Theoretical sampling is the process of determining additional sources of data collection based upon the essence of the emerging theory (Glaser, 2004). Since Grounded Theory is based on the foundation that the theory is generated from the data, the sources of data collection also are generated from the concepts that arise from the data. As the data emerges, the researcher collects, codes, and analyzes the data jointly and determines what additional data is needed and where to collect such data. Through open coding, the researcher should uncover properties that are associated with each code, as well. Open coding is performed until the concepts and codes are saturated; that is, they begin to repeat in the data. The amount of saturation that is appropriate to determine the completion of open coding is at the researcher's level of trust and comfort in the data (Glaser & Strauss, 1967). It is assumed that by this point, the researcher has been immersed in the data and in the natural setting such that the saturation point will be clear.

Axial (Theoretical) Coding

Axial coding is described by Creswell (1998, p. 57) as the exploration of "causal conditions," strategies, context, "intervening conditions," and consequences of the phenomenon of interest. In essence, the purpose of axial coding is to identify relationships between the core variable and other incidents in the data. Through axial coding, the researcher begins to relate the open codes (Creswell, 1998, p 209) by examining their properties and contexts (Glaser & Strauss, 1967). The researcher constantly compares the data collected, the codes, and the relationships to ensure that there is consistency in the theory being generated. The researcher then examines the theory, asks questions regarding the theory, then "returns to the data and looks for evidence, incidents, and events that support or refute the questions, thereby verifying the data" (Creswell, 1998, p. 209). The purpose of the integration of various codes and their properties is to make theoretical sense through comparisons. Thus, grounded theory is an inductive method of theory development (Glaser & Strauss, 1967, p. 114).

Selective Coding

As the theory emerges, the researcher may perform reduction, which is finding uniformities in the coding and properties for which a theory with a smaller set of concepts is developed (Glaser & Strauss, 1967, p. 110). Selective coding

means that coding stops and the code is delimited to generate a theory that is parsimonious (Glaser, 2004). After additional constant comparative procedures are performed until there is theoretical saturation (repetitiveness), the parsimony of the coding, relationships, and scope is better understood. Selective coding is viewed by Creswell (1998) as the task of identifying a 'story line' to integrate the categories coded. This can be done through rich, thick description, propositions or hypotheses.

Theoretical Memoing

Throughout the joint analysis of data collection, coding, and analysis, the researcher relies on theoretical memoing to record notes about reflections of the process (Glaser, 2004). In memoing the researcher records comments, observations, annotations and preliminary interpretations about the conceptual generation and connections between them. These reflections throughout the process can be helpful in following emerging concepts as well as discovering the biases of the researcher.

Length of Grounded Theory Studies

Conducting Grounded Theory studies takes time. It cannot be rushed, and should be paced such that the researcher is allowed to carefully review and investigate the data to generate parsimonious theory (Glaser, 2004). The

systematic and extensive process of data collection, coding, analyzing, theoretical sampling and reflective memoing require time for consistency in method and to allow for creative processes to discover theory. Because sampling is theoretical, it is often difficult to determine the length of time needed for a Grounded Theory study. One can estimate time and what data may need to be collected and from whom, but until theory evolves, the researcher should exercise patience and allow his awareness of the data, coding, and theory to emerge at a personal pace.

Credibility of Grounded Theory Studies

Qualitative methods such as grounded theory have unique techniques to examine the quality of the study. For example, reliability in a grounded theory study is viewed as the accuracy and comprehensiveness of the data in comparison to what actually happened in the setting (Bogdan & Biklen, 2003, p. 36). Because the researcher is the medium for data collection, reliability is focused on the researcher and accurate descriptions of the setting and phenomenon under study. Generally, the rigor of a grounded theory study is viewed as trustworthiness or verification. There are eight procedures to verify the trustworthiness of a grounded theory study, as shown in Table 5 (Creswell, 1998, p. 201-203).

Writing the report of the study is important to communicate the process and results of the study to others in the field, and should be written in a persuasive manner through the use of thick, rich description from the natural

Table 5. Procedures to Ensure Quality of a Grounded Theory Study

(Creswell, 1998, p. 201-203)

Procedures	Description
Prolonged engagement and persistent observation	Refers to spending a lengthy time in the field examining the issue from different contexts or situations
Triangulation	The use of multiple source, methods, investigators and theories to provide corroborating evidence. Multiple sources means to include different types of participants, such as different types of patients and providers; methods refers to using different techniques such as interviews, observations, and document analysis; multiple investigators means the use of more than one researcher.
Peer Debriefing	Using an external check of the process through a peer of the researcher to provide an alternative analysis of the research progress and process. Peer debriefing notes are kept from these sessions.
Negative Case Analysis	In lieu of discarding those individual responses which do not corroborate the theory produced, the researcher examines those outliers to determine why they provide disconfirming evidence.
Clarifying Researcher Bias	The researcher keeps journaling notes throughout the process to understand his perception, position, biases, and assumptions about the research. These biases should be discussed in the study write-up.
Member Checking	The participants in the study are invited to verify the researcher's notes, drafts, and interpretation of their accounts. If members do not agree with the researcher, the researcher determines why there are disagreements and addresses those by either changing the interpretation if appropriate or by keeping the original interpretation and discussing in the write-up the member disagreements regarding the interpretation.
Rich, Thick Description	A detailed account of the participants, their accounts, and settings enables readers to put themselves in the setting.
External Audits	Using an external auditor to examine the process and product of your research to verify accuracy of the product.

setting. The writing should be clear and engaging so that the reader feels as if he is a part of the story. The data sources for the grounded theory approach as applied to the examination of consumer empowerment in HIE will be discussed next.

CHAPTER IV

DATA SOURCES

Three primary sources of data are used for this study: The American Health Information Community (AHIC) Consumer Empowerment Group; North Carolina Healthcare Information and Communications Alliance's Consumer Advisory Council on Health Information (NCHICA CACHI); and a selected group of Everyday Consumers. These three data sources will be explained in detail in later chapters, but were chosen for their three different perspectives on Consumer Empowerment in HIE. The AHIC group was chosen because it is a United States federal group; the NCHICA CACHI organization was chosen due to the state-level view of its members; and the Everyday Consumers were people who were not from either of these groups and not working in the healthcare or Information Technology (IT) fields. Details for the purpose, types of participants and data collection are shown in Table 6.

The focus for these groups is on consumer empowerment in HIE; however, the investigation for this study was to determine how each group, from a federal, state, and individual perspective, views consumer empowerment. It

was expected that these groups would offer a variety of perspectives on consumer empowerment in HIE.

Table 6. Data Sources

Data Source	Purpose	Participants	Dates of Data Collection	Type of Data Collection
AHIC Consumer Empowerment Group	Federal viewpoint of consumer empowerment in HIE	Representatives of patient advocacy group, U.S. DHHS, Insurance companies, vendors	January 2006 to June 2006 (until data saturation)	Meeting transcripts and Meeting audio files
NCHICA Consumer Advisory Council	State of North Carolina viewpoint of consumer empowerment in HIE	A mix of consumers who have at least a moderate level of healthcare or IT experience. Some members represent various groups such as senior citizens.	July 2006 to January 2008 (until data saturation)	Meeting Attendance; transcripts, agendas, presentations Follow-up Interviews
Everyday Consumers	To gain insight into perspectives of consumer empowerment through 'everyday' healthcare consumers in NC	"Everyday"=Consumers who are not working in the healthcare or IT field	January 2008 to May 2008 (until data saturation)	Interviews

AHIC Consumer Empowerment Group

One source of data for this phase of research is from the AHIC, a group formed by the United States Department of Health and Human Services. “The

American Health Information Community (AHIC) is a federal advisory body, chartered . . . to make recommendations to the Secretary of the U.S. Department of Health and Human Services on how to accelerate the development and adoption of health information technology."[23] AHIC is an important group to examine for this study because it is a federal effort and provides a higher-level view of consumer empowerment dimensions. There are few large-scale efforts, such as AHIC, which study consumer empowerment in the context of HIE. It is based on a federally-funded effort and includes a variety of stakeholders expressing their perceptions and views on the phenomenon of interest, consumer empowerment. Because it is a federal workgroup, the meetings proceed systematically, and proper documentation is generated. AHIC workgroups are formed to study specific phenomenon in healthcare information technology. The current workgroups are: Chronic Care; Confidentiality, Security, and Privacy; Consumer Empowerment; Electronic Health Records; Personalized Healthcare; Population Health; and Quality. Because its focus is on empowerment issues, the Consumer Empowerment Group (CEG) was chosen as a data source for this study.

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[23] United States Department of Health and Human Services. *American Health Information Community Background.* Retrieved Jun 2007 at http://www.hhs.gov/healthit/.

AHIC formed the Consumer Empowerment Group to make recommendations for the wide spread adoption of a personal health record that is "easy to use, portable, longitudinal, affordable, and consumer-centered" (Feb. 21, 2006). These Workgroup meetings are held on a monthly basis and are open to the public; therefore, members of the public have access to detailed documentation such as minutes and transcription contents. Document analysis can be performed on these materials, which include agendas, testimony hearings, work plans, meeting summaries, transcripts, and streaming archives. For this study, the meeting transcripts were utilized to perform coding according to the grounded theory approach. Over 300 pages of transcripts from January 2006 to June 2006 were analyzed until the data were saturated. Participants in the Consumer Empowerment Group include individuals representing patient advocacy organizations, the Department of Health and Human Services, insurance companies, vendors, and the Centers for Medicare and Medicaid Services. See Appendix E for a list of Consumer Empowerment Group members. For this analysis phase, only the meeting transcriptions will be analyzed to provide a conceptual foundation for the factors driving consumer empowerment in HIE based on the meetings of the federal AHIC group.

NCHICA CACHI

NCHICA is the North Carolina Health Information and Communications Alliance. The background of NCHICA will be discussed first and then the formation of CACHI underneath the NCHICA organizational umbrella. NCHICA was formed in 1994 by an Executive Order of the Governor of North Carolina. The mission of NCHICA, which is located in the Research Triangle Park, is "to improve healthcare in North Carolina by accelerating the adoption of information technology."[24] The vision for NCHICA is to be a "leader in the drive for innovative applications of IT to improve healthcare in North Carolina and the nation."[25] As a nonprofit organization, NCHICA champions the adoption of information technology to improve healthcare through initiatives such as "informing clinicians, . . .developing secure and private healthcare exchange, and empowering consumers to play a more active role in their healthcare through their use of IT."[26] The organization hosts an annual conference and exhibition to help inform and engage clinicians and other stakeholders. As of December 2007, there were 199 organizations represented through NCHICA membership (not including individuals). These organizations represent various healthcare groups,

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[24] North Carolina Health Information and Communications Alliance. *NCHICA Overview.* Retrieved May 2007 at www.nchica.org/AboutNCHICA/CorpInfo/vision.htm.
[25] Ibid.
[26] Ibid.

hospitals, pharmacies and health systems; healthcare technology vendors; government agencies (such as Departments of Health and Human Services); legal groups; universities; and research organizations (such as RTI—Research Triangle Institute).

The executive director of NCHICA has been successful in fostering collaborative efforts and networking of healthcare stakeholders to allow for the participation of North Carolinians in national projects such as HISPC (Health Information Security and Privacy Collaboration) and the NHIN (Nationwide Health Information Network Prototype Architecture). The NCHICA website[27] states that "NCHICA operates in many venues as a convener, promoter, educator, catalyst, and innovator to . . . .lead demonstration projects, host educational sessions, foster collaborative efforts, and support initiatives that promote standards-based IT in healthcare statewide." Under the guidance of the NCHICA Executive Director, the capability for NCHICA to be involved in many projects has resulted in national recognition. Throughout my participation in this project, I was able to attend regional and national meetings and it was apparent that the Executive Director is acknowledged by many people on a national level for leading NCHICA

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[27] North Carolina Health Information and Communications Alliance. *NCHICA Overview.* Retrieved May 2007 at www.nchica.org/AboutNCHICA/CorpInfo/vision.htm.

to a highly visible status as an innovative organization to foster adoption of information technology in North Carolina.

I first became involved with NCHICA through attendance at a conference in 2005. My initial interest was as a student who was interested in healthcare information technology and becoming involved in an organization through whom I could learn more about current events and network with people working in the field. At this conference, I met the Executive Director and inquired as to the possibility of participating in any projects regarding healthcare IT privacy and security issues. In 2006, the Executive Director and I discussed a new group which was being formed by NCHICA which was the Consumer Advisory Council. The impetus for creating the Consumer Advisory Council was based on the Executive Director's input to the NCHICA Board of Directors. As the Director states "NCHICA was working on a strategy for future activities and we had a major meeting in 2003 with the Board and important members around medication management/e-prescribing and I presented an organization chart showing the key players involved in medication management and one of our Board members asked the question: 'Where are the consumers?' That started an introspective process that ended in the chartering of CACHI in 2006."

Thus, due to their established efforts in the adoption of health IT, the second data source is the NCHICA CACHI group, which was formed to "engage

consumers in providing input and feedback on topics related to health information“ (NCHICA CACHI Charter, 2007—See APPENDIX A. CHARTER FOR NCHICA CONSUMER ADVISORY COUNCIL and APPENDIX B. INITIAL CALL FOR PARTICIPATION FOR CACHIAPPENDIX B. INITIAL CALL FOR PARTICIPATION FOR CACHI). “CACHI is a unique health care consumer group formed for grassroots input and participation to explore ideas and issues surrounding health information, such as privacy and electronic health records.” CACHI’s membership includes consumers who want to voice their opinions on healthcare information issues, and individuals who represent consumer groups (such as HIV/AIDS or the elderly). These members were recruited through NCHICA membership as well as snowball techniques to form a group of individuals who represent the needs of North Carolina healthcare consumers such as the elderly and individuals with HIV/AIDS. The goal of the CACHI group is to have 15 members; as of December 2007 the membership was ten. An unexpected obstacle in forming the CACHI was in finding people to serve as members on a volunteer and non-paid basis. The CACHI members are supported by a Resource Panel which consists of people in different specialty areas such as privacy, security, and healthcare technology. The role of the Resource Panel was to help the council members by providing information,

education, speakers, and any other support needed by the Council to complete the tasks they needed.

"CACHI will provide an opportunity to influence both state and national policy with regard to health care consumers' ideas and concerns about health information and technology, and will participate in trying to find a balance between a patient's need for privacy and the health care system's need for access to personal health information" (NCHICA CACHI Charter, 2007). Because it is a state group, NCHICA CACHI will be important to examine grassroots efforts of consumer empowerment in HIE.

Data were collected from the CACHI group from July 2006 to January 2008 until saturated. During the initial meeting in August of 2006, my role was introduced as a doctoral student who was interested in security and privacy issues in HIE. At this initial meeting, one person volunteered to be the Chair of the Resource Panel. After the second meeting, this person asked if I would be willing to serve as a co-chair of the Resource Panel since my dissertation work would also be in support of the council's activities. Therefore, my role was technically a co-chair of the Resource Panel. The logic in agreeing to this role was to also gain the trust of the council and to emphasize that my work would be an effort that could contribute to their efforts. I was very wary of the potential conflict of interest in serving as a co-chair, and this emphasized my need to be

neutral in my effort to contribute to the group. Therefore it was important to clarify my role to the council members. The following item was added to the Consent form which the members signed: "Ms. Cannoy's role in the NCHICA project is to ask questions when pertinent, observe, record, and transcribe each meeting's discussions. Some additional administrative work may be performed by Ms. Cannoy . . . as appropriate. "

Data were collected through the CACHI group in several ways:

1. Attending monthly meetings from July 2006 to January 2008.

2. Transcribing notes from the meetings was my responsibility since I was taking notes already for the purpose of this study. Therefore, to prevent duplicate efforts, my notes became the foundation for the meeting minutes as well. While this may seem to be a conflict of interest, it actually became an advantage because the council members were responsible for approving all meeting minutes. Therefore, this was a form of member checking to ensure that my notes were accurate and reinforced the credibility of my notes.

3. Agendas were generated from August 2006 to February 2007 by the Resource Panel co-chair. After this time, I became responsible for generating the agendas. The items for the agendas were added based on input from the council members the Resource Panel members in the beginning of the council's formation. During the summer of 2007, the responsibility for what items should be included on the agenda was placed on the council members primarily so that they could drive their own efforts based on their interests and concerns. At no time did I add items that were solely at the interest of this research study and I was very careful to ensure that the agendas were not driven by my own research interests.

4. Supporting documentation such as PowerPoint presentation slides and related articles that are sent to the group by either the resource panel members or the group members themselves. For example, if the Executive Director saw an article that would be of interest to the council, he would forward the link to the council. Sometimes these articles would be topics of discussion at the meetings.

5. Email correspondence with members of the group was important since some items were discussed via email rather than using council meeting time. These emails sometimes were also important to discover issues discussed by the Resource Panel members as a "behind the scenes" view that the council members weren't always privy to know. For example, there were some email discussions sent between the Resource Panel members especially in the beginning which discussed what topics should be included on the agenda. The email correspondence included well over 370 email exchanges. These emails were sent among the Resource Panel members to save time and discussion during the council meetings. Thus, they provide a context for understanding how agendas were set. No quotes for the analysis of this study were taken from these emails.

6. Follow-up questions and interviews with council members and Resource Panel members were conducted after the initial data collection phase to gather in-depth information. This served as a follow-up on initial data analysis and to receive confirmation/disconfirmation on initial findings.

What was difficult in the data collection for CACHI was when to determine an ending date for data collection. Data collection was longest for the CACHI group out of the three data sources. While I was involved from this formation of the group, it took time for the group to form and gain focus. On the contrary, the AHIC group had already been provided with a broad charge and deliverables, so they entered the process with specified goals to achieve.

Everyday Consumers

The limitation of utilizing the AHIC and CACHI groups is that all of the members involved in those groups are or have been involved in working in Information Technology (IT). Therefore, they have an informed and perhaps biased view of the field. As a result, it was important to include consumers who have less work experience in healthcare or information technology. It was decided from the emerging data from AHIC and CACHI that interviews needed to be conducted with 'everyday consumers' who are patients or caregivers who utilize the healthcare system, but have no work experience with healthcare or IT.

This result is an integral component of grounded theory in which additional data sources should be utilized as discovered from emerging theory. Thus, the consumers were chosen according to grounded theory's 'theoretical sampling' techniques (Glaser & Strauss, 1967). Due to the emerging theory, what became important to discover was the perspective of Everyday Consumers---those consumers who had no healthcare or IT work experiences. There were seven consumers who were interviewed. While it was preferable to find a diverse group of Everyday Consumers, ranging in different ages, gender, and ethnicity, the theoretical goal was to find consumers who had no healthcare or IT work experiences. All of the consumers interviewed are from the same race, and it

is acknowledged that this is an area that needs to be addressed for future research to include a diverse set of ethnicities in the data source.

The interviews ranged from 30 minutes to 1 hour and one half. To save time, some preliminary demographic questions were emailed to the interviewees before the interview. Table 7 is a summary of their background information.

Table 7. Summary of Everyday Consumers

Interviewee	Occupation	Age	Level of Education
1	Retired High School Teacher	> 65	Master's
2	Worship Leader	18-25	Some college
3	Office Manager	36-55	Master's
4	Field Service Supervisor	26-35	Bachelor's
5	Welding Supervisor	36-55	Some college
6	Administrative Support Assistant	36-55	Some college
7	Patient Advocate	>65	High School

It is difficult to define 'Everyday Consumer' and these interviewees were chosen because they had no work experience in healthcare or IT, since both the AHIC and CACHI group members seemed to be more informed due to their work in healthcare and/or IT. The following are summaries of responses of the 'everyday consumer' group to questions on their use of IT and knowledge of HIE:

1. All of the consumers had more than three years of experience in using computers and the Internet.
2. All of the consumers accessed computers from home and/or work
3. The consumers saw anywhere from one to eight different healthcare providers.
4. The number of times that each consumer visitied healthcare providers ranged from 1-2 times a year to10-20 times a year
5. None of the consumers had heard of the NHIN (Nationwide Health Information Network)
6. The amount of time each consumer used a computer each week was six hours.
7. Four of the consumers use the Internet to research medical information or to access healthcare provider websites to pay medical bills, etc.

One person to be noted in this group is Interviewee #7, the patient advocate. This patient advocate is Toni Cordell[28] who agreed to let me use her name for this study. (All other interviewees will remain anonymous according to IRB protocol.) Toni speaks to groups of people regarding the issue of health literacy, which was prompted by her history of embarrassment due to her self-described low level of literacy. I discovered Toni's story when reading a Sept/Oct. 2007 edition of the North Carolina Medical Journal, which was a special edition on doctor/patient communication. The article written by Toni was called "Chasing the Monster" and addressed her healthcare experience being a high school graduate with a 5th grade reading level. She tells of her story from

[28] Cordell, Toni. Retrieved April 2008 at www.tonicordell.com.

30 years ago in which she visited her gynecologist, who said she needed an 'easy repair' for a problem. Because of her poor reading skills, she signed all of the paperwork without question and without reading it before her surgery. She did not realize the kind of surgery she had until the follow-up doctor's visit when the nurse asked her how she was doing since her hysterectomy. This experience traumatized her and was one event that prompted her to become a patient advocate. Toni now lives in Charlotte, North Carolina and has completed adult literacy classes. Since Toni lives in North Carolina, I emailed her and asked for an interview over the phone, to which she agreed. Because she speaks to so many groups of people about her experiences, she realizes that many people know her history and, for this reason she agreed to let me use her name. Due to her background, I felt that she was also an appropriate person to interview for this study because she represents the 'everyday consumer' who had no healthcare or IT work experience. The quotes for Toni's experiences are from the phone interview conducted with her, from her website, and from "Chasing the Monster" article and other articles written about her.

Within the grounded theory methodology, it is important to generate enough data that the emerging concepts become saturated and start to repeat. Although it seems that seven interviews is not much data, the information gained from these everyday consumer interviews was rich enough that the concepts

became saturated after five or six interviews. Therefore, seven interviews seemed to be an appropriate number from which to gleam open, axial, and selective coding.

In conclusion, the comparison between the CACHI, AHIC, and the Everyday Consumers is important to investigate the similarities and differences in how consumer empowerment is viewed by each group. The integration of these perspectives may determine how federal and state law, organizational policy, and HIE technology will be created to ensure secure information exchange of health information.

CHAPTER V

DATA ANALYSIS

"I think it is very important we make certain the consumer voice is heard."
-AHIC Consumer Empowerment Group member (Transcript Feb. 21, 2006)

My involvement with the CACHI group from the initial meeting was as a doctoral student who was interested in security and privacy issues in healthcare IT. As time went on and events evolved, my focus became more so on consumer empowerment and how security and privacy issues were encompassed within consumer empowerment. Ultimately, the final overarching theme of this research emerged to encompass the theme of consumer empowerment in HIE and how state, federal, and local groups could affect consumer empowerment.

The analysis of the data from the three sources was performed according to grounded theory methods (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The data were analyzed through constant comparative methods and codes were systematically generated. The discovery of codes was through examining the data for similar concepts. As these similar concepts were found, codes were

developed in which to group the incidents of these concepts. There were times where incidents could be placed into more than one code, but in these situations, the context of the quotes was examined more thoroughly to determine how to code the incident.

Coding was performed in three phases (See Figure 2. Phases of Coding). For each data source, open coding, axial coding, and selective coding were performed (Strauss & Corbin, 1990). The codes were generated from the data for each separate group. For example, the AHIC codes emerged from the AHIC data only and were independently generated as best as possible without regard to codes generated from the other data sources. From the coding analysis of each data source, the categories developed for each data source were then examined for relationships. This was then utilized to perform axial coding. Selective coding was used to make the final categories more parsimonious.

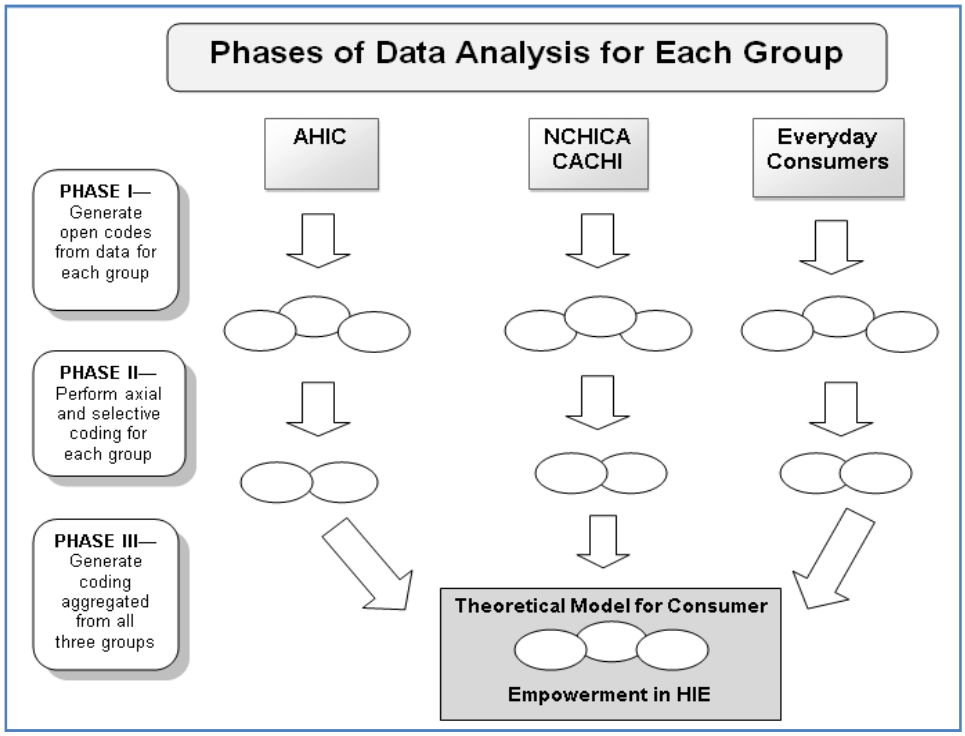

Figure 2. Phases of Coding

CHAPTER VI

AHIC CONSUMER EMPOWERMENT GROUP DATA ANALYSIS

Background

AHIC (American Health Information Community) formed the Consumer Empowerment Group to make recommendations for the wide spread adoption of a personal health record that is "easy to use, portable, longitudinal, affordable, and consumer-centered" (Feb. 21, 2006). These Workgroup meetings are held on a monthly basis and are open to the public; therefore, members of the public have access to detailed documentation such as minutes and transcription contents. For this study, the meeting transcripts were utilized to perform coding according to the grounded theory approach. Over 300 pages of transcripts from January 2006 to June 2006 were analyzed until the data were saturated. Participants in the Consumer Empowerment Group include individuals representing patient advocacy organizations, the Department of Health and Human Services, insurance companies, vendors, and the Centers for Medicare and Medicaid Services. The phases of open, axial, and selective coding were performed for the data analysis, and will be described in detail next.

Phase I Open Coding

In open coding, the researcher analyzes each line of transcript of data to discover the substantive concepts which arise in the data. Patterns in the incidents of codes are recognized and as many codes as possible are generated (Glaser, 2004). Open coding is performed until the concepts and codes are saturated; that is, they begin to repeat in the data. The amount of saturation that is appropriate to determine the completion of open coding is at the researcher's level of trust and comfort in the data (Glaser and Strauss, 1967).

The AHIC data analysis was based on transcripts from the meetings from January 2006 to June 2006. To understand the context of the discussions, I downloaded and listened to the streaming audio files for the first two meetings (rather than listen to the total 17 hours for the first six months). This was completed because it was found that some transcript contents were not accurate or were difficult to understand without listening to the conversation. Sometimes extraneous words were left out of the transcription, making it difficult to determine the meaning. At times, there were changes in speakers without the names being inserted into the transcript, making it unclear as to who may be speaking. Also, it seemed that the transcription may have been generated by an electronic software package, because some of the terms were phonetically spelled out instead of using the correct term (the term 'bedded' was used instead of 'vetted'

in the February 2006 transcript) It was also impossible to determine which words were emphasized and the tone of the meeting notes. There were a few statements that were said in jest which could have been taken completely out of context without listening to the audio files. Any other statements which were not clear were verified through the audio streaming files.

A total of 307 pages of meeting transcripts were read and coded manually, with notes and reflections written in the margins of the transcripts. The documents were reviewed for content and context so that codes generated are grounded in the data. Key words and short phrases (for example "consumer involvement") for each month were circled and then recorded in an Excel spreadsheet. For each month, there were approximately 50-70 key words/phrases recorded. From each month's open coding, the codes were then aggregated into one set of open codes for the entire six months (for example, "consumer involvement" and "consumer input" would be aggregated into one term such as participation or either one of the terms would be chosen which encompassed the context the best). Table 8 shows the codes generated from using the constant comparative method to generate open codes (Strauss & Corbin, 1990). These were generated through patterns in the incidents of codes.

The transcripts were also entered into the qualitative software package, QSR NVIVO 7.0 to make the management of the data and analysis more

effective. Included in NVIVO's functionality is the ability to code across documents to investigate the data for open codes. As the transcripts were

Table 8. Results from the AHIC Open Coding Process

Open Coding	
Awareness	Consumer Trust
Education	Information Integrity
Literacy	Data Elements
Consumer Input	Information Sources
Consumer Voice	Standards
Enforcement	Access
Law	Control
Information Privacy	Information Ownership
Rights	Value of PHR
Consumer Responsibility	Information Security
Situational Context	

analyzed manually for content, NVIVO was utilized as a data management tool to search for quotes which related to coding generated during the analysis. See Figure 3 for a screen shot of NVIVO's document view. This shows the result from automatically highlighting the words coded, within the context of surrounding sentences. This allows a researcher to easily view the coding results of a query by looking at the highlighted sections. Because the option was made to highlight the results in context, sentences surrounding the query coding are also selected.

As the analysis progressed, the open codes were grouped into similar concepts. Axial and Selective Coding are discussed next.

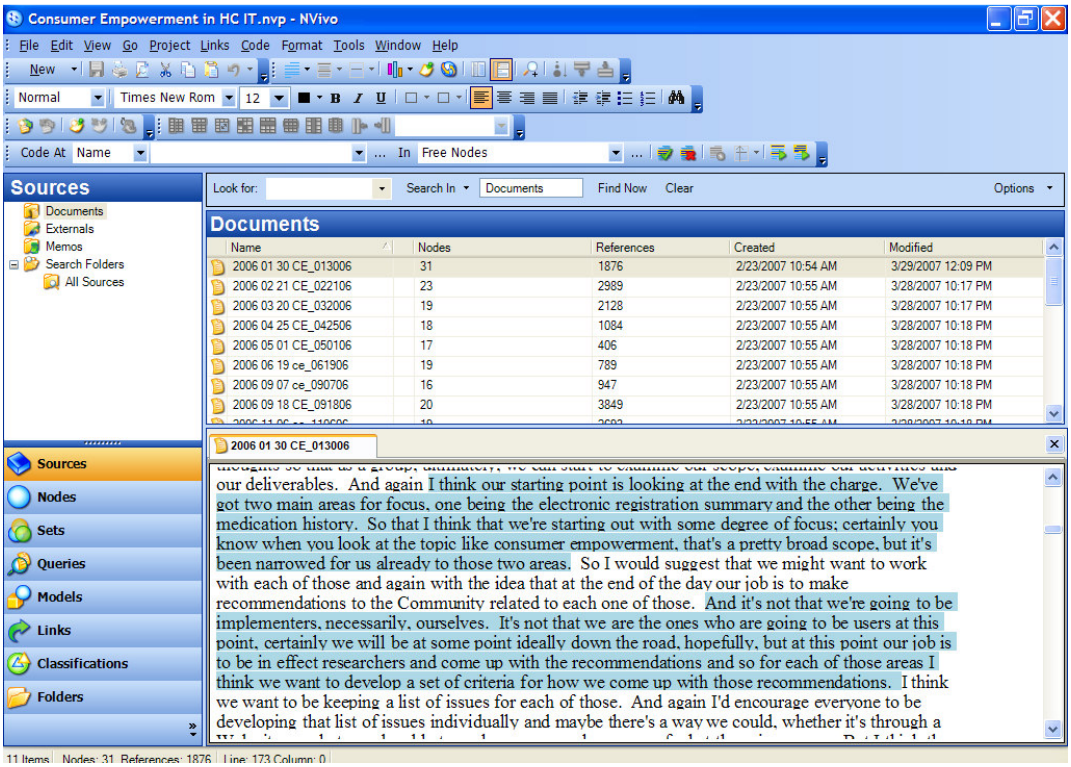

Figure 3. NVIVO Software Screen Shot

Phase II Axial and Selective Coding

Axial coding is described by Creswell (1998, pg. 57) as the exploration of "causal conditions," strategies, context, "intervening conditions," and consequences of the phenomenon of interest. In essence, the purpose of axial

coding is to identify relationships between the core variable and other incidents in the data. Through axial coding, the researcher begins to relate the open codes (Creswell, 1998, pg 209) by examining their properties and contexts (Glaser & Strauss, 1967). The researcher constantly compares the data collected, the codes, and the relationships to ensure that there is consistency in the theory being generated. As the theory emerges, the researcher may perform reduction, which is finding uniformities in the coding and properties for which a theory with a smaller set of concepts is developed (Glaser & Strauss, 1967, pg. 110). Selective coding means that coding stops and the code is delimited to generate a theory that is parsimonious (Glaser, 2004). Selective coding is viewed by Creswell (1998) as the task of identifying a "story line" to integrate the categories coded. This can be done through rich, thick description, propositions or hypotheses. As the description is provided, the affiliations (companies, organizations) of the AHIC Consumer Empowerment Group members will be utilized instead of their names. Although their names are public via the website, the title is appropriate to confer the perspective of the speaker.

As a result of in-depth data analyses, the following major categories were identified: Consumer Engagement, Fairness, and Consumer Confidence as related to consumer empowerment in HIE. The results of axial coding are shown in Figure 4 (Consumer Engagement in HIE), Figure 5 (Fairness in HIE), and

Figure 6 (Consumer Confidence in HIE). Each of these major categories is discussed in depth in the following sections.

Consumer Engagement in HIE

From the transcripts, the AHIC Consumer Empowerment Group felt that consumers would be more Engaged in health information exchange if they Understood HIE, provided Voice and Input to AHIC's meetings (through public input or surveys) and were Active in adopting and using HIE technology. In order to become Engaged, according to AHIC, the consumers needed to be convinced to use HIE technology. While the members of AHIC discussed Consumer Voice and Input as a form of being Engaged, AHIC members did not actively seek the Voice and Input of consumers. If consumers were Actively Involved in using HIE technology (specifically PHRs; Personal Health Records), and Understood how to adopt and use the technology, they would be more Engaged. One AHIC member stated, "I think the success that we are going to have as a committee is going to be measured ultimately by the consumer engagement with our recommendations and support thereof and utilization of . . . ." (Member from the National Patient Advocate Foundation, 3-20-2006). An initial step to Involve consumers was to determine what features they would like in PHR technology, and the AHIC Group planned to include the Consumer Voice in the Consumer

Empowerment Group's efforts to achieve this goal. Figure 4 shows the results of Axial and Selective coding for Consumer Engagement in HIE based on the AHIC transcripts. Consumer Engagement will also be investigated from a process view in the chapter on the Process Model of Consumer Empowerment in HIE.

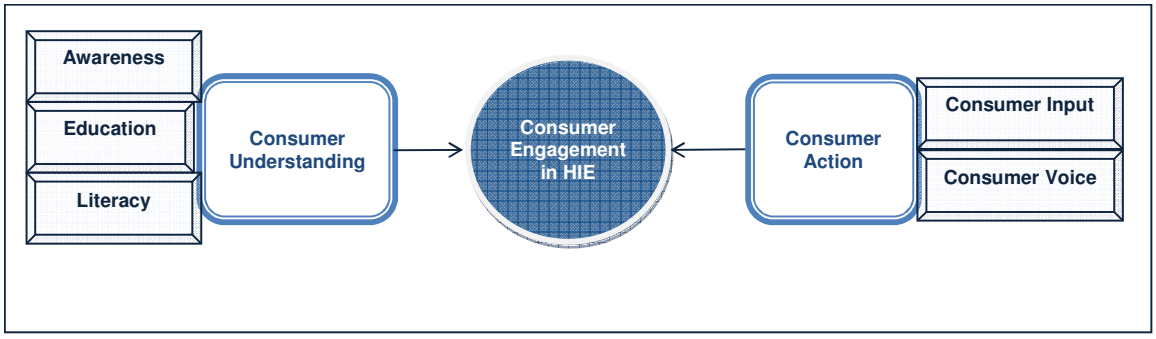

Figure 4. Results of AHIC Coding Process for Consumer Engagement in HIE

Consumer Understanding

One facet of Consumer Engagement was Consumer Understanding, which was comprised of Awareness, Education, and Literacy. According to the AHIC transcripts, these codes were used as a continuum of understanding. There should be a level of Awareness which is an initial understanding of Health Literacy, and to move from an initial level of Awareness to becoming more Informed involves some type of education. In their first meeting in January 2006,

they discussed how Hurricane Katrina brought about a level of Awareness for the need to have the capability to share medical information electronically:

> Member from Pharmaceutical Company: . . . .I think Katrina did highlight the need to build awareness. And this is not just awareness on the clinician level but also on the consumer level. We can build all this stuff, and it can actually work, and it can meet all the needs that we've been addressing. But if there's not some sort of public relations, public information campaign associated with it, we'll not get the penetration that will be needed. There will be some word of mouth eventually, but we need to get awareness built once we've got a solution available. . . . . but if [the consumers] are the ones physically giving permission to a clinician to say, "My health information is kept at" – be it their payer, be it KatrinaHealth.org – and they're aware of that, and they give the release at that time, they can choose at that point what level of information is provided. . . .(1-30-2006)

In the March meeting, they discussed the idea of having a "consumer campaign" called a "Consumer Awareness Initiative," as an educational component for consumers to learn more about PHRs and sharing their medical information. One facet of understanding PHRs and HIE was that of understanding the technology, which was considered a

> ". . . .barrier that I wanted to sort of change over to was more of the consumer themselves being comfortable with using the technology that this type of registration or medical list would require a consumer be aware of. The younger you are, the more adept you are at using the technology, I guess, but more of our older population shy away from using the Internet or can't use the Internet for various reasons and can't use some of the other

> technological equipment and systems that we all take for granted" (1-30-2006, Member from National Institute of Standards and Technology).

This incorporated an awareness regarding literacy in HIE, as well, and the AHIC members felt that it was important to recommend "messages that would in fact raise awareness, overcome unnecessary concerns about protection of information while recognizing real, viable concerns and having people understand and expect to have the electronic personal health records and demand them and know how to use them" (3-20-2006, Member from National Health Council). This understanding of technology related to HIE could be considered HIE Literacy. This seems to be different than Literacy, which was also discussed by AHIC members.

Literacy was mentioned in several contexts in the AHIC meetings. During the March 2006 meeting, they discussed it in terms of being able to read English and function in society at a basic level:

> Member from American Medical Informatics Association: "So about somewhere between 20 and 40 percent of our population read at low literacy levels, and if you think about low health literacy on top of that, the population that we might go after is easily probably about 40 percent. That is that the language we use has to be at about, I don't know, you know, roughly about a sixth-grade reading level. Most commercial Web sites nowadays and health information probably is somewhere between 8th and 11th grade.

> So one, I just sort of bring out the issue of low health literacy and low reading literacy as being challenges for us. And then I want to bring up the issue of alternative languages such as Spanish, for one, and 23 other languages that we might want to consider, depending upon where we are. Are we intending to go after some other languages in addition to English in the early phases here?"
>
> Member from Markle Foundation: "So I think we should -- and the issue . . . . raised about the scope, in terms of language populations, literacy population, geography -- again, I think we should figure out where are things that will -- that either could be accelerated by virtue of our action or could be expanded in scope, for example, to low literacy, because we said that was a population. Perhaps a company already serves the affluent, well-insured, English-speaking population but needs to serve another population that isn't served by a commercial enterprise. . . "
>
> Member from Vendor Company: ". . . Consumer campaign. I'll use that term loosely, because I'm not a marketeer. However, I do really -- the internationalization hit home with me. I speak several languages myself. I hear it every day. Can we get patient instructions in Spanish? I think about the population we're potentially looking at, and yeah, you know, how could I have missed that? I did. And I think that -- how do we get those people engaged into this program? It will be tough -- let alone someone who is a Native English speaker in a demographic where there's a high literacy rate. And how do we ensure we give access equally amongst all? That's another barrier, definitely."

Therefore, it seems that in order to have HIE Literacy, a consumer first needs to have a level of functional Literacy. Literacy in this context is seen as a concern for Equity because not every consumer has the same level of Literacy or the resources to become Literate. Cultural and language barriers were mentioned throughout the meetings. Two suggestions were given for this problem: Using

plain-language experts and incorporating literacy levels into PHR interfaces. These were directly recommended by members of AHIC:

> Member from the National Health Council: "A recommendation would be to sort of the right entity to do some research about what has been done when you're dealing with large systems, consumer information that is critical to their welfare, and how -- what have we learned about how to -- in an easy way, a simple way as possible -- get these -- get the material into languages and prejudices and formats that really are user friendly and add value to the end user, the consumer or the patient, using professional expertise like plain-language experts"
>
> Member from the U.S. Department of Health and Human Services: . . . .I have a suggestion. There might be some experts who would be willing to come in and give a presentation in April and sort of summarize what is known in the literature, for example, around plain language or what are current practices with industry right now with PHRs providers in trying to develop interfaces that are sensitive to these literacy issues.
> (3-20-2006).

One member from an HIE vendor company suggested working with patient advocacy and other organizations to help Educate consumers: "An example of an action item for education could say [*sic*], 'The government should team with the American Cancer Society, or etc., to come up with a consensus consumer education program using the groups that are most representative of some of the areas or study groups that wanted to focus in on'" (3-20-2006).

During the June 2006 meeting, there were several discussions of health literacy, which seemed to become encompassed within other issues, and never really addressed. One member from the U.S. Department of Health and Human Services brought up the idea of health literacy on at least five occasions during this meeting. On almost every occasion, it was either ignored or never resolved because other related and important issues arose. For example, this conversation evolved into provider awareness:

> Member from National Health Council: Okay. How about consumer awareness and provider awareness and then also health literacy since we had a fair amount of conversation around those three areas, although I think many of the subgroup members aren't present. Although, ...if you're still on the phone, you might have some ideas on how we should scope this out.
>
> Member from Medical Group Management Association: Yeah, I think . . . .that you think about the effectiveness of a PHR, it's really going to be a tandem between the patient and the provider, and I think what we have to do is develop a workplan which would not only educate the provider on PHR, the technical side of it, but also the philosophical side, how can this improve the care they deliver to patients, what are they going to expect from patients as we walk through the door. So I think outreach materials that we could develop that could be given out to medical specialty societies, to government agencies that are working with both type community health centers, Indian health services and all those folks, the more consistent the message I think probably the better for providers.

Other ways were suggested to improve Consumer Understanding. To become more informed beyond an initial level of Awareness, they suggested ways to

Educate consumers. Education should take place through “patient education materials” (3-20-2006). An Education Subgroup was created, but it is unclear from the six months of transcripts exactly what deliverable or information was produced from this group. While discussing their main priorities, the members developed three “buckets”: policy review, interoperability, and education. The members typically discussed both consumer Education and provider Education, because their research revealed that consumers trust providers to relay information to them. The following conversation describes this perspective:

> Member from National Patient Advocate Foundation: I think that consumer education also has to include the educational component for the provider community. It's almost as though we need to think of those in tandem thoughts.
>
> Member from the Medical Group Management Association: I wanted just to return, to a second, to the issue of education. In my mind, we've got several audiences, and the primary one being the consumers. . . . I think we have to do a proactive approach. I think we need to reach out to folks like AAFP, the Consumers Union, and folks like that, letting them know what we're doing, why we're doing it -- again, try to engage those folks. Just last week at the House Energy and Commerce Committee hearing on health IT, 90 percent of the conversation revolved around privacy. So I think we have to do a very good job of being proactive on this. And similarly, I think the way to get to a lot of consumers, frankly, is through provider offices. For example, the Part D program -- many of the questions are being addressed to physician practices, because they're sort of gatekeepers to the health care system for most consumers. (3-20-2006)

In essence, in order for consumers to be Engaged in HIE, primarily through PHRs, they need to be Aware, Educated, and have a level of Literacy to understand HIE. The other component of Consumer Engagement is Consumer Action, which provides an avenue for Consumer Input and Voice in HIE efforts.

Consumer Action

Consumer Action can be provided through Input and Voice. At face value, these are very similar terms. One would need to provide a Voice for Input. The AHIC members discussed Consumer Voice and Input through conducting surveys and focus groups to discover for example, what consumers preferred in a PHR's features. However, in their terminology, the AHIC members tended to refer to Voice as the Voice of the everyday consumer (for example, through responses to surveys), whereas Input was referred to as Public Input. At least five times during the January and February meetings, the term "Consumer Voice" was used:

1. Member from AHRQ (Agency for Healthcare Research and Quality): ". . . .And one of the things we would be interested in is thinking about how to bring more of the consumer voice to those information exchange efforts as they get off the ground" (1-30-2006)
2. Member from National Patient Advocate Foundation: "The fundamental process needs to be one in which the consumer voice is represented in all discussions, all levels, when we're going through the process" (2-21-2006).

3. Member from National Patient Advocate Foundation: ". . . But at the same time, I think it is very important we make certain the consumer voice is heard" (2-21-2006).
4. Member from U.S. Department of Health and Human Services: ". . . .that whatever process we complete over the next, you know, year, you know, starting very soon, it will ensure that the consumer voice is represented through every step" (2-21-2006).
5. Member from U.S. Department of Health and Human Services: ". . . .we propose a process for the workgroup that will ensure that the way that we set agendas and the way that. . . you act as a Co-chair will ensure that the consumer voice is represented. . . . " (2-21-2006).

There were several times throughout the meetings that the members stated the importance of creating value for the consumer and getting consumer input in the process. A member of AHIC who represented the Centers for Medicare and Medicaid Services stated "the PHR by definition, I think we have to keep reminding ourselves, is consumer driven. It is the individual, so what is in there and who see it and what gets done to it is absolutely driven by the individual, and I think we have to keep reminding ourselves of that for this particular initiative" (2-21-2006). However, they often felt that they did not have time to gain consumer input because of deadlines. The following is an excerpt from the March 20, 2006 meeting regarding input from the consumers:

> Member from National Patient Advocate Foundation: And the medication history with consumers -- we were talking about focus groups that you might be able to do survey work with cancer and

> chronically ill patients, caregivers, patients of children ages 0-12, users of provider portals and users. . . It might help us identify what is important to the consumer when you think about having a personal health record. . .but we would also have some very current survey data that could be very helpful to us moving forward.

The conversation continues:

> Member from the Department of Health and Human Services: If we're doing surveys, we have to comply with the Paperwork Reduction Act, so that would require us to get approval of a survey instrument through OMB, and that can be an extensive and time-consuming process.
>
> Member from the Department of Health and Human Services : . . . .I think there's an opportunity for asking -- saying we're interested in these particular topic areas or this type of information, and you can have people not necessarily fill out a survey instrument or form but come in and give testimony or provide written testimony that addresses some of the issues of what you're interested in and having more information about.

From this conversation, it can be interpreted that due to time pressures and the need to comply with the Paperwork Reduction Act and other review processes, a formal survey of consumers was not feasible. During the six months of transcripts analyzed, the AHIC group did not complete a formal consumer survey. However during the April meeting, two very limited surveys were presented, based on limited surveys of consumers and subscribers of an insurance company.

The other type of Input was that provided by the public at the end of every meeting and during testimony at meetings. Those from the public could be everyday consumers, representatives of patient advocacy groups, or even representatives from healthcare stakeholders such as insurance companies. Although Public Input was a broad category due to this, the term Consumer Input was used to clarify the perspective of the Consumer that is being examined. At the end of one meeting, the phone line was opened for public comment, and one consumer from the general public spoke for approximately six to seven minutes about her concerns. Note that, even though this member of the public's affiliation was not named in the transcript, it seems that she is linked to a healthcare provider or company of some kind. She spoke about a number of issues, including the need to access patient PHRs to integrate their insurance claims information with the PHR; problems with incomplete information on insurance claims; and concerns with being able to share patient medical information with the patient and for secondary uses, which is not possible under HIPAA regulation. She ends her comments with:

> So these are things that when I was reading some of the notes, we weren't seeing addressed. We're struggling and trying to get information to the consumer, and the only one right now really making efforts and strides toward getting that information to people. So guidance on how we should approach this would be very helpful (May 1, 2006).

Although she provides good feedback and asks appropriate questions of the workgroup, she only receives a moment of silence after her lengthy and thought-provoking comments. This is the conversation that began after the pause:

> Member 1: Okay, thank you very much.
>
> Member 2: That's it for public comments.
>
> Member 1: All right, then. We have our assignments. Please get any additional comments you might have to the staff at ONC. And we'll look forward to the -- I guess we're getting two products now. The -- a quick look at what recommendations might go into the PowerPoint slide, as opposed to the letter or holding off, and then the second thing will be by the end of tomorrow or the next day, I can't remember. Tomorrow, a revised letter.
>
> Member 3: . . .Is there going to be any response now or later to the person that just raised the issues on the phone from the public comment?
>
> Member 1: I think that will have to be from ONC. [Office of the National Coordinator]
>
> Member 4: Yeah, you're welcome to respond to the comment as a Workgroup member.
>
> Member 3: I don't know if I'm the best person to comment. I just think that the individual needs to be acknowledged and maybe it's whether our group will take these -- or we'll try to find the right place to have them addressed. I thought they were important issues, really important. Or to ONC, but somebody would somehow get back and let them know that we heard and we're at least getting the information before the right people.
>
> Member 4: Yeah, I mean I think there's now a public record of the comments. I think -- I think it would be even more helpful to have

> something in writing. Okay. So I think written testimony would probably be easier to respond to. And I think that that will probably happen. It's already prepared.

Perhaps they were in a hurry to end the meeting, but the member from the National Health Council wanted to make sure that the person's comment was acknowledged. In summary, to achieve consumer engagement in HIE involves a level of Consumer Understanding and Consumer Action which encompasses Awareness, Education, and Literacy in conjunction with Consumer Input and Voice.

Fairness in HIE

To instill a sense of Fairness in HIE technology and processes, consumers should believe that there is Social Justice and Legal and Institutional Provisions. If there is Equity in HIE access and Situational Contexts, as well as Enforcement of Law and Privacy, Fairness can be attained as a component of consumer empowerment in HIE. AHIC members discussed Information Privacy as a Right which can encumber consumers with Responsibility of understanding HIE and managing their medical records. Figure 5 shows the Open, Axial, and Selective coding steps for Fairness in HIE.

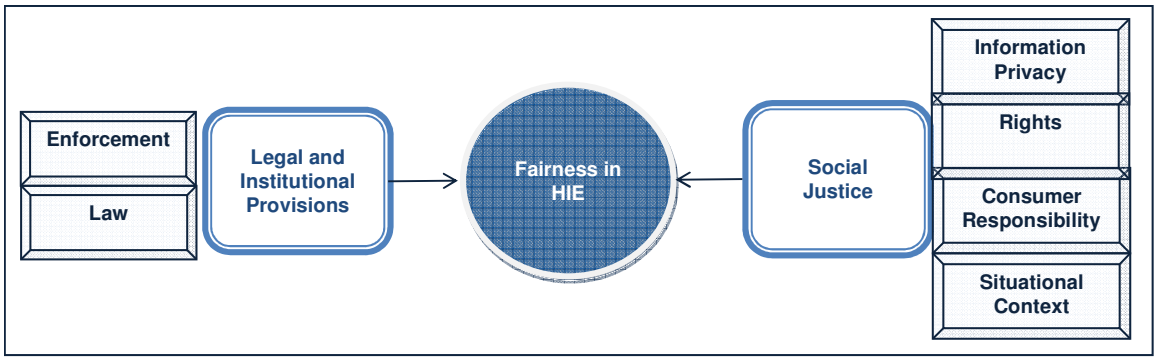

Figure 5. Results of AHIC Coding Process for Fairness in HIE

Legal and Institutional Provisions

AHIC members often discussed Legal and Institutional Provisions in the context of federal and state Law, and the Enforcement of these provisions. Much of the Legal aspects involved examinations of HIPAA and how it related to HIE. The following excerpt from the March 2006 meeting emphasizes that, although some of HIPAA's concepts for privacy and security can be applied to HIE, there are differences. These differences need to be reconciled for proper Enforcement of unauthorized disclosures of information and so that a sense of Fairness is experienced in HIE.

> Member from Department of Health and Human Services: In some of the scenarios that we have been talking about, there will be distinctly different HIPAA impacts depending upon whether or not the personal health record is being run or made available by a covered entity itself or by a covered entity through a business associate. In either of those two scenarios, there would be HIPAA

> controls over how that information is used and disclosed, and I'll come back to that in a minute. If it is an independent vendor that is not in a relationship with a covered entity but is marketing a personal health record to consumers at large, that entity has no -- it's not a covered entity, and so HIPAA does not apply to that entity. The only HIPAA implication for that entity would be how information would move directly from a covered entity into that vendor's database. . . . Once that information moves from the covered entity to the vendor through the authorization process, there's no further HIPAA protection of that information. And whatever privacy and security is desired for that information, and whatever is needed to be done in terms of affording the individual with rights with respect to that information, would have to be constructed outside of HIPAA. There would need to be some sort of marketplace factors brought to bear in terms of how those protections would attach to that independent vendor.
>
> Member from the Markle Foundation: I think it leaves us with a challenge as we think about this breakthrough, how do we put -- what Sue said at the end of her comments about the marketplace may address some of these open areas. I think to act in a relatively rapid fashion, our workgroup needs to think about mechanisms to establish privacy protections for users of whatever we recommend that address -- that are outside of HIPAA, specifically addresses, as we've heard. HIPAA was not -- did not develop an environment of electronic networks or personal health records.

The above excerpt reveals that HIPAA does not necessarily protect medical information that is not handled by a covered entity (usually an organization which is involved with treatment, billing, or direct care of the patient). Because Personal Health Records (PHRs) may not be provided by a covered entity (for example, it could be provided by Microsoft or Google), HIPAA would not apply. Once medical information moves from the physician's EHR to the patient's PHR,

it is no longer protected under HIPAA if the provider of the PHR is not a covered entity. This is a fact that many consumers may not be aware. However, with the PHR, the primary goal is that the consumer controls and manages their own medical record, so, inherent in this is the idea that the consumer is giving access to those who need it. A suggestion provided by a member who represented the Department of Health and Human Services was to "do a more careful analysis of what activities . . . are covered under HIPAA versus not being covered under HIPAA and what are the mechanisms through, for example, certification or through contract law we can rely on to ensure some of the more specific requirements or principles as they are developed" (3-20-2006). In essence, instead of relying on federal law such as HIPAA to provide protection, perhaps PHRs should be certified by an authorized organization to have certain security protections. Or the vendors of the PHRs should supply contractual obligations when a consumer purchases a PHR.

Enforcement of privacy policies and laws was discussed by AHIC members, and a concern was "who could be, you know, overall the enforcement arm over industry" (6-19-2006, Member from the Department of Health and Human Services)? There were two alternatives discussed, the Federal Trade Commission (FTC) and the Certification Commission for Health and Information Technology (CCHIT). The member from the Department of Health and Human

Services stated that “we also recognize that the Certification Commission for Health and Information Technology, which has already talked about Certification in part of its business plan, while it's not in their current contract, there would be the potential to incorporate privacy and security requirements in a certification process” (4-25-2006). The FTC could act as an “arm of enforcement” as suggested by another member of the Department of Health and Human Services:

> . . . .but this is really getting at sort of the group that of PHRs that are often not going to be covered by a HIPAA clause and that may not be adequately addressed by the privacy and security contract. So we're trying to think about what other mechanisms there may be for enforcing -- you know, for privacy and security practices and enforcing privacy and security practices through other mechanisms, like the FTC Act, that will enforce against an entity that has a privacy policy up on its Web site but then doesn't act in accordance with its privacy policy and that is misleading advertising or misrepresentation and they can enforce against that and whether or not there may be other mechanisms out there that can be used to enforce privacy policies (4-25-2006).

If there is a violation, there are state laws which can be applied; however,. “. . .only a few States have notification lines that we regard as policy decision that any violation of patient privacy by someone managing this data should result in notification or some sanctions, consequences for those who violate privacy . . “ (2-21-2006, Member from the Markle Foundation). This quote implies a sense of Fairness so that consumers could be empowered to use HIE technology.

Social Justice

The idea of Social Justice involves justice in consumer Situations and the inherent Right to Information Privacy. According to AHIC, associated with the Right to Information Privacy is the Responsibility to manage one's medical information. Social justice is a broad term which, in other contexts such as social work, politics, or education, is used to imply activism. According to the Center for Economic and Social Justice,[29] the term social justice

> is the virtue which guides us in creating those organized human interactions we call institutions. In turn, social institutions, when justly organized, provide us with access to what is good for the person, both individually and in our associations with others. Social justice also imposes on each of us a personal responsibility to work with others to design and continually perfect our institutions as tools for personal and social development.

Therefore, in the context of HIE, Social Justice implies a sense of Information Privacy Rights to manage one's own health records. This is in consideration of Situational Contexts which can determine how a patient may view the sensitivity of his medical information, for example, if there is a diagnosis of a stigmatizing condition. Within this context is the notion of societal institutions which should implement HIE Fairly. Also associated with a consumer's Right to

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[29] Center for Economic and Social Justice. *Defining Economic Justice and Social Justice*. Retrieved May 2008 at http://www.cesj.org/thirdway/economicjustice-defined.htm.

Information Privacy and to be able to manage her own medical records is a Responsibility to use it in an informed manner. In order to understand HIE technology and processes, a consumer also has a Responsibility to become informed on these topics to make informed decisions and manage their own medical records. Information Privacy was one of the key components for the AHIC members to consider:

> It's been said time and again on this call that privacy is the principal design issue and any time we talk about health information. And so we established here that consumer privacy is the most important principle for guiding the selection of the data elements and the data sources, as well as the process in which the health information is collected and exchanged (2-21-2006, Member from AHIMA, American Health Information Management Association).

Much of the conversations regarding Information Privacy revolved around HIPAA and "How do we protect personal health information in PHRs" (2-21-2006, Member from Department of Health and Human Services)? The members realized that HIPAA may not be adequate, though, and wanted to "identify what we know exists in other policy venues that does and does not provide privacy adequately for patient records and transfer of those records" (3-20-2006, Member from National Patient Advocate Foundation). Because HIE involves the transmission of sensitive medical information electronically, there is a heightened awareness of the AHIC members to protect Information Privacy.

> To me, it breaks into three types of data: demographic data, insurance-related data, and clinically related data. And as you go down that tree, there is greater sensitivity and greater need to address the privacy issues that become triggered by the availability of this information moving across the network (2-21-2006, Member from Markle Foundation).

The types of information that are protected can have varying degrees of sensitivity. Medical information can be handled differently based on the diagnosis or type of patient, as well.

AHIC members examined many different situational contexts which they felt needed to be considered. If PHR vendors and HIE efforts considered the needs of these different populations, consumers may feel that there is a sense of Fairness in HIE. This could be through specific features in PHRs offered for certain populations of people, or through equitable distribution of HIE resources. Therefore, Situational Context includes a facet of equity. One member of the public, during time for comment at the end of the January 2006 meeting stated that "the key to opening up market participation is in a way that is beneficial to provider and the patient really seems to be around, first and foremost, getting the technology in the hands of those people as cost-effectively as possible." In the February 2006 meeting, the Digital Divide (inequitable access to computers) issue was mentioned, "on the negative side, some of these data will be difficult to

obtain, and many of these patients may not have access to computers or the Internet. Although some data suggests when they have computer and Internet access, they do just as well [in community health care settings]" (Member from Agency for Healthcare Research and Quality).

The AHIC members investigated different needs for health information. If a consumer feels that her needs have been considered in HIE processes and technology, she may be more likely to view HIE as being Fair. The populations of consumers that the AHIC group felt were important to consider in their efforts included: Children (for immunization record access); Patients with Chronic Diseases; Patients on Multiple Medications (primarily Medicare and Medicaid patients); Uninsured and Underinsured Patients (for community health clinic access); Elderly Patients (who often have caregivers who need access to their medical records) (2-21-2006, presented by Member from Agency for Healthcare Research and Quality) . Depending on the patient's circumstances, there may be needs for special types of information to be shared:

> It also may be useful for us to have another category called conditional, meaning it really depends upon the specific situation. As somebody already brought out, if you are not focusing on a child and immunization records, that may not be the particular issue. (2-21-2006, Member from Pharmaceutical Company)

Because there could be sensitive information in the medical records, it is important to

> . . . .allow the patient to declare what is true or to have different truths for different purposes, which people may want to disclose information – not disclose it in some circumstances, disclose it in others: the sensitive information. For example, on this list, Don, you have previous hospitalization, previous treatments, previous diagnoses. Some of those will be things people will certainly want to withhold, not consider automatic treatments for mental history, reproductive health issues, whatever. We shouldn't default it to assume that everything we think of as minimum as opposed to transferred upon request. And in fact our research says that some people will want to have several versions of the truth be used in different circumstances (2-21-2006, Member from Markle Foundation).

In essence, a consumer can create "different truths" about themselves based on the Situational Context and what they feel comfortable disclosing. This is the Right to Information Privacy that was discussed by one member from the Veterans Health Administration in that "patients hold back information and/or lie. But, often it's more holding back information from providers here and there. And having an electronic [record] shouldn't take that right away from them" (1-20-2006).

The facet of Rights beyond that of Information Privacy was that of the Right to Control and Access one's medical record, which is also discussed in the section Consumer Confidence in HIE under Consent Management (Information Ownership). One example of this is when a member of AHIC stated "we looked at the issue of

rights and who has the right to sort of controlling data flow and data closure. . . ." (4-25-2006). Although HIPAA does provide Rights (to notice, to access, and to amend their information), they are "not absolute" because they have the "right to access their information and to obtain a copy of their health information that is in a particular subset" (3-20-2006, Member of the Department of Health and Human Services). The member from the Veterans Health Association stated that "this provider certainly has a copy of what they generate. We seem to endorse the patient also has a right to a copy of that" (4-25-2006). Guarantees of the Right to medical records were discussed by AHIC members: " . . . nowhere in the principles does it say that consumers have a guaranteed right to their own personal health record. . .and perhaps that needs to be a foundational premise" (2-21-2008, Member from National Patient Advocate Foundation).

However, what comes with the Right to have a PHR is a Responsibility for the consumer to understand the consent processes, technology, and management of the record. When discussing how insurance plan information could be included in the PHR, including coverage and benefits, the discussion was whether it would be too much to manage when it changes: "The question is, is that something that goes into the PHR? Because if it goes in the PHR, then what we are encumbering or may encumber the consumer with just the responsibility for maintaining that information on an annual basis. . . . " (2-21-2006, Member from American Health Information

Management Association). However, if the insurance information can be accessed automatically by the PHR from the insurance carrier's website, "what it does is it relieves the responsibility of the PHR to have that and the consumer to maintain that information" (2-21-2006, Member from AHIMA). Another statement regarding Consumer Responsibility is that the PHR

> . . . .is not a legal record, like the EHR, and therefore it makes the PHR a separate record out of necessity. The electronic health record at the hospital or the provider or the physician must go through all of the Federal rules of evidence and health information management practices to—for discoverability and submission into court evidence and those kinds of things. . . we wouldn't want to encumber the consumer with that kind of responsibility" (2-21-2006, Member from AHIMA).

When consumers experience forms of Social Justice such as consideration of Situational Context and the Right to Information Privacy, the associated Responsibility needs to be considered. Consumers should be prepared (through Awareness, Education, etc.) to understand these associated Responsibilities. Activities which could support this preparation are discussed in the chapter on the Process Model of Consumer Empowerment in HIE. Therefore, Social Justice and Legal and Institutional Provisions can provide a sense of Fairness in HIE.

Consumer Confidence in HIE

Consumers need to have a level of confidence in HIE to adopt the technology, according to AHIC. Part of AHIC's goal was to incorporate the Value of the PHR to the consumer so that consumers would use the technology. Value of the PHR was viewed as offering features such as Information Security and Consent Management features, which also could serve to boost a consumer's Confidence in HIE. Conventions in HIE were considered to be certain practices which would be consistent throughout HIE, no matter which PHR a consumer used or which provider they visited. Having consistency in PHR features, such as ways to exchange information also provide a level of confidence in HIE since consumers know what to expect. Having Trust in HIE and feeling that Information Integrity is enforced are also supporting facets of Consumer Assurance, which enables the formation of Confidence in HIE. Figure 6 shows the Open, Axial, and Selective coding for Consumer Confidence in HIE as found from the AHIC data analysis.

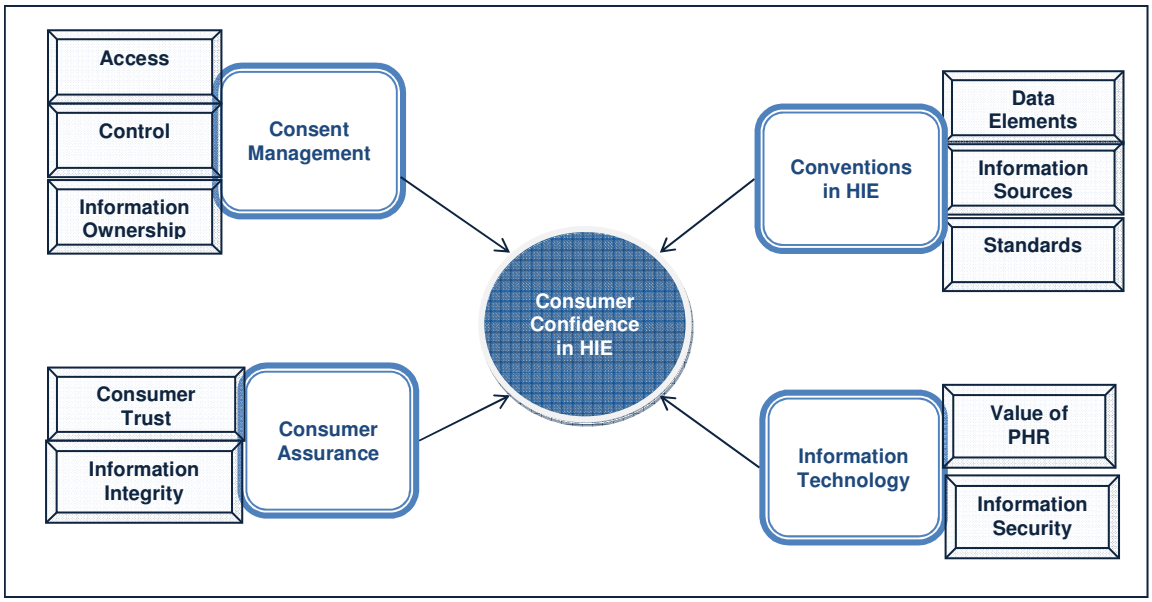

Figure 6. Results of AHIC Coding Process for Consumer Confidence in HIE

Consumer Assurance

Consumer Assurance is a critical component of Consumer Confidence. If a Consumer is not Assured of HIE processes and technology, she is likely not to be as Confident. Consumer Assurance consists of Consumer Trust and Information Integrity. "Who is the patient going to trust with this data?. . . .They are certainly concerned about vendors, and they are very concerned about employers and insurance plans. . . .So, in general, in the healthcare field, patients trust their physicians more than anybody" (2-21-2006, Member of the Veteran's Health Association). The member from Markle Foundation

emphasized the need for trust when he said “I think the ultimate challenge to all of us is creating a trustworthy system in the minds of the American public” (2-21-2006). He also said that “I think public trust is a critical outcome of this process. . . and how we choose to architect the technology will itself either create more or less trustworthiness in the system. . . .In short I’m acknowledging against haste [in the HIE group efforts]. If we do this wrong. . . the entire national enterprise of wired health care system will be destroyed because of newspaper headlines” (2-21-2006). The AHIC members felt that part of Consumer Assurance was through the communication of information between the provider and patient to further learning about HIE. The members discussed the fact that, in surveys, consumers have said that they trust providers to help educate them on HIE topics. Another way that consumers can be Assured of HIE is to ensure Information Integrity.

Information Integrity is ensuring that as medical record information is stored and exchanged, it’s accuracy and completeness is maintained. If a consumer finds incorrect information in her PHR, she may not be Assured that HIE technology is high-quality or protects the accuracy of her information. One concern is “if a patient discovers a mistake in the data stream that becomes available through this breakthrough, is there any recourse? Who do they contact to seek a correction? Now there are several steps removed from the original

source of the data, making three or four steps removed by the time they have it in front of the patient" (2-21-2006, Member from Markle Foundation). This creates a liability risk for providers which could be handled in two ways: offering audit trails on the record and features which allow patients to append their record with comments.

> How does a consumer modify information within personal health records or add information and how does the provider understand and get information that says this was modified by the consumer so that they know it comes from a modified source or an entirely separate source. . . . (6-19-2006, Member from Pharmaceutical Company)?

The paradox is "how to provide consumer control while maintaining data integrity" (1-30-2006, Member of Department of Health and Human Services). Perhaps a solution is to ensure that "the information that's been delivered has either the audit trail thing—that if it's there, we know where it came from; if it's been changed, we know that it's been changed—and ultimately allow the clinician to determine that that's sufficient information at this time in order to treat the patient and let the patient assert that this information accurately reflects what they're sharing with the doctor" (1-30-2006, Member from Pharmaceutical Company). Therefore, the consumer should be able to understand the flow and exchange of medical information so that they can "assert" it's accuracy. The responsibility

also may on the consumer to be aware of the data sources and to sign off that the information is accurate to their knowledge.

Conventions in HIE

Conventions in HIE were considered to be certain practices which would be consistent throughout HIE, no matter which PHR a consumer used or which provider they visited. Having consistency in PHR features, such as ways to exchange information also provide a level of confidence in HIE since consumers know what to expect. From the AHIC data analysis, these Conventions include consistency in the types of data elements included in PHRs, the types of data sources from which information can be gleamed, and Standards of information portability, certification of technology, and interoperability. Without these Standards, HIE would be very disparate and difficult for consumers to utilize.

Data Elements may seem like a technical aspect of a PHR. Choosing the type of fields that vendors include is important to consumers, especially if those are consistent between PHRs so that, if necessary, moving from one PHR to another would be easy.

> "It's been said time and again on this call that privacy is the principal design issue and any time we talk about health information. And so we established here that consumer privacy is the most important principle for guiding the selection of data elements and data sources, as well as the process in which the health information is collected and exchanged" (6-19-2006,

> Member from the American Health Information Management Association).

Not all patients may require the same types of Data Elements, as suggested by the member from the Veterans Health Administration: "I think the other broad issue is one of medical specialty. What is not important for one patient may be critical to another. For example, birthweight. . . and immunizations are critical for some patients and not others" (such as pediatrics versus cardiac specialties) (6-19-2006). There was a comprehensive list developed of possible data elements, which included 174 items. The need to incorporate what was important for patient care was emphasized again since "things like eye color. . . .was listed as a patient identification feature, though. . . .those in acute care settings and ambulatory settings would probably not be concerned about that" (6-19-2006). Therefore, according to the AHIC data analysis, the types of Data Elements chosen are important for the consumer's interface and functionality of the end-product.

Another related issue was the origin for the Data Elements which are incorporated into the PHR. A member from the Markle Foundation suggested that ". . . .what we're trying to do here with consumer empowerment is to create some tools to kind of kick-start the process, pre-populate some data, get some patients involved" (1-30-2006). The patient could present a different source of

truth to each provider based on which information they decide to share. Sources of information were referred to as the "source of truth" and one member felt it was "naïve to think. . . .that anything that we build as part of the NHIN or through any applications is going to solve every possible issue in determining the source of truth, and the reality is that the source of truth is going to be still disparate" (1-30-2006). These Information Sources include caregivers, family members, providers, insurance companies, and the patient. One AHIC member in particular (from the Centers for Medicare and Medicaid Services) stated that a ". . .source of data could be a caregiver or family member. . . and we have to take that into consideration because it has all kinds of other implications" (1-30-2006). Such implications could include Consent Management features for those who want to have different levels of access to a family member's medical record. These Sources of information can provide Confidence because the patient is able to see a comprehensive view of their medical record and, hopefully, be able to better manage their health care. The implication of this is that each Source of Information be trustworthy.

Standards were considered in terms of information portability and certifications of technology. If information is exchanged in a consistent format, this should make the HIE process easier for the patient, therefore creating a level of Confidence in HIE. The AHIC members discussed how "part of our charge is

having the personal health record ultimately be portable" (1-30-1006) and to consider the portability between the patient's PHR and the physician's EHR (Electronic Health Record) so that a comprehensive medical record can be built. Portable PHRs and HIE requires Standards upon which the data is stored and transmitted, such as Health Level 7 (HL7) scripts. In fact, "HLT actually has an initiative underway, and they're in the process now of developing consumer criteria for this. . . " (Member from the Department of Health and Human Services). Certification of PHRs was primarily discussed as a sort of "Good Housekeeping Seal of Approval" in which the PHR would be Certified that it included certain components, such as security or privacy features. The Certification Commission for Health and Information Technology (CCHIT) was discussed as an organization which could handle this task: "We also recognize that the Certification Commission for Health and Information Technology. . .would be the potential to incorporate security and privacy requirements in a certification process" (4-25-2006, Member of Department of Health and Human Services). These Conventions can provided consistency for the secure exchange of health information, therefore offering an opportunity for increasing the level of Consumer Confidence in HIE.

Consent Management

Consent Management is known in the healthcare industry as the capability of someone to Control the Access to a medical record. From the AHIC data analysis, it was found that Consent Management involves both Control and Access, as well as an understanding of the perspectives for the Ownership of medical records.

Access seems to include the notion of being able to view one's medical record. For example, the AHIC members mentioned "access to patient-specific clinical information" (1-30-2006), "we give patients a right to access information" (2-21-2006), and "you explicitly allow someone to access your information" (2-21-2006), "caregivers that should have access to personal health records" (2-21-2006). However, through giving someone Access to a medical record, there are also levels of Control that can be provided. Control encompassed setting permissions for who could have Access and at what level. AHIC members felt that "consumers want to have complete control, give explicit permission to use information" (1-30-2006). The member from the Veteran's Health Administration felt that "unless we have the consumer have whole control of their information, then this personal health record isn't going to be adopted" (1-30-2006). Control over the content of the record and how it could be edited by the consumer were also concerns. This emphasized the idea of Ownership of the medical record.

The member from the pharmaceutical company asked, “have we really defined who owns the PHR data itself” (4-25-2006)? But he felt that it was a difficult question to answer since he again asked, “have we established that definition and that ownership understanding? And is that a –are we butting up against that in this again?” There is no federal or state law that provides an answer for this question, and the following lengthy excerpt from the April 2006 meeting is an exchange of ideas on this topic. It also reveals their frustration through the use of humor and inaudible discussion (of many people talking at once) regarding the idea of ownership.

> Member from the Department of Health and Human Services: It depends, ownership is a really complicated issue. Ownership of data. And it's something, I know, that when we -- when the department dropped at HIPAA we’d stay very far away from, because –
>
> [Multiple speakers]: (Laughing.)
>
> Member from Department of Health and Human Services: To be honest. Because, they're, typically at least where there is State law on ownership of health information, that usually resides with the provider who is creating the medical record, although there is certain laws on rights with certain information I don't think there's any laws that I've seen on personal health records and how and whether there's ownership rights or not that –
>
> Member from the Veterans Health Administration: . . . . I think a number of people point out when there's electrons involved the issue of ownership is an interesting one. And before you get a little bit different about it, the word “ownership” has a very different meaning. This provider certainly has a copy of what they generate.

> We seem to endorse the patient also has a right to a copy of that. The interesting thing then is who has the right to [relieve] that. Does it remain the patient's right as to when the provider can or cannot release that and under HIPAA there is the control that there so if you have differentiate the roles the patient has a right to a copy, the provider has the copy.
>
> [Multiple speakers]: (Inaudible.)
>
> Member from the Centers for Medicare and Medicaid Services: . . . .I think that's very helpful. The approach we were taking is we looked at the issue of rights and who has the right to sort of controlling data flow and data closure, and in some ways it's a as much more fruitful discussion because it avoids the issue of how you assign ownership of electrons and data and the like and turning into a discussion about rights is actually in many ways a more productive and helpful discussion when you're talking about electronic health information.
> Member from the American Medical Informatics Association: So some -- this is a $5,000,000 business. And some health organizations are getting $40,000 a quarter. So I think in a commercial sense the word ownership is already out of the bag, so-to-speak, in that, you know, there's a commerce that has occurred with this data. . . . .So I think ownerships a -- I mean, I hear that there's a nice way of talking about it, without using the word, ownership, but I think ultimately, although charged, it's -- it's a relevant concept. And you can sell it. So you must in order to sell it.
>
> [Multiple speakers]: (Inaudible.)
>
> Member from the Office of Personnel Management (DHHS): I'm going to step in for a second. I think the ownership might go a little bit beyond the scope of what's going to be in our letter to the Secretary, this first letter. . . . .

The concept of Ownership of one's medical record is, therefore, a controversial topic that has not been clarified through federal or state law. This will be an interesting concept to follow as PHR technology evolves.

Information Technology

From the broad charge of the AHIC Consumer Empowerment Group to make recommendations for the wide spread adoption of a personal health record that is "easy to use, portable, longitudinal, affordable, and consumer-centered" (Transcript, Feb. 21, 2006), it is apparent that Technology was considered a solution to support Consumer Empowerment. Therefore, the Value of the PHR to the consumer was critical to consumer use of PHRs and HIE Technology. Technological features also provided Information Security.

If the consumer sees Value in the PHR and feels that their information is Securely protected through Technological features, they may feel a level of Confidence in HIE. It was difficult to understand the value to consumers, as stated by Secretary Leavitt (of the U.S. Department of Health and Human Services), because "this movement has lacked lots of vision; lots of belief in its underpinning, underlying value. But we have not yet generated broad demand" (1-30-2006). The member of AHIC from an insurance company felt that

> that's one of the biggest barriers of how do you get consumers to use this and how do you get them to see value. . . .those primarily with chronic conditions who can really use this to help manage their care on a day-to-day basis. Parents with young children that they want to track their immunizations. . . and also individuals who are managing their elderly parents' care. . . . (1-30-2006).

One reason for Value is to improve the quality of health, as suggested by the member from the Veteran's Health Association: "This is the consumer empowerment strategy. What we need to do is ask people sitting with nothing to do in waiting rooms and examining rooms across America, 'What can we do with this technology to make your life easier, better, safer, by delivering this information around'?" (2-21-2006). As one member from the National Health Council stated, "I do think it's critically important that we find ways to focus in on having people, patients, consumers, and others understand the benefit and also we have messages that help reassure them about their privacy and reliability types of concerns" (6-19-2006).

Convenience was also considered to be a Value to the consumer:

> One of the biggest values is just convenience. If they really believe—if a person believes that they can have a record that wherever they go in this world, it is interoperable and they can bring up all their health information needed at that moment in time with that provider, that is a huge value for people with acute conditions, emergency situation to people with chronic conditions (3-20-2006, Member from the National Health Council).

A study by one of the members from the insurance company with their subscribers revealed that "what we found is that PHRs in the groups that we surveyed were popular for centralizing their record. . . .the second reason was it

empowers them with health information, and then. . . .the third was helping me take control over my health care, and fourth, helping me coordinate information among my family and providers" (4-25-2006). From the members of AHIC, if consumers feel that the PHR will be of Value, they will become more Confident to adopt and use the technology.

The focus on Technology as the solution, or as the "ultimate tools that are going to be developed" was the emphasis of the member from the National Patient Advocate Foundation: "Those are areas that we will want to give careful consideration to as the consumer empowerment group tries to marry both the world of information technology with the need of a consumer that is ultimately going to be using these tools" (1-30-2006). Part of the foundation for a PHR which the consumer will feel Confident using is ensuring Information Security. While Privacy and Security concerns were addressed by another workgroup in AHIC, the Consumer Empowerment group also discussed the need for Information Security through Technological features. The risk of adding a PHR to HIE processes to exchange information was a concern because it adds another level of vulnerability as the member from the Department of Health and Human Services suggested: "Whether or not the addition of a consumer interface might increase the risk of compromises to the security of the network" (2-21-2006). If the consumer does not perceive or feel Confident that the system

is Secure, they will not use PHRs. As the member from the Markle Foundation stated, “If we do this wrong. . . the entire national enterprise of wired health care system will be destroyed because of newspaper headlines” (2-21-2006). Therefore, the Value of the PHR and Information Security, as supported by Technology can evoke Consumer Confidence in HIE.

Theoretical Model and Dimensions of Consumer Empowerment in HIE from the AHIC Analysis

Based on the properties of the codes and relationships of the codes to one another, it was determined that these codes could be reduced, which is selective coding. Table 9 shows the results from the open, axial, and selective coding from the AHIC data analysis. These codes are the dimensions for Consumer Empowerment in HIE based on the AHIC data that was analyzed.

Table 9. Results of the AHIC Coding Process

Selective Coding	Axial Coding	Open Coding
Consumer Engagement in HIE	Consumer Understanding	Awareness Education Literacy
	Consumer Action	Consumer Input Consumer Voice
Fairness in HIE	Legal and Institutional Provisions	Enforcement Law
	Social Justice	Information Privacy Rights Consumer Responsibility Situational Context
Consumer Confidence in HIE	Consumer Assurance	Consumer Trust Information Integrity
	Conventions in HIE	Data Elements Information Sources Standards
	Consent Management	Access Control Information Ownership
	Information Technology	Value of PHR Information Security

CHAPTER VII

NCHICA CACHI DATA ANALYSIS

Background

Another source of data for this study is the Consumer Advisory Council on Health Information (CACHI), a group formed by the North Carolina Health Information and Communications Alliance (NCHICA). As a nonprofit organization, NCHICA champions the adoption of information technology to improve healthcare through a variety of initiatives.[30] According to the Executive Director of NCHICA, the impetus for the creation of the Consumer Advisory Council was when

> NCHICA was working on a strategy for future activities and we had a major meeting in 2003 with the Board and important members . . . and I presented an organization chart showing the key players involved in medication management and one of our Board members

[30] North Carolina Health Information and Communications Alliance. *NCHICA Overview.* Retrieved May 2007 at www.nchica.org/AboutNCHICA/CorpInfo/vision.htm

> asked the question: "Where are the consumers?" That started an introspective process that ended in the chartering of NC CACHI in 2006.

CACHI is "a unique health care consumer group formed for grassroots input and participation to explore ideas and issues surrounding health information, such as privacy and electronic health records," (NCHICA CACHI Charter, 2007). CACHI's membership includes consumers who want to voice their opinions on healthcare information issues, and individuals who represent consumer groups (such as HIV/AIDS or the elderly). They are supported by a Resource Panel of experts in different facets of healthcare. The CACHI charter is "to provide an opportunity to influence both state and national policy with regard to health care consumers' ideas and concerns about health information and technology, and participate in trying to find a balance between a patient's need for privacy and the health care system's need for access to personal health information."[31] Thus, CACHI is a reliable source and important to examine grassroots efforts of consumer empowerment in HIE to answer the research questions for this study.

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[31] North Carolina Health Information and Communications Alliance. *NCHICA Overview.* Retrieved May 2007 at http://www.nchica.org/CACHI/main.htm

Several different documents from CACHI were sources for this analysis: meeting agendas, minutes of meetings, supporting documents such as articles and PowerPoint slides shared with group members, email correspondence and interviews with council members. Some of the Council members attended the NCHICA Annual Conference to hear speakers and give their feedback on what they heard. Their feedback was also used as a data source. Determination for when to cease data collection was based on the concept of saturation. From these emerging sources, the length of data collection was approximately 18 months (July 2006 to January 2008) since data saturation was experienced during this time period. The grounded theory methodology was used, including the three phases of open coding, axial coding, and selective coding, which will be discussed next. In presenting the data analysis from CACHI, there are no potentially identifying pieces of information that are provided. Because there are a smaller number of members and their confidentiality was to be maintained as an agreement to perform this research, their titles, affiliations, and dates of meetings are sparingly used. This is to protect members from being identified with specific quotes.

Phase I Open Coding

In open coding, the researcher analyzes each line of transcript of data to discover the substantive concepts which arise in the data. Patterns in the

incidents of codes are recognized and as many codes as possible are generated (Glaser, 2004). Open coding is performed until the concepts and codes are saturated; that is, they begin to repeat in the data. The amount of saturation that is appropriate to determine the completion of open coding is at the researcher's level of trust and comfort in the data (Glaser & Strauss, 1967).

The open codes were those topics frequently discussed or stressed as being important by the council members. When performing the open coding analysis, it became apparent that there were relationships between some codes and that these related codes could be combined into categories. This is known as axial coding.

Table 10 shows the codes which were generated from the constant comparative method (Strauss & Corbin, 1990). Open codes were first developed. These were generated through "patterns" or "reoccurrences" in the incidents of codes.

Phase II: Axial and Selective Coding

Axial coding is described by Creswell (1998, p. 57) as the exploration of "causal conditions," strategies, context, "intervening conditions," and consequences of the phenomenon of interest. In essence, the purpose of axial coding is to identify relationships between the core variable and other incidents in the data. Through axial coding, the researcher begins to relate the open codes

(Creswell, 1998, p. 209) by examining their properties and contexts (Glaser & Strauss, 1967). The researcher constantly compares the data collected, the

Table 10. Results from CACHI Open Coding Process

Open Coding	
Awareness	
Education	Control
Participation	Access
Communication	Level of Distrust
Equity	Accountability
Resources	Information Technology
Policy	Information Security
Law	Processes
Enforcement	Standardization
Rights	
Information Privacy	

codes, and the relationships to ensure that there is consistency in the theory being generated. As the theory emerges, the researcher may perform reduction, which is finding uniformities in the coding and properties for which a theory with a smaller set of concepts is developed (Glaser & Strauss, 1967, p. 110). Selective coding means that coding stops and the code is delimited to generate a theory that is parsimonious (Glaser, 2004). Selective coding is viewed by Creswell (1998) as the task of identifying a 'story line' to integrate the categories coded. This can be done through rich, thick description, propositions or hypotheses.

As a result of in-depth data analysis based on the three coding techniques, the following major categories were identified: Consumer Engagement, Fairness in HIE and Consumer Confidence as related to consumer empowerment in HIE. These three major categories encompass the 19 open codes shown in Table 10. The results of this axial coding are shown in Figure 7 (Consumer Engagement in HIE), Figure 8 (Fairness in HIE), and Figure 9 (Consumer Confidence in HIE). Each of these major categories is discussed in depth in the following sections.

Consumer Engagement in HIE

The Consumer Engagement in HIE category consists of two major components: Consumer Understanding and Consumer Action. These are discussed below.

Consumer Understanding and Consumer Action in HIE

From the analysis of the CACHI meetings, a strong relationship arose between Awareness, Communication, Education, and Participation, so these will be discussed congruently. Figure 7 shows the coding for the relationship between these categories. Awareness and Education were grouped into the construct Consumer Understanding since both of those related to how the consumer ultimately learns about HIE. Communication and Participation were

grouped into a construct for Consumer Action since these both require some level of activity on the consumer's behalf, even if it is listening to a speaker versus actively being involved in an HIE initiative such as CACHI. These constructs are tightly woven together, and are, as discussed later (in the chapter on the Process Model of Consumer Empowerment in HIE), part of a process in which consumers become Educated, therefore Engaged and empowered. As discovered from this analysis, being empowered is not a bipolar issue, it is a continuum upon which consumers become more Aware and Educated about HIE.

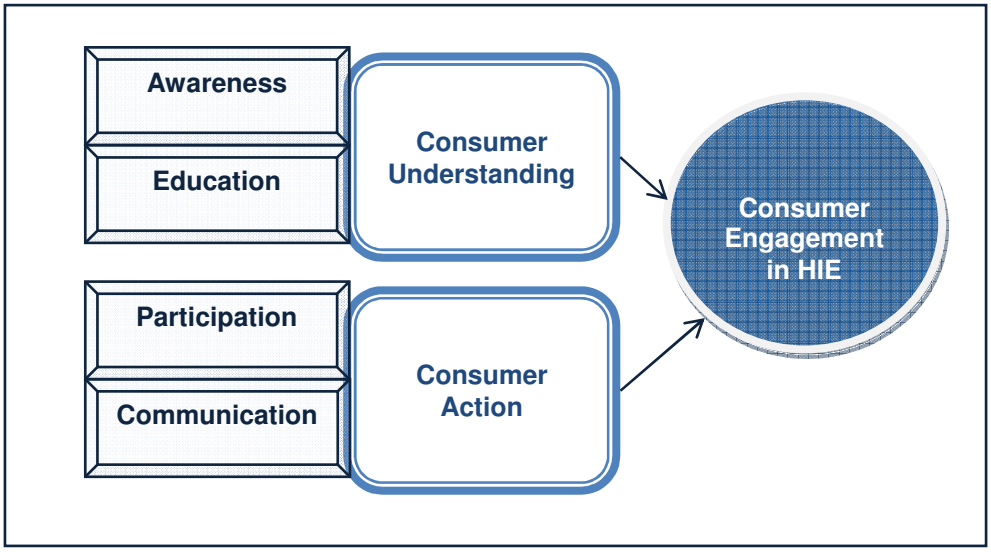

Figure 7. Results for CACHI Coding Process for Consumer Engagement in HIE

When the CACHI meetings began, most of the discussions revolved around individual members' stories with the healthcare system and how they felt the council could have a voice and help to Educate other consumers. For example, one council member said in August, 2006, "I'm a real believer in education." It was recognized that the CACHI group had a lot of pertinent healthcare knowledge and IT experience to help them Understand the issues involved. As the Executive Director stated, "We characterize the council based on their backgrounds. The credibility of the council is that you know what's behind the curtain and have a background."

HIE is complicated to Understand. During her presentation, Dr. Peel from Patient Privacy Rights Organization stated that there is a wide variety of people involved in HIE, and even the so-called experts aren't as knowledgeable as one may think. As she suggests, it is very complex: "IT people don't get healthcare. Healthcare reporters don't understand the issues; legal reporters don't know about health or IT. This issue sits right in the middle. Conceptually, very few people have all of the pieces. It's hard to talk about policy at a level people can understand." After listening to several external speakers from organizations such as Connecting for Health, Academy Health, and Patient Privacy Rights Organization, and after several of the council members attended the NCHICA Annual Conference, they realized that, although they were fairly well-educated

and had some type of work experience in either healthcare or IT (or both), they found it difficult to understand much of the terminology and jargon discussed by the presenters. One council member asked, “How do we involve and educate the consumers? There are professional representatives to speak on behalf of other people. I’m fairly educated and still find it hard enough to understand. . . .and to know what kinds of information to ask.” From the NCHICA Annual Conference, members were clearly concerned that they weren’t as aware or informed in HIE as they originally felt. One member commented about one of the presentations that

> I was a little overwhelmed by the national update presentation. I think there was so much detail and acronyms that consumers needed so much background [to understand]. I was not adequately prepared myself and my background is in IT policy. I was snowed.

Some members felt that they were more Aware about HIE topics after attending some of the presentations. One member said, “I understand more clearly the opt-in/opt-out range and the negatives/positives of those. I’m much more educated about that. I was much more open with an ‘I don’t care attitude’ and am now more sensitized to the gradation.”

Awareness is an initial questioning and inquiry-oriented behavior, which provides receptiveness for further Education. After they became Aware that HIE is complex, they were more outspoken when asking questions on HIE. It

seemed that after they were willing to reveal their weaknesses in what they didn't Understand by asking questions, that they felt more empowered. So, as part of being empowered, it seems that one would need to be comfortable in revealing those weaknesses and in taking action to correct the weakness (by looking for more information, for example). Since the council members felt that they also needed to be more informed and Educated to participate and provide input effectively, they also were very cognizant of the paradoxical change that this could create in their identities. A council member states it very clearly, "To advocate, it's representation. We have to know the alphabet soup and be uberconsumers to understand where these people are coming from and talk at the same level. But then you may not have the consumer perspective anymore." The council members felt that, as they went through the process of becoming Aware and Educated, they also changed from being 'everyday consumers' to becoming representatives. When they reached the level that they were Educated enough to advocate and represent groups of consumers, the council members felt that perhaps they wouldn't be able to genuinely address the 'everyday consumer's' needs. As the council progressed through time, some council members came to see themselves as advocates for individual consumers. In essence, the transformation through Education which they needed to pursue to actively and effectively participate in HIE initiatives paradoxically

places them in the role of being representatives that could create a type of barrier between them and the 'everyday consumer.' Ideally, the goal should be to empower all 'everyday consumers' so that they have sufficient knowledge to make informed decisions. The process of becoming Educated in HIE will be discussed in a later chapter on the Process Model of Consumer Empowerment in HIE.

Fairness in HIE

In axial coding, there were obvious concerns with the equitable allocation of resources as well as how Policy and Law affected patients' Right to Privacy. Figure 8 shows how the categories of Equity and Resources are grouped into a construct for the Digital Divide due to lack of equitable allocation of computer access, and how Policy, Law, Enforcement, Rights, and Information Privacy are fundamental for the construct for Legal and Institutional Provisions.

Digital Divide

There is an underlying theme within the concept of consumer empowerment which included power and the distribution of resources. The Digital Divide of electronic inequity is often not as apparent to middle class consumers because many of them have Internet access either at home or through work. There is, however, in HIE, an inequity in access to resources for information which provides awareness and education. Not everyone has the

capability to take time from work to participate in these initiatives or to search for medical information on the Internet.

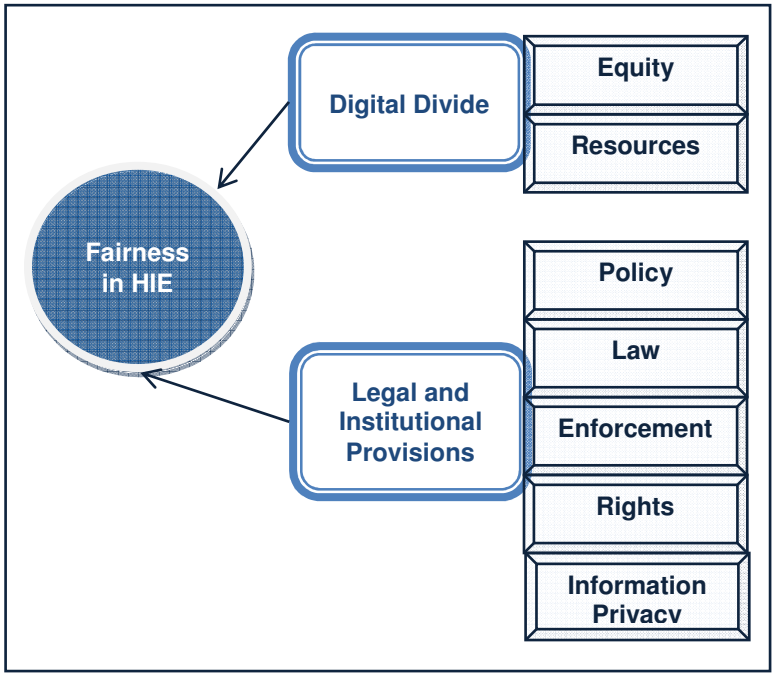

Figure 8. Results for CACHI Coding Process for Fairness in HIE

Another equity concern is that there are some populations who perhaps may have electronic access, but do not have the knowledge and skills to adequately utilize their access. E-NC Authority is an initiative in North Carolina which "is dedicated to increasing prosperity for North Carolina citizens and

businesses by creating jobs through technology-based economic development, which requires a broadband Internet platform for success[32]." According to a report from e-NC Authority, "computer ownership is the basic port of entry to the Internet. . . .and that 65% of North Carolinians had computers in their homes in 2004" (North Carolinians Online, 2004, p. 4). However, according to the same report, "North Carolina home Internet users are, on the whole, younger, more educated, and wealthier than non-Internet users. A predominance of older, less educated, and lower income populations in rural counties is the principal factor reducing average rural area take rates" (p. 2). E-NC Authority has launched technology telecenters which have free Internet access to the public in rural areas. E-NC Authority also encourages technology to be available in libraries for public access. This type of grassroots outreach seems to be ideal for building a foundation for computer and Internet access. The goal is that people should have access to technology and should feel comfortable taking advantage of the opportunity to use it.

The inherent power inequities in the institution of healthcare and politics were also a matter of discussion. In response to a presentation by Dr. Robert Kolodner (Office of National Coordinator for Health Information Technology) at

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[32] E-NC. North Carolina Rural Internet Access Authority. (2008) Retrieved May 2008 at www.e-nc.org.

the NCHICA Annual Conference, one member said, “It sounded like a political situation of powers that be and that [power] obviously not being the consumer. There’s a whole lot of politics back there.” This was reiterated by another council member during the next meeting, “I see us as being considered gnats by some; people we have to be polite to or otherwise it won’t be kosher; how are we going to do that?” Sometimes this understanding of power inequities (and perhaps level of distrust) was communicated against the technology vendors and providers, as suggested by the following exchange of comments by members (The member numbers were assigned randomly by the researcher.) (9-07):

> Member 9: “There’s a business model piece and a political piece. The vendors see it as how to make them [consumers] convinced that [their] product is good. That’s not necessarily bad, they want a happy consumer; they sell the technology and are not providing the care”
> Member 5: “They didn’t see the consumer as equal stakeholder but as objects to consider.”
> Member 9: “They almost saw the consumer as an obstacle.”

The idea that there was a background political and organizational component in which consumers were not privy resulted in a perceived lack of consumer control, thus a political Digital Divide was occurring. As stated by a council member, “I’m by nature a calm, easy-going [person]—there are things we aren’t going to change and corporate control of our government is one of them.”

Because of the 'powers that be' and perception of their lack of understanding in at least some areas of healthcare information technology, the consumers also stressed the need for legal and institutional provisions to enforce and provide privacy rights.

Legal and Institutional Provisions

In order to lay the foundation for consumer empowerment in HIE, there should be Policies, Laws, and Enforcement which are supportive of consumer Rights to Information Privacy. Policies were usually described in context of organizational Policy to collect, store, and exchange health information. Laws were described as regulations enacted by the U.S. and state legislature.

Policies and Regulations were the topic of discussion throughout the CACHI meetings. When mentioned, it was typically a secondary theme of discussion, woven into the discussion of primary subjects such as technology. "Technical design decisions that were made in synchronization with policies and rules will foster trust and transparency. Policies have to be part of how the system is designed" (Official Minutes, 7-07). Policies were discussed in terms of consent management and in the use of technology. (Consent Management was usually referred to in terms of controlling access to one's medical records. This is discussed in a later section.) "Retrofitting the policy to the technology is a deficient process and turns into a debate about consent. Consent is one of

several that are required for healthcare information exchange" (Official Minutes 7-07).

The regulation HIPAA (Healthcare Insurance Portability and Accountability Act) was discussed in terms of Enforcement of Law and Policy (see APPENDIX f. Information About HIPAA). One council member felt that a presentation at the NCHICA Annual Conference didn't appropriately emphasize HIPAA or security: "Maybe they assume the audience is not consumers and are taking for granted that everyone is burned out on HIPAA." A council member stated, "The penalties are not enforced. . . If they were enforced, it would go a long way," which suggests that enforcement would create more trust in HIE." Another emphasis was that Regulations should be Enforced and applied consistently. For example, "HIPAA doesn't go away in the middle of an emergency. We still need to secure the privacy of those people at the best of our ability [to protect the patient's dignity] at that time." The overarching idea of Policy was that it be standardized, Enforced, and support the privacy and security of health information.

One common idea that emerged was that of Civil Rights. For people to feel that they have been treated equitably, the notion of Civil Rights is important. As one speaker stated, "We need to protect privacy and civil liberty while ensuring privacy and security." Another speaker stated that privacy is "the

essence of freedom and liberty to be left alone." The following are excerpts of a conversation from a CACHI meeting which discusses Information Privacy as a Civil Right (8-07):

> Member 16: "What about the data that is out there now? We've got to make it a crime to use it or hold it without consent. It should be a crime to re-identify data and to keep secret databases. There are still a lot of things that are really private and we still need privacy for stigmatizing conditions."
> Member 1: "It's civil rights violations in those cases [of stigmatizing conditions]. "
> Member 16: "There has been compliance through consequences [which are monetary]. Sixty percent of reported compliance issues are not considered violations because HIPAA allows so much to be shared. Shouldn't someone defend the consumer? Who can afford lawyers? Should the Attorney General in each state be the one to defend consumers?"
> Member 1: "Especially if you're still sick and need treatment."

From this fragment of conversation, the idea is that having socially stigmatizing conditions such as mental health illnesses, substance abuse issues, or diseases such as HIV/AIDS, may need additional protection for the right to Information Privacy. Recognizing Information Privacy as a Civil Right is important for building confidence in HIE.

Consumer Confidence

The construct of Consumer Confidence was formed from meeting discussions which emphasized ways in which the consumer could ultimately become more confident in HIE. Consent Management, Consumer Assurance, Conventions in HIE, and Technology Mediation were categories which the council members spoke about as ways to ensure confidence in HIE. The relationship between these is shown in Figure 9.

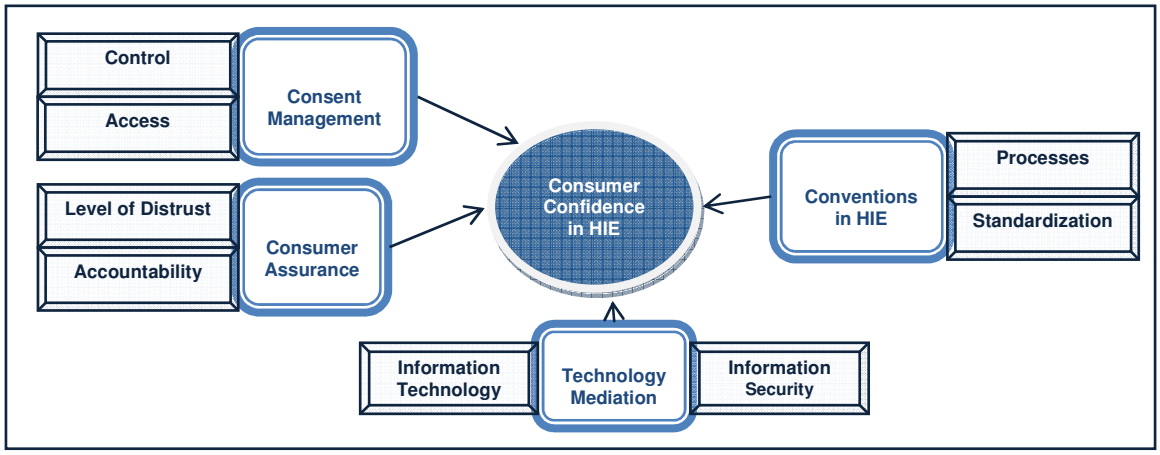

Figure 9. Results of CACHI Coding Process for Consumer Confidence in HIE

Consent Management

Consent Management is a term used in the healthcare industry to describe how someone Controls the Access to a medical record. The concepts

of Control and Access are highly related, and when mentioned in the council members' discussions, it was often difficult to determine what they thought the difference was between the two concepts. Access to the health record generally meant that the council members could view the content of their records. Control of the record was ideally being able to determine who could view which portion of the record, as well as being able to annotate the record for inconsistencies found by the consumer.

If patients have access to their records and can control how the record is shared to create a comprehensive view of their health, will this improve the quality of health? One council member relayed a story about a doctor who couldn't retrieve information in the hospital and had to request the test be performed again due to this. "The whole point of the health record is to provide better care for the patient. We have point-of-care consent and patients don't think about these issues at that time."

The opportunity for patients to control their medical records through Personal Health Records (PHRs) was of great interest to the council members. "There is an opportunity for consumers to be in possession of their own records. Patients will be stewards of our own data. Will this be private and secure?" With management of their own records, the consumers were concerned about being able to dispute inaccuracies in the record. 'What if they [the healthcare

providers] made a mistake in the record?" One member said that her child's "test said that [the child] was 61 years old. The consumer can catch those [errors] more quickly than doctor's offices or labs." Vendors state that the patients will be able to annotate the records, rather than change the information in the existing record. The notion of being able to control access to the record is referred to in the healthcare industry as 'consent management.' According to the representatives who spoke regarding the Dossia PHR, "a rich set of consent management policies is needed" and "consent management is the key [and it needs to be] understandable to the patient; not a blank check [to disclose everything]." They also referred to Article 29 of the Working Party Definition of Consent from Europe in which consent is "freely, specifically given with full understanding." Most importantly, these vendor representatives said that "Consent has a life and is revocable."

The conversations regarding Control and Access often revolved around Opt In and Opt Out procedures. The unauthorized sharing of health information was of concern to the council members: "As long as the [medical] record exists, there are people who will want it." One speaker stressed the capabilities of data mining when suggesting that "they're [third parties] accumulating information. They want to give you a PHR. The issue is not necessarily with the vendor, but that employers want the keys to the kingdom." When discussing the

unauthorized disclosure of health information, another member said, “you want to pull control back to yourself if you see other bad cases [where information has been disclosed in unauthorized means].” The purpose of HIE technology such as the Nationwide Health Information Network (NHIN), Electronic Health Records (EHRs), and Personal Health Records (PHRs) is that health information can be shared across the United States.

In seeking different models of consent Opt in and Opt out, the consumers looked towards the financial industry. There are “lots of applications similar [to PHRs], such as FAFSA/student loans, but you have predatory lenders who gained unauthorized access. Requiring consent for all uses is a good idea. Are there consents for portions of the record?” This suggests that there could be different levels of consent, which could be an impetus for patients to share information in the way they determine to be appropriate. To the council members, Opt in and Opt out choices were a good beginning for consent management, but not sufficient to protect consumers. “The choice to allow consumers to opt-in and opt-out is not really a choice; a binary choice is not appropriate.” For example, if a patient wanted certain physicians to be able to access sensitive information such as mental health records, they should be able to give a more granular level of consent. This could prevent situations where patients avoid care or withhold information because the Opt In and Opt Out

choices are not acceptable because they paint a picture of the medical information with a broad stroke of the brush to many different people.

The idea of collecting a patient's consent through HIPAA disclosure forms was found to be unacceptable to most council members. The primary reason is that a patient, although educated and well-informed, in time of sickness at the point-of-care still may not make the best decisions regarding consent. The question to ponder is whether the right to control one's medical records is also associated with the responsibility to manage and maintain those records in an informed manner. As one council member stated, "while empowering the patient, it has the danger of it not being managed. For example, the person who takes 14 medications" may not be able to maintain the records appropriately. For consumers to feel Confident in HIE, Consent Management features should provide a granular level of control and access to records.

Consumer Assurance

For consumer empowerment in HIE to occur, Consumer Assurance is a necessary component. What emerged from the CACHI meetings was their lack of Trust in some healthcare stakeholders, such as insurance companies. They felt that healthcare stakeholders should be Accountable for how they protect sensitive medical information. If the consumers felt a level of Trust and Accountability, they were more Assured and Confident in the use of HIE.

In order for consumers to be empowered, they should feel Assured in the HIE process that there is Accountability for the actions of stakeholders involved. The concept of Accountability was not mentioned frequently in the meetings. However, I felt it important to preserve the concept since it relates to other facets of HIE in several contexts:

1. the consumer being accountable and responsible for managing his medical record;
2. the notion of vendor and provider accountability to offer fair consent management procedures;
3. the idea of providing enforcement of policy and regulation.

One council member felt that there was no accountability to protect the records by following appropriate and fair consent management procedures: "There needs to be accountability throughout the information chain for privacy and security, regardless of where the information is. People need to be responsible for the breach and the protection needs to follow the data." This relates closely to the notion of Enforcement and Equity as discussed in a previous section, and to Level of Distrust.

Accountability can also breed Trust. The term utilized here is Level of Distrust because the council members held a healthy Level of Distrust which prompted them to question what the stakeholders were doing in HIE. While this will be discussed in the more positive light of Trust, the construct is considered

Level of Distrust to recognize that while the council members wanted trust in the HIE process and in the stakeholders involved, their level of distrust in the system allowed them to appropriately question why stakeholders acted in the ways that they did. Perhaps to become Engaged in HIE, a person needs a Level of Distrust and for Consumer Assurance, a person would need a Level of Trust. These will be discussed in the Integrated Theoretical Model chapter.

Comments such as “there is still a lack of trust between the patient and provider regarding security and privacy” clearly emphasize that there is a Level of Distrust in HIE. One council member stated it very succinctly when the discussion regarded trust: “It’s gone. . . .” Council members did not trust pharmacies, the government, insurance companies, or technology vendors. “I have skepticism on national and political levels. Congress is owned by corporate special interests and is in the pockets of special interests.”

Trust in the health information and technology was also a factor. One council member was very candid in her distrust of technology: “I have technical skepticism; I am more paranoid than the usual consumer.” There was a recognized need that the health information that is exchanged must be accurate and trustworthy for both the consumers and the healthcare providers. “If we go to the shelter [in time of disaster], is [the medical record] going to be up-to-date. . . .?” The accuracy of the information will also affect the level at which

consumers Trust HIE. If they find information that is inaccurate or incomplete, they may place the fault on HIE technology or processes, which may result in a lower level of Trust in HIE. The technology must be reliable to be trustworthy, as well. "The networked system must be SLA (service level agreement-compliant) and operational and functional. It must work." The speakers from vendors and privacy organizations also recognized that trust is critical. "Trust is essential; employees put information into it [the PHR] and we need to earn their trust. We need the trust of patients and of people who hold the data. There is a distance between employers and information."

Trust seems to have some basic foundations upon which all of the council members communicated, but there were also some aspects of trust which differed between council members. For example, "the elderly are suspicious of what they are going to share. I'm not sure even if they are dealing with the Meals on Wheels program that they give us all of their information." Certain populations of consumers have different levels of Distrust. As discussed earlier in the Equity section, there are also different levels of trust for those who have stigmatizing conditions. Because society may stigmatize a specific condition, and therefore, the person, those consumers may begin with less Trust than others with fewer or less stigmatizing health conditions.

What creates a trusting relationship has many components. “Privacy creates much better trust” according to one of the speakers. Honesty and genuine interest from healthcare stakeholders also builds trust. For example, members appreciated when they felt that speakers spoke honestly and gave correct information. “The doctor [that presented] was good and enthusiastic. I was convinced that [their use of technology] improved patient care. The way she cited the improvement of quality of care was true.” This suggests that because the council member felt the doctor was enthusiastic, was sincere, and gave correct information, the council member could be confident in trusting that person. The key word in the statement is convinced. Because the council member was convinced, a form of Trust was developed in believing the speaker. Trust is related to the technology, the people, information, and policy. As one speaker said, “Technological design decisions that are made in synch with policies and rules foster trust and transparency.” Trust may be built through a perception that privacy is ensured through HIE technology, processes, and policy, and through trusting relationships with healthcare stakeholders.

The question from this analysis of Trust is at what level is a level of distrust from consumers considered to be appropriate? While a deeper level of distrust may result in a patient avoiding treatment, a healthy level of distrust may lead to questioning those stakeholders in authority and power positions, which is

a component of empowerment. There is a level of Trust which involves trusting the healthcare stakeholder's intentions to 'do the right thing.' When discussing the motives of HIE decision-makers, a council member said, "[They] have pretty good ideas, they just need to make sure it is driven by the right interests." If a consumer is Assured by appropriate levels of Trust/Distrust and Accountability, this may also lead to Confidence in HIE at some level.

Conventions in HIE

Conventions in HIE are practices which can support Consumer Confidence in HIE. For example, if there are Standard forms to fill out and Standard Processes in HIE, this provides a level of comfort since the consumer knows what to expect.

There are two facets to Processes and Standardization. One facet is ensuring best practices within processes to protect health information because "there is no holistic view for processes in healthcare." The council members mentioned several times that "where we look for success and models is in the states and the U.S. We're not looking at Canada, England, etc. We need to look at other models." To emphasize the needs for standardized processes, one council member relayed the following scenario: "I was asked at the physician's office, 'Is ##-##-#### your birthdate?' instead of 'When is your birthday?' An Alzheimer's patient came into their office and answered yes to the first question.

That patient's blood was drawn and sent to be examined. The problem was that the office employee asked the wrong patient, which should have been the council member instead of the Alzheimer's patient, who didn't know the answer to the birthdate question and just said yes." Therefore, the council member's blood test was based on the wrong blood sample. If there were standardized processes which were followed (manual or computerized), these types of problems would occur less frequently.

Another facet is that within these best practices there is a level of Standardization which serves to provide consistency for the consumer. An instance of this was by Dossia, a PHR vendor when two of their representatives spoke to the CACHI group. "To develop Dossia based on best practices, they had employers to share their best practices to create a model privacy policy." If there are Standard definitions, policies, and forms for consumers to use, they may feel more Confident in what to expect when they visit the healthcare provider. This Confidence may lead to empowerment to ask necessary questions rather than worry about items that are secondary and could be Standardized. There are also technological interoperable standards that need to occur before health information can be exchanged. For example, there need to be Standardized ways in which the data is stored on computer systems of different physicians, so that the information for the patient can be matched with

the medical record at a different office. Also, there need to be Standards for Technology so that medical record information can be transmitted between disparate computer systems at various physician offices.

Technology Mediation

For HIE to occur, there needs to be supporting Technology which mediates the Secure transmission and storage of medical information. The role of Technology for the CACHI group tended to be that of a tool that supports HIE and Security of patient information, rather than as a solution to a problem. Initially the discussions within the group meetings revolved more so around Technology and eventually around needing education about the types of HIE technologies. Some of the Resource Panelists thought the focus should be on Technology, whereas the council members felt that "the consumer doesn't care about what technology is being used. . .we care about cost, quality of care, and privacy." Much of the conversation regarding Technology was how it could support healthcare, such as "As a result of the interface with electronic systems, do you get better care?" To which another member replied: "Care will be better with the electronic record." A council member stated that due to Technological innovations, quality of healthcare would be improved: "[We] will get better quality of healthcare because it's [technology] easily accessible and secure." However, as one Resource Panelist asked, "Where is the balance between providing the

information to the physician and controlling the way that it is handled?" Finding this balance was a theme woven throughout much of the conversations which motivated the members to act and make their voices heard.

Overall, the council members felt that Technology could support the protection of privacy and Security of patient health information. However, some of the council members felt that "HIT [Health Information Technology] is coming, whether it's secure or not, whether we know how to use it." As a council member said, "there's a proliferation of EHRs without appropriate safeguards for privacy and security. All of these organizations are running full-steam ahead and until you address basic issues, some of these things may slip up." Security was a concept which was woven into other codes, such as Technology and Policy. When speaking about the presentations they observed at the NCHICA Annual Conference, the council members felt that "privacy and security were totally absent" and that it was "an afterthought" because it "didn't fit into the business plan." They felt that the presenters did not emphasize privacy and security enough. However, the CACHI members also realized that the speakers may be targeting a different audience (ie healthcare providers, vendors, insurance companies instead of consumers).

Theoretical Model and Dimensions of Consumer Empowerment in HIE from the CACHI Analysis

Based on the properties of the codes and relationships of the codes to one another, it was determined that these codes could be reduced, which is selective coding. shows the phases from creating open coding, relating those to discover the axial codes, and then further grouping them using selective coding to form a parsimonious Theoretical Model of Consumer Empowerment in HIE with the dimensions as shown in Table 11. First, through the application of the principles of grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1990), three major components of Consumer Empowerment in HIE have been identified, as was shown in Figure 7, Figure 8, and Figure 9. These are Consumer Engagement in HIE, Fairness in HIE and Consumer Confidence in HIE.

Table 11. Results from the CACHI Coding Process

Selective Coding	Axial Coding	Open Coding
Consumer Engagement in HIE	Consumer Understanding	Awareness Education
	Consumer Action	Participation Communication
Fairness in HIE	Digital Divide	Equity Resources
	Legal and Institutional Provisions	Policy Law Enforcement Rights Information Privacy
Consumer Confidence in HIE	Consent Management	Control Access
	Consumer Assurance	Level of Distrust Accountability
	Technology Mediation	Information Technology Information Security
	Conventions in HIE	Processes Standardization

CHAPTER VIII

EVERYDAY CONSUMER ANALYSIS

The third source of data for this study is a group of Everyday Consumers. These seven consumers were chosen based on theoretical sampling, which is "the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes [her] data and decides what data to collect next and where to find them, in order to develop [her] theory as it emerges" (Glaser & Strauss, 1967, p. 45). What emerged from the AHIC and CACHI data collection and analysis was the need to examine consumer empowerment in HIE from the perspective of people who were not biased by work experience in healthcare or IT (Information Technology). Therefore, the third data source was focused in interviewing consumers who were not working in healthcare or in information technology jobs, thus the term "Everyday Consumer." It was difficult to find consumers who were comfortable with participating and sharing potentially sensitive information. It was not predetermined how many consumers should be interviewed. From the data which emerged from these interviews, the coding was saturated and no more interviews were needed. For future studies, different

types of consumers based on ethnicities and stigmatizing conditions could be investigated to determine if the theory resulting from this study will be upheld or should encompass different facets for those groups of people.

Phase I Open Coding

Grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1990) was used to analyze the everyday consumer data. Each consumer was interviewed for approximately 30 minutes to one hour or more. The quotes from interviews with each consumer were transcribed and then inserted into a Word document, and the Insert Comment feature was used to write reflections and possible open coding categories. These were then inserted into an Excel file for manipulation purposes.

The everyday consumer quotes were very organic, meaning that they were not biased by an information technology or healthcare work background as those were in AHIC and NCHICA. Table 12 summarizes the consumers who were interviewed. One consumer, Toni Cordell gave permission for her name to be utilized in this study. She graduated from high school with a fifth grade reading level and is now a patient advocate who speaks to groups about health literacy. Names of other consumers interviewed will remain confidential.

Table 12. Summary of Everyday Consumers

Interviewee	Occupation	Age	Level of Education
1	Retired High School Teacher	> 65	Master's
2	Worship Leader	18-25	Some college
3	Office Manager	36-55	Master's
4	Field Service Supervisor	26-35	Bachelor's
5	Welding Supervisor	36-55	Some college
6	Administrative Support Assistant	36-55	Some college
7	Patient Advocate	>65	High School

The open codes generated were those topics frequently discussed or emphasized as being important by the everyday consumers. When performing the open coding analysis, it became apparent that some of these related codes could be combined into categories, which is axial coding (Strauss & Corbin, 1990).

Table 13 shows the codes generated from using the constant comparative method to generate open codes (Strauss & Corbin, 1990). Open codes were developed first based on patterns in the incidents of codes.

Table 13. Results from the Everyday Consumer Open Coding Process

Open Coding		
	Situational	
Authorization	Context	Knowledge
Access	Equity	Sources of Information
Consent	Rights	Being Informed
Disclosure	Responsibility	Involvement
Control	Privacy	Communication
Protection	Ethics	
Records/Information	Power	
Processes	Law	
Trust in Provider Competence	Policy	
Distrust in Non-Provider Stakeholders	Enforcement	

Phase II Axial and Selective Coding

Axial coding is described by Creswell (1998, p. 57) as the exploration of 'causal conditions,' strategies, context, 'intervening conditions,' and consequences of the phenomenon of interest. In essence, the purpose of axial coding is to identify relationships between the core variable and other incidents in the data. Through axial coding, the researcher begins to relate the open codes (Creswell, 1998, p. 209) by examining their properties and contexts (Glaser & Strauss, 1967). The researcher constantly compares the data collected, the codes, and the relationships to ensure that there is consistency in the theory being generated. As the theory emerges, the researcher may perform reduction,

which is finding uniformities in the coding and properties for which a theory with a smaller set of concepts is developed (Glaser & Strauss, 1967, p. 110). Selective coding means that open coding is complete based on saturation of emerging concepts. Then the code is delimited to generate a theory that is parsimonious (Glaser, 2004). Selective coding is viewed by Creswell (1998) as the task of identifying a 'story line' to integrate the categories coded. This can be done through rich, thick description, propositions or hypotheses.

As a result of in-depth data analyses, the following major categories were identified: Consumer Confidence in HIE, Fairness in HIE and Consumer Commitment to HIE as related to consumer empowerment in HIE. The results of axial coding are shown in Figure 10 (Consumer Confidence in HIE), Figure 11 (Fairness in HIE), and Figure 12 (Consumer Commitment to HIE). Each of these major categories is discussed in depth in the following sections.

Consumer Confidence in HIE

From the interviews, consumers felt that they would be more confident in health information exchange if there were features for Consent Management in place, along with Security features and consistency in Processes to ensure that HIE was performed consistently and in a protected manner. If the consumers trusted the people, processes, and, to some extent, the technology involved in

HIE, they seemed to be more confident with HIE. Figure 10 shows the Open, Axial and Selective coding for Consumer Confidence in HIE based on the Everyday Consumer interviews.

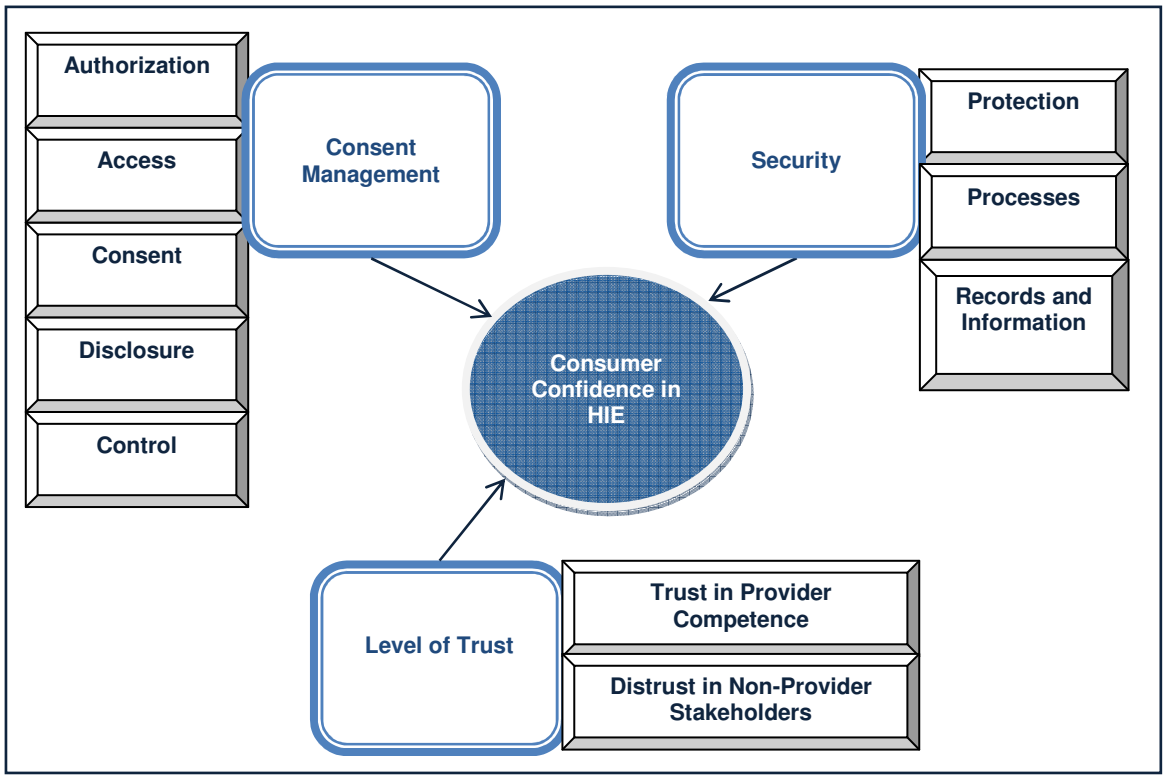

Figure 10. Results of the Everyday Consumer Coding Process for Consumer Confidence in HIE

Level of Trust

Trust, or lack thereof, is an important facet of consumer empowerment. According to the consumers, it is not necessarily a lack of trust in the HIE technology or in computers, but a lack of trust in the people and processes. Most of the consumers understood that there is a level of risk with storing medical information on computers, and they trusted that processes were in place to protect their information. One consumer stated that "I don't think my doc would share" my medical information, revealing that he trusted the doctor to protect his records appropriately. Physicians function according to the Hippocratic Oath,[33] which states that they will "do no harm." Perhaps since he trusted his doctor as a healthcare provider who would "do no harm," he then trusted that his doctor had implemented proper security. For the purposes of this coding, this was called Trust in Provider Competence since the consumer felt that the physician's competence in medicine was a proxy for competence to provide security of his medical information. For example, Trust in Provider Competence was relayed in the following comment, "I would rather let a doctor handle my medical records (control them), refer them to other specialists, or be able to study the medical data so that my overall health can be seen from a professional point of view."

[33] National Library of Medicine. National Institutes of Health. History of Medicine Division. *Greek Medicine: The Hippocratic Oath*. http://www.nlm.nih.gov/hmd/greek/greek_oath.html

When the consumers were asked from whom they would like to learn about HIE issues, they said that they trusted their physicians primarily. Again, this trust in the competence of a physician also conveyed their Trust in the physician to provide accurate and necessary information.

Another component of Level of Trust is that consumers did not seem to have the same level of trust in other healthcare stakeholders (for example, the government and insurance companies) as they did in their healthcare providers. One consumer did not seem to trust the employees in the office: "I'm not sure about the security of the systems used. However, I am less trustworthy of office/hospital personnel. Hospital personnel are used to talking amongst themselves; they are out in the hall and talk with each other---'I've already given them a bath, or cleaned the wound'---Any technology can be hacked. I trust it more so than I do people, and people who hack---see I don't trust people because they can also hack the system." Another comment was that "I have no control over my medical records and how they are used. It's all based on trust of the individuals that have access to the records. . . .I do have a problem with the government, insurance companies, and hospital /office personnel." This is the primary reason that, although the consumers discussed technology in very broad terms, they see the issue as Trust of people; therefore, technology was not used as an open code in the analysis of the consumer interviews. Therefore, this code

was called Distrust of Non-Provider Healthcare Stakeholders, with non-providers including employees, the government, insurance companies, and others not directly related to the patient's care and treatment.

Consent Management

One of the most commonly occurring themes in the data for the everyday consumers was that of Control and Access. The overarching theme of Consent Management encompasses terms that were used such as Access, Control, Consent, Disclosure, and Authorization. This terminology used is socially constructed such that it recognizes the doctors Control the medical records. Using a term such as Disclosure more often, as the consumers did, suggests that the physician's office has the authority to Disclose records because they Control the records. Typically when using the word Control, the consumers emphasized that the provider's office has Control of their medical records. The term Authorize was used when the consumers discussed their preference for being able to give Access to their medical records if the technology were available.

From some of the comments some interviewees felt that their current level of Access was satisfactory because they didn't necessarily need full Control of their records. The consumers interviewed felt that Control is "entering the information into the record" and "the ability to alter," whereas Access was

defined as “view only.” Ownership of the information was also subtly encompassed in the topic of Control and Access. One consumer referred to them as “my medical records” while also saying that she felt that she had no Control or Access over them. This is paradoxical since she claims ownership of the information although she feels has no Control or Access to that information.

Because each physician could Access the Information they need at the time of care, some of the consumers emphasized that they wanted to ensure that the information in the record was accurate. A consumer mentioned that “I really have no access to my medical records; hopefully they are entered correctly. . .Access means being able to see your record and to verify the accuracy of it.” Toni Cordell thought that there is a benefit to being able to carry health information with you (such as a PHR) for improved accuracy and quality of care: “Many people who are around my age, some take 15-20 medications; they should have that information with them.”

When asked how they felt about the Control they have over their medical records, the consumers’ responses were mixed. They ranged from “I have no control over my medical records and how they are used” to “I’m okay with it.” Some felt ‘okay’ with their current level of Control without any additional comments about the levels of Control they would prefer. One said that “we have absolutely no control. If I change doctors I have to pay for the doctor to send my

records to the new one, I can't even get a copy or see them. A little weird if you ask me."

When asked how they felt about the level of Access that they have over their medical records, again, the responses varied. Some felt "fine" or 'ok." A consumer interviewed said that she liked the idea of her providers having access to her comprehensive health information,

> Yes---they actually enter it [medical information] right there when I'm in the office. When you go to a new doctor's office—since it's [Name of Doctor's Office], they all use the computer system and have access to my records; I'm like an open book. Every doctor is like a different chapter in the book. . . It's better than having to repeat everything over and over and that I had surgery 10 years ago. . . .

The youngest consumer felt that "As long as my medical records can be accessed by me and whoever else needs the information to take care of me, I'm okay." Yet another consumer says "I really have no access to my medical records. . . unless you ask or they [providers] decide to show them to you." One consumer states that she is "very frustrated that [she] can't get a copy or see them!" This is of interest since there are laws and regulations which require doctors to provide patients with a copy of their medical records when requested:

> "The federal law giving patients and family members access to medical records is the privacy section of the Health Information Portability and Accountability Act. HIPAA allows health care

> providers to withhold records in some circumstances, as long as they explain why they are doing so. Among the records that may be withheld: psychiatric documents and documents generated in preparation for a legal action" (Davis, 2008).

The level of control was mentioned by one of the consumers (the youngest interviewee), who said "I'm okay with [the level of control I have] as long as I know what's on it and who's allowed to alter it." The consumers did not discuss at all the fact that there could be granular, detailed levels of Control and Access based on what type of information was in the record and who wanted authorization to view or edit the record. They viewed it as an opt-in/opt-out decision, in which they would choose to share all or none of the medical record with authorized people. When asked about a particular situation in which a patient (who was at risk for Huntington's disease) could remove pages from a medical record to prevent her insurance company from finding out, the consumers who were interviewed said that "It is not right. She should not remove the records," and that "it was very sneaky and shouldn't be done, but I can see someone doing that with the economy the way it is!" One interviewee responded that "the patient should not have this healthcare information removed. Once in the record, it's part of the record and should not be deleted or removed," and that "it should be changed back and not be allowed to be altered by the patient."

Perhaps this is because consumers recognize the traditional paternalistic relationship between the doctor and patient (i.e. the doctor owns the record) or if they feel that the record should be kept intact for accuracy and so that the doctor can make accurate medical decisions. One consumer said that patients shouldn't "be allowed to change their own medical records for personal reasons. This could illegally affect insurance and treatment policies," another patient reconciled the patient's removal of the records by saying that the patient should have had "Access to her records as a rule anyway." Electronic medical records could provide a method for patients to add comments without being able to edit the physician's notes.

Security

Security was framed by the consumers within the term "Protection." While Protection sometimes referred to the Processes in place for keeping medical records safe, there were conversations in which the interviewees referred to the use of technology as a way to ensure the Security of medical records. While six of the seven consumers felt that computers can be trusted to keep information Secure, "if handled properly," they also understood that there were risks involved: "I'm not sure about the security of the systems used. . . .any technology can be hacked." During the interviews, several scenarios of healthcare information disclosures were discussed. These were actual instances of information

disclosures that were found in newspaper articles and presented to the interviewees. After talking about the case in which a patient at risk for Huntington's disease removed pages of her medical record, the consumers were asked how it made them feel. Two of the interviewees said that they felt that perhaps "my information is less secure/protected than I thought it would be." Another consumer felt that "electronic records would be more difficult for a patient to erase or remove. . .[and] should only be accessed by physicians, nurses, and physician assistants by a secure password; however, passwords are not that secure because they can be shared."

Although most of the consumers seemed to be aware of the risks associated with using health information exchange, they didn't discuss the actual technology that could be used to provide Security measures. Only one consumer, who was the youngest of the group, discussed more detailed technological aspects such as Security software and encryption. Only one other consumer mentioned passwords. Their understanding of the risks also seemed to evolve from news stories because they mentioned hacking, identity theft, and breaking into the records of financial institutions. In this situation, the cases of unauthorized disclosures which they read in the paper, although not always related to healthcare information disclosures, biased their opinion of the Security of health information exchange.

Records and Medical Information is an underlying foundational concept of healthcare information exchange. This refers to the Information contained in the Medical Record. At the core of Security is the protection of the Medical Record Information. The consumers wanted to know about the Security of their Medical Record Information. A consumer stated that "I would want to know where my records are being stored. . . .as well as what the company/office plans to use them for. I like having the security of knowing what is IN my records, what they are being used for, and who they will be shared with." In essence, this person felt that he wanted to know the content of the record as well as the Security of its location. This particular statement by the consumer relates his own Security and comfort with knowing what is in his medical record with knowledge of how his records are stored and shared.

One identifying feature of Medical Record Information which consumers emphasized in their discussions was the level of sensitivity of the Medical Record Information. "Given that it is personal information, controlling the data is also important," according to one consumer. Some of the consumers stated that the medical information should be used for its original purpose (treatment) unless otherwise given consent. For example, when talking about a scenario in which medical information was disclosed to a marketing company who then solicited a patient for advertising purposes, Toni Cordell said "Why don't they tell the

community what he is on and put it on a billboard? There are some medications that show poor decisions [that people make]. We are supposed to guarantee that it is private information, like our banks." This suggests that because Medical Records contain sensitive and private Information, they should be kept Secure and protected from unauthorized use.

Since Toni speaks to many groups about her experiences with health literacy, she understands that she has disclosed her health information through her speeches. She says "my records don't divulge anything horrible about me; I'm not hypersensitive; I don't think anything in my records can reveal anything bad about me. . . .[if there are] any contagious things or cancer [in your record, an] employer could then decide not to hire you." While keeping the sensitive information Secure is important, there are different types of medical information that could be considered more sensitive, such as mental health diagnoses, substance abuse, or even cancer diagnoses. These varying levels of sensitivity have varying degrees of protection in the medical community. For example, many states, including North Carolina, have very strict laws that provide more stringent protections for the Security of mental health information. The concept of Information being classified differently in the healthcare system based on stigmatizing conditions is also related to Situational Circumstances in Fairness in HIE, which is discussed next.

Fairness in HIE

Fairness is a spirit of Equity and Social Justice, with assurance that violations will be reported so that Laws and Policies are Enforced. Within this is the Right to Privacy and the Responsibility of the consumer to make informed decisions to manage their own medical information and the Ethical matters of Equity in HIE. Figure 11 shows the open, axial, and selective coding for Fairness in HIE, each of which is discussed next.

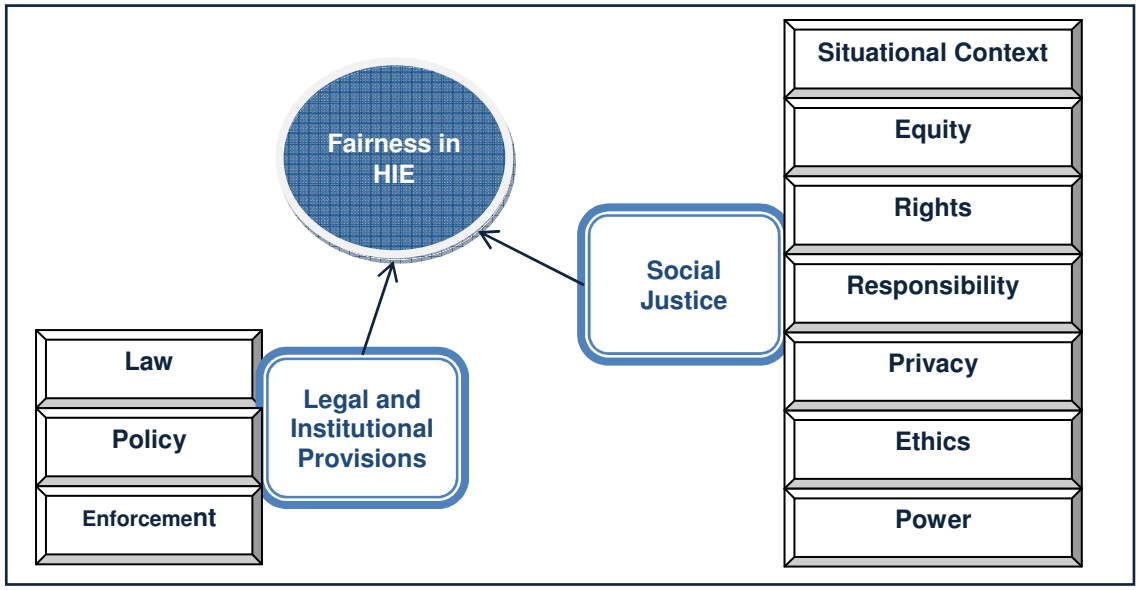

Figure 11. Results of the Everyday Consumer Coding Process for Fairness in HIE

Social Justice

Social Justice involves many facets in which the consumers felt there was lack of Equity and Power, and, in some cases, violations of Privacy Rights. Overall, the Social Justice factors provide a facet of Fairness in the healthcare system and in society in general. Although the consumers often felt that there was Social *Injustice*, through inequity or lack of privacy rights, the term Social *Justice* was utilized for selective coding because it suggests that to achieve consumer empowerment in HIE there should be a level of Justice. Social justice is a broad term which, in other contexts such as social work, politics, or education, is used to imply activism. According to the Center for Economic and Social Justice[34], the term social justice

> is the virtue which guides us in creating those organized human interactions we call institutions. In turn, social institutions, when justly organized, provide us with access to what is good for the person, both individually and in our associations with others. Social justice also imposes on each of us a personal responsibility to work with others to design and continually perfect our institutions as tools for personal and social development.

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[34] Center for Economic and Social Justice. *Defining Economic Justice and Social Justice*. Retrieved May 2008 at http://www.cesj.org/thirdway/economicjustice-defined.htm.

Therefore, in the context of HIE, Social Justice implies a sense of Equity, Ethics, Rights and Information Privacy to manage one's own health records. This is in consideration of Situational Contexts which can determine how a patient may view the sensitivity of his medical information, for example, if there is a diagnosis of a stigmatizing condition. Within this context is the notion of Power of societal institutions which should implement HIE Fairly. Also associated with a consumer's Right to Information Privacy and to be able to manage her own medical records is a Responsibility to use it in an informed manner.

As stated in the interview with Toni Cordell, "there are some excellent reasons [to share information]. The patient should have the right to control all of that, but sometimes the patient doesn't know." Because patients have varying levels of education, there is an inherent lack of Equity of the level of understanding they have in order to make Responsible, informed decisions about how their information could be shared. In the case of the consumers interviewed, Privacy was seen as a Right that should be protected. For example, one person said that disclosure of information was an 'invasion of privacy."

There were consumers who mentioned Responsibility of patients as another dimension of having the right to control the access to her medical records. "Patients [should be] Responsible for their own records. I think people should have all important things written down anyway." Toni Cordell said that

she carries a card with her that lists her medications, because it is difficult to remember the names, dosages, and how to spell them. This is the case for some of her friends, who take over ten different medications. Being able to control her list of medications and give access to that list was important. But associated with that Right to control her list (whether on paper or electronic form) is the Responsibility to keep the record updated. Responsibility is also closely related to the idea of Consent Management and patients controlling access to their records. Because Responsibility seems to be a result of having the Right to one's medical record, it is placed within the concept of Fairness in HIE.

Situational Circumstances involves the type and sensitivity of medical information, and the actual situation which requires the medical information. In certain cases, sensitive medical information (i.e. diagnoses of AIDS, mental health or substance abuse) was viewed as information that needed special protection. Other Situational Circumstances, such as being treated in an emergency situation, were seen by the consumers as problems for providing proper consent in HIE. Toni Cordell also emphasizes that giving consent for access to medical records is not appropriate at the point-of-care:

> ". . . .Even those with advanced educations may not be at peak performance while visiting the doctor. What happens to those with college degrees when their temperatures soar over 100 degrees? Are they able to understand and follow every bit of instructions coming at them. . . .?"

Although the consumers felt that there are certain Situational Circumstances in which medical information should be shared, they also wanted to ensure that they give consent or that the data is not aggregated when the data were used for purposes other than treatment. The youngest consumer interviewed stated:

> "I believe that some of this information can be distributed to help people. Whether the data ends up in a medical journal, a clinical research project, or on a billboard, I suppose I wouldn't mind. As long as it states a general hypothesis or study, rather than any personal information about myself, I suppose I could deal with that. However, I wouldn't want to have my records being shoved around to random places that might have an "interest" in me. . .Basically I don't mind sharing the information, I just want to know who it is going to."

The same consumer when asked what consumer empowerment meant to him, stated: "It means that I am able to know who has my records and who I will allow to have them. If someone has my records for purposes other than helping me, I would like to be able to take it away from them." This is a strong statement, with an underlying theme of Ethics, enforcement, and a Right to control his own records. This person felt that it was not Ethical for someone to have his records for situations other than his treatment. Legal and Institutional Provisions,

including enforcement are factors closely related to how a consumer views Fairness in HIE and will be discussed next.

Legal and Institutional Provisions

The consumers emphasized the need for federal Laws such as HIPAA and organizational Policy to enforce the protection of medical records through HIE. The consumers did not seem to understand how their medical records are currently shared although they most likely sign the HIPAA privacy policy forms at the physician's office. As one stated: "I need to know more about my healthcare providers' policies with disclosing my medical records with other parties." They expected that the law will protect their privacy and sensitive medical information. As one consumer stated: "What happened to HIPAA? If I can't even get information about my husband, why should a marketing company be allowed to have the information?"

The consumers were very strict about the types of Enforcement that should be applied towards illegal disclosure of medical information. When presented with news stories in which illegal disclosures of medical information occurred, the consumers were asked what they thought should have happened in these cases that were extracted from newspaper articles. The consumers stated that the disclosure was "wrong and he should have been punished" and that it seemed to be a case of identity theft and the Enforcement should be to

"lock him up!" One extreme answer in response to the story about a healthcare employee (who used the names of cancer victims to get credit cards in their names) was that he should be "sentenced to death." Other ways that the consumers said the Law should be Enforced was to "remove [the doctor's] license," provide "prosecution and jail sentence," and to "pay everyone [the victims] back and throw [the offender] in jail. Maybe the company should pay everyone back if the person [offender] can't, for letting just anyone have access to the files." Although most felt that both organizations and the government should Enforce Policies and Laws, one consumer suggested that the patient in the scenario "should complain to her doctor and if it happens again, then find a new doctor." This implies that the consumer doesn't trust that there will be Enforcement (because he seems passive about acting to report a violation and believes a violation may happen again), or perhaps that it is difficult to confront a physician about such a disclosure. One consumer stated that Policies and Laws need to be in place: "[the disclosures of information in the scenarios] makes me feel like my records aren't secure and that healthcare organizations have some new policies to make for my behalf." Again, it emphasizes the paternalistic nature of the government and healthcare institutions protecting the consumer by creating Policies and Laws on their behalf.

Consumer Commitment

For consumer empowerment to be realized, the consumer should experience a level of Commitment in their Participation and information-seeking behaviors. This level of Commitment reflects the importance a consumer places on healthcare information exchange. A consumer may Commit to become Literate and to have a Voice in their care and ultimately feel empowered by these actions; however, a consumer may also feel empowered by making the choice NOT to seek information or participate in their care. A consumer could choose to be Committed to, for example, ask the doctor questions when needed, or NOT to ask questions. The difference is perhaps the motivation behind the actions and the comfort with the consumer with their decision. One may not ultimately feel empowered, for example, if they are too embarrassed and ask questions of the doctor when they don't understand the terminology. However, a patient may feel that she understands the given situation, perhaps because she is comfortable with the amount of information she has about her treatment. In this case, the motivation behind choosing not to seek additional information is because the patient is comfortable instead of being afraid or overwhelmed. It should be stated that the level of Consumer Commitment lies on a continuum and can change over the course of a patient's life. Figure 12 shows the open, axial, and selective coding for Consumer Commitment. Consumer Commitment will also be

investigated from a Process Model of Consumer Empowerment in HIE perspective in a later chapter.

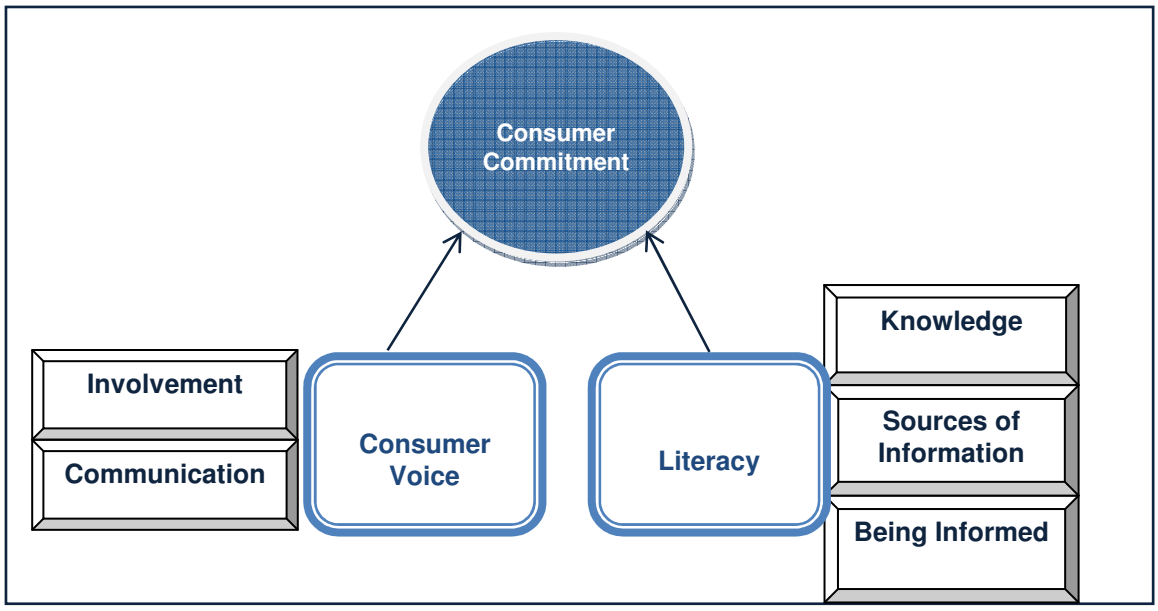

Figure 12. Results of the Everyday Consumer Coding Process for Consumer Commitment to HIE

Literacy

Level of Literacy emerged from the data analysis for the everyday consumers within the dimension of Consumer Commitment. The term Literacy was utilized to preserve the context of the level of understanding that the group of consumers had regarding health information exchange.

> “The Workforce Investment Act of 1998 defines literacy as "an individual's ability to read, write, speak in English, compute and solve problems at levels of proficiency necessary to function on the job, in the family of the individual and in society." This is a broader view of literacy than just an individual's ability to read, the more traditional concept of literacy. As *information and technology* have increasingly shaped our society, the skills we need to function successfully have gone beyond reading, and literacy has come to include the skills listed in the current definition” (National Institute for Literacy).

It was apparent from the everyday consumer interviews that there is a process in Being Informed. Literacy is an initial level of understanding which provides proficiency necessary to be functional in society (National Institute for Literacy). Although Literacy typically means functional Literacy, the term can have different facets such as Health Literacy or Technological Literacy. Since HIE is an emerging innovation, it will be proposed that there is such a concept as HIE Literacy. The term Literacy is preserved in this analysis, with the understanding that Literacy can hold different meanings, which will be investigated.

By asking physicians questions or searching for Sources of Information on the Internet or from family members, consumers become more Informed and gain Knowledge. This is an iterative process that will be discussed in further detail in a later chapter on the Process Model of Consumer Empowerment in HIE.

None of the consumers interviewed had heard of the NHIN (Nationwide Health Information Network) and only two had heard of PHRs (Personal Health Records). They discussed their level of understanding in terms of Knowledge and in Being Informed by looking for Sources of Information. One consumer stated that "I need to know more about my healthcare providers' policies with disclosing my medical records with other parties." Another consumer felt that she didn't need as much access to her records as the physicians since "I don't know what to do with the information; they [the physicians] know what to do with the information." When asked if he would like to be empowered in the exchange of his healthcare records, one consumer felt that he would like to be empowered, "with knowledge about who's sharing my information and the ability to protect my records." This echoes the concerns of Toni Cordell, the patient health literacy advocate, who says that the patient doesn't know all of the options involved with the sharing of their information.

It is difficult to navigate the healthcare system, and the concept of understanding how to navigate the healthcare system is called 'health literacy' (North Carolina Institute of Medicine, 2007). The traditional doctor/patient relationship is one in which the doctor is seen as the person in power, because he/she holds the medical Knowledge that patients do not have. Toni states that the doctor "is so authoritative"' that is makes it difficult for patients to be

comfortable asking questions to learn more. Toni graduated from high school with a 5th grade reading level and discovered she was dyslexic when she was in her 40's. Throughout her life she struggled with challenges of having a low Literacy level. At one point in her life, she was told by her doctor that she needed a 'simple repair' that surgery could correct. She signed all of the forms and did not ask questions regarding the type of surgery that would be performed. It was not until she went to the doctor for her follow-up visit and the nurse asked how she had been since her hysterectomy that she realized what surgery had been performed.

Toni still does not fully understand HIPAA and other privacy policy and consent forms that she is asked to complete at the doctor's office, but she still signs them because "we know that in order to have treatment we have to sign them." This is a quid pro quo exchange---in essence she feels that she could be giving up control over her medical information and how it is disclosed in exchange for treatment. Several consumers who were interviewed discussed the lack of Knowledge about how information is shared, even though it can be assumed that they sign HIPAA forms at the physician's office. For example, one consumer said that she would feel empowered "to know how my medical information would be shared." Toni Cordell summarized this sentiment when she

stated that “sometimes we are giving consent for far more intrusion than we realize.”

One other facet of asking questions is that “when I say or do something that reveals my lack of education, I get slammed in the face with humiliation” (Cordell, 2007, p. 332). This statement reflects the vulnerability that one feels when in the face of the “authoritative doctor.” To reveal that you don’t know something takes courage. Consumers seek different Sources of Information. Some patients are passive and wait for the doctor to tell them what information is important. Other patients are active and ask questions of the doctors or seek additional sources of information through the Internet or other means. The consumers interviewed primarily felt that the responsibility for educating consumers could be through their providers and also through consumers searching for information, for example, on the Internet. The notion of the traditional doctor/patient relationship is now changing to a “peer relationship” in which both parties are responsible for healthcare and the sharing of information which supports one’s treatment (Cordell, 2007, p. 332). This continuum of being an actively informed consumer is especially important to understand in the context of the evolving environment of healthcare information exchange and its associated acronyms and jargon.

The process of becoming aware of issues and the continuum of education will be discussed in a later chapter. Being literate is similar to becoming aware of issues; it is a first step to learning about the navigation of the healthcare system, and through further education and Knowledge, one can become more Informed on the details and complexities intertwined in healthcare information exchange. The use of the term "literacy" was utilized in this coding because it reflects an initial level of understanding, awareness, and Involvement above being a passive patient. This is emphasized in Toni Cordell's statement "I've spent my life facing challenge after challenge and attempting to gain enough knowledge so I can feel normal" (Cordell, 2007, p. 331). This feeling of inequity for Toni Cordell motivated her to become more Involved and to find her Voice to become a speaker and patient advocate.

Consumer Voice

Consumers need to be Involved and Communicate with their healthcare providers. Being Involved, as suggested earlier, can range from being passive and waiting for information to be Communicated to you by the doctor, or to more active Communication such as going to the Internet to find information or asking the doctor questions. The consumers who were interviewed felt that in order to learn about healthcare information exchange, the consumers should be Involved in actively seeking information. Communication, according to Toni Cordell,

"offers an opportunity for understanding and success or misunderstanding and failure" (Cordell, 2007, p. 331). Another consumer stated that "Patients should talk with healthcare providers about the way information is shared electronically. Patients can keep up with political issues that affect their medical information and let legislators/Congressmen know how they feel about laws that are being considered." From these statements, it seems that the patients are more comfortable with providing their voice at the individual level by talking with their providers and legislators rather than a larger-scale HIE project.

The individuals who were interviewed also felt that consumers should be Involved in HIE efforts. The "patients should be involved. I don't know the best way, but it would be nice to be informed about these issues and able to give an opinion that is considered while systems are being developed." Other consumers interviewed felt that consumers could be Involved in surveys or volunteering for HIE workgroups. Although they did not seem familiar with HIE initiatives (such as the NHIN), the consumers definitely wanted at least a small role in providing their voice to HIE efforts. Their overall perspective was not of participation in HIE efforts, but having a Voice in Communications with their healthcare providers.

Theoretical Model and Dimensions of Consumer Empowerment in HIE from the Everyday Consumer Data Analysis

Based on the properties of the codes and relationships of the codes to one another, it was determined that these codes could be reduced, which is selective coding. Table 14 shows the results from the coding process, relating those to discover the axial codes, and then further grouping them using selective coding to form a parsimonious theoretical model for consumer empowerment in healthcare information exchange from an everyday consumer perspective.

Table 14. Results of the Everyday Consumer Coding Process

Selective Coding	Axial Coding	Open Coding
Consumer Confidence in HIE	Consent Management	Authorization
		Access
		Consent
		Disclosure
		Control
	Security	Protection
		Records/Information
		Processes
	Level of Trust	Trust in Provider Competence
		Distrust in Non-Provider Stakeholders
Fairness in HIE	Social Justice	Situational Context
		Equity
		Rights
		Responsibility
		Privacy
		Ethics
		Power
	Legal and Institutional Provisions	Law
		Policy
		Enforcement
Consumer Commitment to HIE	Literacy	Knowledge
		Sources of Information
		Being Informed
	Consumer Voice	Involvement
		Communication

CHAPTER IX

FINDINGS AND INTEGRATED THEORETICAL MODEL

Before presenting the Theoretical Model of Consumer Empowerment in HIE which has been integrated from the findings of the three data sources, it is important to examine the differences and similarities between the three groups and general findings about consumer empowerment. After each of these is explained, the Integrated Theoretical Model of Consumer Empowerment in HIE will be discussed.

Findings from the Differences Between Groups

Data sources were chosen because they were thought to have similarities as well as differences due to their backgrounds, but it was not apparent what types of differences would be discovered. The findings of these avenues of data collection revealed differences among concepts such as how technology is viewed in consumer empowerment, time constraints, views of information privacy and rights, as well as the differences in stakeholder perspectives. These are briefly discussed next.

Role of Technology

The AHIC members tended to view technology as a solution to consumer empowerment in HIE. This is since the broad charge for the workgroup was to "gain widespread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered." The primary focus of the group during the six months studied was to examine what features should be incorporated into the technology and how to provide suggestions for PHRs that would be accepted by the market and utilized by consumers. From the initial six months of transcripts, the discussion was on a "good enough" PHR, which included basic features which consumers would utilize, such as a medication summary listing, and the ability to share that information with the provider. From this "good enough" PHR, it was expected that the market would then add features of value. The focus of the AHIC Consumer Empowerment Group was that of network-based PHRs, rather than web-based PHRs.

NCHICA's mission is to accelerate the adoption of healthcare IT and the focus of CACHI in the beginning was more technology-focused, especially in PHRs for senior citizens to use in times of crisis. However, this changed in April of 2007 when the group decided to change their name from Consumer Advisory Council on Healthcare Information Technology to the Consumer Advisory Council on Healthcare Information. They felt that the underlying foundation in HIE was

health information and that the role of technology was to support the security of that information. CACHI members talked about many types of technologies besides the PHR, including the use of USBs, EHRs, the NHIN, and NC HIE (North Carolina Healthcare Information Exchange). Therefore, CACHI viewed technology as a tool to support consumer empowerment in HIE.

The Everyday Consumer group, as mentioned in the Data Analysis chapter, did not mention technology very often. Only two of the consumers discussed technical topics such as encryption or passwords. Their primary concern was not the technology, but the organizational policies and government regulations. The consumers in this group seemed to believe that technology was a tool with which there was a certain amount of anticipated risk. They felt that their providers utilized technology which was as secure as possible. The interpretation of this was that the consumers understood that there was a risk with technology and perhaps didn't feel like they needed to know about encryption, passwords, and other details. Consumers felt that they had a better understanding about Policies and Processes than they did about technology. One interpretation is that the technology was easier to control than people and processes. Therefore, it seems that Everyday Consumers see technology as a tool that supports the security of medical information, and, perhaps, as a tool

which supports consumer empowerment in HIE. More information would need to be gathered to further study this interpretation.

Time Constraints

The difference in time constraints was revealed primarily between the AHIC Consumer Empowerment Group and CACHI. The time constraints placed on the groups seemed to affect how the groups evolved. These time constraints may have affected the types of concepts that emerged from the data. Because the Everyday Consumers were not working with HIE groups or weren't as familiar with HIE initiatives, they did not discuss time constraints. Because the AHIC workgroup was given a charge by the AHIC community, the goals of AHIC were defined in terms of one year. There was a great sense of urgency for the group to develop deliverables related to the adoption of PHRs. They were very concerned with barriers to PHR technology, the acceptance of the marketplace, and how to approach a solution to produce these deliverables within one year. The scope of the project was important, as well as prioritizing and delegating tasks between members and subcommittees to accomplish goals. During the March 2006 meeting, they spoke of the "urgency of personal health records," and that "we need to do an awful lot of work offline. I'm a little concerned about the timing, " "we may not have quite enough time," and "we could actually turn this thing around more quickly." The sense of being rushed was the atmosphere for

all of the meetings analyzed. The sometimes overwhelming need to push tasks forward for the AHIC group translated into a solutions-based approach. This was different than that of CACHI, which viewed it as a process-based approach.

The members of CACHI were not under a deadline like AHIC, and usually did not seem to be rushed in getting to a finish line. Overall, the CACHI members were more interested in the process of how consumers could be educated and involved in HIE efforts. Their journey across the year and a half of meetings was one of self-reflection and learning. They often had many personal stories and concerns to share. While both AHIC and CACHI struggled with project management concerns (discussed in the Similarities Between the Groups section), CACHI viewed it as an opportunity to revisit their goals and objectives to ensure that their activities were synergistic with their goals. There were occasions when members of CACHI openly stated their concerns that while listening to presentations and discussing concerns were valuable, they were ready to act upon what they had learned.

Information Privacy and Rights

AHIC's Consumer Empowerment Group often discussed privacy and control of information in terms of rights to which the consumers are allowed by

the providers. One member of the group who worked with a pharmaceutical company stated that

> "while we give patients a right to access information. . . .are they allowing them [providers] to just see it or incorporate it into their record because once it is in their medical records, as, for example, I'm seeing a patient and they give me their personal health information from their PHR, now it is part of my record. I'm not going to give them [patients] an audit trail that goes back to their personal health record of every time somebody within my organization necessarily looks at that, processes it, has to do something with claims or something related to that" (Feb. 21, 2006 Transcript).

This comment suggests that patients are allowed to access their information and this person is concerned with giving patients full audit trails which are very detailed such that they show every time someone views that record. Privacy and related policies were seen as obstacles by one of the members who represented a vendor: "patient privacy may be one of these barriers." However, this sentiment may vary depending on the member within the Consumer Empowerment Group. Members who were from the vendor point-of-view, as stated, tended to see privacy as a right that patients were given by stakeholders such as vendors and providers. Members of AHIC who represented consumer-oriented groups saw privacy as an inherent right which people were entitled, especially through legal provisions. For example, in the February 21, 2006

meeting, a member of the National Patient Advocate Foundation, who co-chaired the meetings, stated:

> I think there is one area that I would want to call to everyone's attention on behalf of consumers and that is that within the principles, nowhere in the principles does it say that consumers have a guaranteed right to their own personal health record. And perhaps that need to be a foundational premise, that as we try to just work on the other two areas, we incorporate that as a fundamental premise for all of the principles. Then indeed, our consumers have to be guaranteed a right to their own personal health record.

The conversation between three members of the group after this statement made was whether HIPAA already provided this right:

> Member from U.S. Department of Health and Human Services (U.S. DHHS): ". . . .The point of clarification is, under HIPAA, there is a right of access to health information that's held by a covered entity. . .So, there are some provisions for that already under existing law for access to health information. So I just wanted to make sure that we were calling on something that was already a right under existing Federal Law."
>
> Member #2 from the U.S. Department of Health and Human Services: "Is it also the case we need to have a principle that would support what HIPAA has already created, such that on an operational level, consumers would truly have access to their information, because it is their right?"
>
> Member from Markle Foundation (a patient advocacy group): ". . .The principles [that] consumer groups have been developing are more explicit on this question. And, for example, one of them as an individual should have access to all electronic records pertaining to

themselves. . . HIPAA may provide formal, nominal access, but not effective access."

This conversation suggests that the members of the group from the U.S. DHHS feel that HIPAA already appropriately "created" the right for patients to have access to their medical records. Note that they discuss this in terms of access instead of control. However, the member from the patient advocacy group suggests that HIPAA may provide some coverage for the right to access information, but it is not enough in the amount of coverage it provides.

Overall, the CACHI group viewed privacy as a right that they were provided to by law and as an inherent right to which they were entitled. They also did not feel that HIPAA provided the proper amount of coverage to protect their right to privacy. One member stated that "it's civil rights violations" when sensitive information is disclosed.

Overall Perspectives

The perspectives of the three groups were motivated by different interests. The AHIC group was more oriented towards providers and vendors of PHR technology. CACHI perspectives included those of knowledgeable, but concerned consumers who were interested in learning and providing input to HIE initiatives. Lastly, the Everyday Consumer viewpoint was fairly narrowly-focused in how it viewed HIE. They tended to focus on health information disclosures

and how those should be handled through policy and law. They did not focus as much on the technology, but rather the process and people aspects of HIE, as discussed earlier.

AHIC

The AHIC Consumer Empowerment Group consisted of people from various backgrounds. During the first six months of transcripts; they discussed the importance of providing a consumer-centric PHR based on technological feasibility. The member from the National Patient Advocate Foundation stated:

> And certainly those are areas that we will want to give careful consideration to as the consumer empowerment group tries to marry both the world of information technology with the need of a consumer that is ultimately going to be using these tools, at the same time addressing the question of how do we positively incentivize utilization of these tools and programs by the providers in the United States (Transcript, Jan. 30, 2006).

Although there were many calls during the six months' of transcripts for consumer involvement and input into the recommendations for a PHR that was "easy-to-use, portable, longitudinal, affordable, and consumer-centered" there seemed to be no true consumer input. At the end of every AHIC Consumer Empowerment Group meeting, there was an opportunity given for the public to give input after listening to the discussions. At the end of one meeting, the phone line was opened for public comment, and one person from the general public (who seemed to represent an organization, but it wasn't clear), spoke for

approximately six to seven minutes about her concerns. She spoke about a number of issues, including the need to access patient PHRs to integrate their insurance claims information with the PHR; problems with incomplete information on insurance claims; and concerns with being able to share patient medical information with the patient and for secondary uses, which is not possible under HIPAA regulation. She ends her comments with:

> So these are things that when I was reading some of the notes, we weren't seeing addressed. We're struggling and trying to get information to the consumer, and the only one right now really making efforts and strides toward getting that information to people. So guidance on how we should approach this would be very helpful (Transcript, May 1, 2006).

Although she provides good feedback and asks appropriate questions of the workgroup, she only receives a moment of silence after her lengthy and thought-provoking comments. This is the conversation that began after the pause:

> Member 1: Okay, thank you very much.
>
> Member 2: That's it for public comments.
>
> Member 1: All right, then. We have our assignments. Please get any additional comments you might have to the staff at ONC. And we'll look forward to the -- I guess we're getting two products now. The -- a quick look at what recommendations might go into the PowerPoint slide, as opposed to the letter or holding off, and then the second thing will be by the end of tomorrow or the next day, I can't remember. Tomorrow, a revised letter.

> Member 3: . . .Is there going to be any response now or later to the person that just raised the issues on the phone from the public comment?
>
> Member 1: I think that will have to be from ONC.
>
> Member 4: Yeah, you're welcome to respond to the comment as a Workgroup member.
>
> Member 3: I don't know if I'm the best person to comment. I just think that the individual needs to be acknowledged and maybe it's whether our group will take these -- or we'll try to find the right place to have them addressed. I thought they were important issues, really important. Or to ONC, but somebody would somehow get back and let them know that we heard and we're at least getting the information before the right people.
>
> Member 4: Yeah, I mean I think there's now a public record of the comments. I think -- I think it would be even more helpful to have something in writing. Okay. So I think written testimony would probably be easier to respond to. And I think that that will probably happen. It's already prepared.

Perhaps they were in a hurry to end the meeting, but the member from the National Health Council wanted to make sure that the person's comment was acknowledged. From the six months of data that was analyzed, it is not clear that the person's comments were specifically addressed, although some components of what she presented were discussed within the context of the meetings. This set of comments from the members does represent an overall lack of deeper interest in getting input from consumers.

While the AHIC group was named “Consumer Empowerment Workgroup,” there was not a definition of consumer empowerment given for which to drive their efforts. The member from the National Patient Advocate Foundation alluded to it when she said, “ There should perhaps be within this road map a section that would address the objectives of the consumer empowerment, the required desired functions offered to consumers, in the registration information, and in the medication history” (March 20, 2006). What the members of the group were charged with was the recommendation for the widespread adoption of PHRs, in essence,

> We've got two main areas for focus, one being the electronic registration summary and the other being the medication history. So that I think that we're starting out with some degree of focus; certainly you know when you look at the topic like consumer empowerment, that's a pretty broad scope, but it's been narrowed for us already to those two areas (Transcript January 30, 2006).

This seems to narrow consumer empowerment to a technological focus, primarily through the capability of a registration summary and medication history within a PHR, and doesn’t really address what the scope is for consumer empowerment.

One way that they suggested to discover what empowers consumers was to survey consumers. This was mentioned by a member from the Markle Foundation:

> I'd like to ask the ONC staff or to commission outside contractor or poll the big provider organizations in a structured way to do a little survey of them or something, to find out what is currently valuable to people. I mean, it seems to me the word "empowerment" should be the watch word of what we're doing here. And rather than saying our goal is to display in front of people a set of data they may or may not have any interest in, we should say what is it people feel empowered by. And if there are a couple million people with access to a medication list, I'd like to know what they are using it for and what they feel empowered by (Transcript, March 20, 2006).

Unfortunately, the group felt time pressure, and was only able to perform a superficial survey during the six months analyzed. However, they did utilize as set of guiding principles generated by the Markle Foundation and Blue Cross Blue Shield. These include Principles for Personal Health Records, for Information Access and Control, for Disclosure and Accountability, and Functionality of PHR features.[35]

CACHI

The CACHI group was very consistent in its view of consumer input. They felt that it was a necessary component of HIE efforts so that the consumer voice was heard. Although they realized they were educated compared to most

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[35] United States Department of Health and Human Services. Consumer Empowerment Workgroup. Proposed Principles for Consumer Empowerment Breakthrough. http://www.hhs.gov/healthit/ahic/materials/meeting02/cemp/CEmp_principles_breakthrough.pdf

consumers, they also discovered that there were facets of HIE which they did not understand, and were not afraid to admit their own deficiencies. They included many personal views through stories and this allowed for a synergistic approach through discussion to develop ideas on HIE concerns and opportunities.

Overall, the Executive Director of NCHICA was protective over the CACHI members. He did not feel that they were advocates or lobbyists of any type, and also was concerned that NCHICA, as a nonprofit group, could not by its Executive Order, perform any lobbying activities. The feeling was that the group should not be "involved in conflict" arising from activism or lobbying efforts. He also wanted to ensure that researchers, vendors, or organizations who were interested in input of CACHI were genuine in their efforts.

Everyday Consumers

The group of Everyday Consumers used some of the same terms as the federal AHIC group. Ironically, the terms used by the Everyday Consumers and AHIC that were common included disclosure, protection, control and access. One interpretation is that the groups which were represented in AHIC were also those who may be well-known to everyday consumers, especially Microsoft, Blue Cross Blue Shield, and the Department for Health and Human Services. Therefore the consumers were possibly accustomed to hearing the vocabulary of these companies in advertisements or through web sites. However, it is also

possible that the terms for disclosure, protection, control, and access are relatively technology-independent and common within news stories of financial information disclosures as well. Since the Everyday Consumers were not as interested in or familiar with the details of the technology, they did not typically use terms such as security, encryption, or USB in these types of conversations.

Findings from the Similarities between Groups

It was found that between AHIC and CACHI, there were similarities in their views of project management, setting goals, education, collaboration and model seeking. Both AHIC and CACHI seemed to struggle somewhat with their goals and objectives. They often questioned what the scope of their tasks should be and what deliverables would be important to accomplish their goals. Ultimately, both groups found it necessary to use a set of guiding principles for which to steer their work. Within the framework of their guiding principles, they also found it essential to set goals and prioritize what could be completed within a specific time frame. The common concern of both groups was to feel that they were being active in their meetings, using their time efficiently, and achieving their goals.

AHIC's Consumer Empowerment Group had been provided some specific goals and deliverables by the overarching AHIC organization, but still struggled with the process to achieve those. Because AHIC did seem to have a 'head

start' on the CACHI group in this way, they seemed to progress more quickly towards producing deliverables. However, given that AHIC was provided with those goals and deliverables, they became tied to those, unlike CACHI, which was able to explore in more depth the topics of their interest.

Both AHIC and CACHI felt that in order to perform effectively they needed more information. The groups sought out different ways to learn primarily about the policy and technology concerns that they had. Their sources of information were speakers, testimony from groups (for AHIC), use of a Resource Panel (CACHI), and collaborating with other groups with similar objectives. AHIC collaborated with other federal efforts such as the HITSP (Health Information Technology Standards Panel) and other AHIC Groups (such as the Privacy and Security workgroup, and also sought ways that their members' organizations could be employed for synergistic efforts. For example, they used surveys of consumer preferences that their member organizations had generated as a way to utilize the efforts of others.

As part of NCHICA's mission, there was motivation to view education as an important component of being informed on changes in the HIT (Healthcare Information Technology) landscape. There were many times in which the Executive Director suggested that education and collaboration were overarching methods to achieve consumer engagement and empowerment.

Lastly, both groups looked for other models for best practice solutions. This was part of the collaborative effort to see what others were doing in similar efforts. They wanted to see what other types of models worked for secure and private information exchange. Probably the most-often utilized example was that of financial institutions. Both groups discussed the ways that financial institutions could be models for HIE. For example, this comment from a member of the AHIC group (who was affiliated with Microsoft):

> I think that if we look at breakthrough models, we may want to consider one in which the PHR is not in the clouds, but the consumer has more direct access to control of that PHR. Say on a storage card or a USB port or interesting models out there that the financial institutions are driving today related to health savings accounts and debit cards. . . . (Transcript, February 21, 2006).

The CACHI group also mentioned looking towards law enforcement and chain of evidence models for the purpose of audit trails to see who has accessed a medical record (August 2007 meeting). One related comparison made by a CACHI Resource Panel member for an audit trail model is that of art provenance (August 2007 meeting). Art provenance is the concept of proving that a piece of art is genuine based on documentation or paperwork which accompanies and authenticates the piece of work. It is, in essence, a history of ownership for a piece of art to prove that the artwork is authentic (Sullivan, 2005). The parallel model to HIE is to prove that the integrity of health information is intact when

many different people may be accessing or editing a health record. There should be an audit trail of ownership for how the record was changed.

General Findings about Consumer Empowerment

Overall, it was found that Consumer Empowerment depends on perspective, and is context-specific, and is difficult to define in a concise way because of its many facets. There is a considerable amount of wordsmithing and framing for consumer empowerment in HIE. One example of wordsmithing is in the term for the NHIN. Originally it was an acronym for National Health Information Network and was changed from “National” to “Nationwide” because people tended to think “National” referred to one national database of patient records, which most consumers and patient advocates do not like due to security and privacy reasons. The term Consumer Empowerment seems to be a term utilized in a superficial way, at least by the AHIC group. They include consumers and patient advocates as ‘tokens’ and don’t seem to incorporate true consumer input.

The importance of framing HIE and HIT (Health Information Technology) for legislative purposes is also critical. What I found from working with NCHICA and the HISPC projects was that it is better to frame HIT as a necessity for improvement of healthcare and decreasing healthcare costs. It is difficult to enter a room of legislators and discuss the technical details of HIT such as encryption

and the transmission of information in a secure manner. Most legislators have limited time to discuss these details. Providing an overall view of the main bullet-point concerns in HIE is better approach. This is similar to what Berger and Luckman (1966) refer to as the social construction of reality.

Empowerment is seen as a bipolar issue. People are often referred to as being either empowered or not empowered. However, empowerment is a continuum. It is a process which is relative to each person, and often involves conflict. Whenever one person moves on the empowerment continuum, another person is usually affected. In this case, it seems that as consumers are empowered, there are ramifications for providers who will need to view their own power in a different way. Some people in both AHIC and CACHI saw the providers as giving up power so that consumers could gain power through control of their medical records. However, others saw it as a partnership between the provider and patient to share responsibility of an individual's healthcare. Whether either of these views holds true may be apparent in time, when these efforts have been implemented long enough to determine the results of HIE efforts.

Proposed Integrated Theoretical Model

From the codes generated from each of the data sources, a second phase of coding was performed. Open, axial, and selective coding was performed

according to the grounded theory approach (Strauss & Corbin, 1990). The integration of the coding was performed by aggregating the open codes from each of the three data sources, and then performing axial and selective coding from this aggregation. The codes from the data sources were aggregated and combined according to core concepts to create a parsimonious theoretical model of consumer empowerment in HIE. These are shown in Table 15.

Critical to the generation of the model and relationships between the dimensions of Consumer Empowerment in HIE is the nature of the constant comparative method and how researcher interpretation is enmeshed in the process. According to Isabella, "This approach requires that data and theory be constantly compared and contrasted throughout the data collection and analysis process. Evolving theory directs attention to previously established important dimensions while the actual data simultaneously focus attention on the theory's suitability as a frame for the most recent data being collected. The result of this fluid movement between theory and data is a reconceptualization, often based on a creative leap" (1990, p. 12).

Table 15. Results of Integrated Coding Process from Three Data Sources

Selective Coding	Axial Coding	Open Coding
Consumer Commitment and Engagement in HIE	Consumer Understanding	Awareness Education Literacy Sources of Information
	Consumer Action	Consumer Voice Participation Communication
Fairness in HIE	Legal and Institutional Provisions	Policy Law Enforcement
	Social Justice	Equity Consumer Responsibility Situational Context Rights Information Privacy
Consumer Confidence in HIE	Consumer Assurance	Level of Distrust Information Integrity Accountability
	Consent Management	Access Control Information Ownership
	Conventions in HIE	Processes Standardization Data Elements Information Sources
	Technology Mediation	Information Security Value of PHR

As the data revealed the Dimensions of Consumer Empowerment in HIE through the systematic method of coding, what is vital to understand is that the

researcher's interpretation is integral to this process. This is what Isabella refers to as a "creative leap" and what Glaser refers to as researcher trust in the result of constant comparisons. As the researcher delves into the data, with each iteration, there is a deeper understanding of what transpires in the data. The researcher is peeling back layers to find the core essence of what the data reveals. As the layers are peeled, relationships between the resulting concepts are also exposed. It is the responsibility of the researcher, and the purpose of the grounded theory approach, to interpret these layers and relationships to determine how the theory seems to unfold. It is not until these layers are exposed and relationships and codes are generated that the researcher can then step back and begin to build the theory. As an example, if I didn't understand how a computer worked, the process is similar to taking the computer apart and then building it back together, with an understanding of how the parts initially fit together and are thus related. In grounded theory, as the pieces fit back together to build theory, thus tell a story, the researcher makes creative leaps based on trusting her depth of understanding of what the data has revealed. The following discussions and resultant theoretical model are based on many hours of data collection, many levels of iterative data analysis, and researcher interpretation. The logic behind the "creative leaps" made by the researcher are explained as thoroughly as possible.

Table 15 shows the Integrated codes, the next sections will describe how this final integrated coding was performed. The following sections discuss how the original open coding was aggregated to generate the codes in Table 15. The tables in the following sections show *all* codes generated from the original open coding steps. In those tables, the codes which are italicized are ones which were aggregated into other codes in Table 15. Therefore, those codes are shown in the tables in the next sections, but are not shown in Table 15.

Consumer Commitment and Engagement in HIE

The final selective coding category for Consumer Commitment and Engagement in HIE was fairly consistent in its meaning across the groups. Table 16 shows a side-by-side comparison of the open and axial coding for each group.

Consumer Understanding

From AHIC and CACHI, the open codes for Awareness and Education were preserved under the concept for Consumer Understanding. They felt that consumers should have an initial level of Awareness about HIE topics before they could become more Educated in HIE. As more is learned and Understood about HIE, consumers become Aware of different HIE facets, such as security or consent options, and may want to learn more about those. The Everyday Consumers viewed this same process as gaining Knowledge to Be Informed using different Sources of Information (such as the Internet) to learn more about

HIE. Therefore, for the final integrated coding in Table 15, Knowledge and Being Informed were merged into the code for Education (thus they are italicized in Table 16).

Table 16. Original Open and Axial Coding for Each Group for Consumer Commitment and Engagement in HIE

AHIC		CACHI		EVERYDAY CONSUMER	
Axial Coding	**Open Coding**	**Axial Coding**	**Open Coding**	**Axial Coding**	**Open Coding**
Consumer Understanding	Awareness	Consumer Understanding	Awareness	Literacy	*Knowledge*
	Education		Education		Sources of Information
	Literacy				*Being Informed*
Consumer Action	*Consumer Input*	Consumer Action	Participation	Consumer Voice	*Involvement*
	Consumer Voice		Communication		Communication

AHIC and the Everyday Consumer data sources viewed an initial level of Awareness as Literacy in HIE. This involves learning the basics of HIE and how it affects consumers. However, in AHIC, the concept of functional Literacy was also discussed since consumers need to have a certain reading level in order to read privacy policies and Understand HIE. Although the term Literacy in this context will refer to HIE Literacy, it is assumed that consumers need to have a level of functional Literacy which allows them to read privacy policies, search for

additional information, and other activities which allow them to Understand and learn more about HIE.

Consumer Action

The level of Action needed to learn and participate in HIE was viewed differently by each group. Both AHIC and CACHI saw consumers being involved in Participation in HIE efforts, specifically by making their Voice heard to provide Consumer Input on decisions such as which features they would use in PHRs. AHIC seemed to view Consumer Voice and Input in a superficial way, with Consumer Voice including the everyday consumer and Consumer Input involving Public Input to their meetings, which could be any member of the public. CACHI viewed consumers being Involved through Participation in HIE efforts, such as their HISPC, NHIN, and HIE projects. CACHI members wanted to provide their Voice through Communication in these projects. For the purpose of integrating coding from the three data sources, Consumer Voice will be preserved as a code, and Consumer Input will be merged within this code since Consumer Voice is a necessary component of Consumer Input. Therefore, Consumer Input is italicized in Table 16.

Within the notion of Participation and Involvement, there needed to be a level of Communication. Communication was needed to learn about and to educate others on HIE concepts. This could range from the consumer asking

questions of the physician, searching for information on the Internet, or from the AHIC and CACHI members listening to speakers. The Everyday Consumers interviewed saw Involvement at a micro level. This included asking the physician questions and searching for information on the Internet. In essence, they seemed to be finding their Consumer Voice to Communicate and learn more about HIE and to be more Involved in their own healthcare. For them, it was a personal action which was to be Involved in the transformation of the paternalistic nature of healthcare. To ask the physicians questions can be difficult due to feeling intimidated, lack of time during the visit, or not knowing what to ask. Therefore, they did not view Action as being Involved in HIE efforts, but rather, as a more personal move to use their Voices to be heard by their physicians. Involvement and Participation are codes with similar meanings. These terms were used because they were the ones utilized by the members of those groups. For the integration of codes, the code Participation was preserved and Involvement was dropped because they are similar in definition. The choice to use Participation instead of Involvement was made after a search[36] for both terms and a definition of Participation was: "The act of taking part or sharing in something." This relays that Participation can be an individual or group activity.

[36] From http://dictionary.reference.com.

Also, the term Involvement can have many different connotations, some of which were negative. Therefore, Involvement is italicized in Table 16.

Overall, the selective coding for these codes was named Consumer Commitment and Engagement in HIE because the AHIC and CACHI groups both viewed consumers as being Engaged in HIE efforts at a different level than what the Everyday Consumers perceived. The Everyday Consumers felt that they were involved in HIE by asking questions of their doctors and perhaps searching for information on the Internet. For the Everyday Consumers, it was a matter of personally Committing to being involved in their own healthcare. For them, it involved making a conscious decision to be Committed because the paternalistic nature of traditional healthcare doesn't motivate consumers to ask many questions of their physicians. Therefore, the level at which the Everyday Consumers felt they needed to be involved in HIE was at a personal, micro level. The AHIC and CACHI groups viewed involvement at a more macro level of Participating in HIE efforts. To preserve the idea that there needs to be a level of personal Commitment by the consumer to ask questions and be Involved in Understanding HIE, the selective coding category was named Consumer Commitment and Engagement in HIE. This reflects the idea that there should be a level of personal Commitment to be Engaged in HIE. This process is explained

in further depth in the chapter on How to Achieve Consumer Empowerment in HIE.

Fairness in HIE

The integrated open and axial coding for Fairness in HIE was mixed among the groups. Table 17 shows the open and axial coding for each group.

Legal and Institutional Provisions

For all three groups, there was consensus that there should be federal Law to support the notion of privacy rights. The CACHI and Everyday Consumers felt that organizations should also generate Policy to protect the medical information of consumers from being accessed and disclosed in an unauthorized manner. As part of Legal and Institutional provisions for the protection of medical information, there should also be appropriate Enforcement so that consumers can feel that there is Fairness in HIE. The CACHI group did view the Right to Information Privacy somewhat differently than the other groups. They tended to discuss it in terms of HIPAA and Enforcement. Since the other groups viewed the Right to Information Privacy as an inherent human right, upon which federal and state laws should be created, Rights and Information Privacy are preserved under Social Justice (and italicized for CACHI in the Legal and Institutional Provisions category in Table 17), therefore, support a feeling of Fairness in HIE.

Table 17. Original Coding for Each Group for Fairness in HIE

AHIC		CACHI		EVERYDAY CONSUMER	
Axial Coding	**Open Coding**	**Axial Coding**	**Open Coding**	**Axial Coding**	**Open Coding**
Legal and Institutional Provisions		Legal and Institutional Provisions	Policy	Legal and Institutional Provisions	
			Law		Law
	Enforcement		Enforcement		Policy
	Law		*Rights*		Enforcement
			Information Privacy		
Social Justice		Digital Divide		Social Justice	Situational Context
	Information Privacy				Equity
	Rights		Equity		Rights
	Consumer Responsibility		*Resources*		Responsibility
	Situational Context				Privacy
					Ethics
					Power

Social Justice

Social Justice is a notion of Equity in Resources, Representation, and being treated Fairly in different Situations within the Power of those involved. CACHI and the Everyday Consumers felt that there should be Equity in HIE, especially through equal access to HIE technology and enforcement of HIE.

HIE with PHRs involves a level of Consumer Responsibility for their own actions to manage their medical records, as well, as both the Everyday Consumers and members of AHIC discussed. Toni Cordell stated that, "patients [should be] responsible for their own records. I think people should have all important things written down anyway." Toni Cordell said that she carries a card with her that lists her medications, because it is difficult to remember the names, dosages, and how to spell them, especially for some of her friends, who take over ten different medications. Being able to control her list of medications and give access to that list was important. But associated with that right of controlling her list (whether on paper or electronic form) is the responsibility to keep the record updated.

Because there are various types of patients, with different diagnoses and capabilities, the concept of Situational Context was important. For example, patients with mental illness diagnoses or substance abuse treatment may prefer that additional protection be used for their records so that employers or others aren't privy to that information. Also, people with chronic conditions have special Situational Contexts because they have to remember many medications, treatments, tests, and surgeries. Other Situational Contexts, such as being treated in an emergency situation were seen by the consumers as problems with

providing proper consent in HIE. Toni Cordell also emphasizes that giving consent for access to medical records is not appropriate at the point-of-care:

> . . . .Even those with advanced educations may not be at peak performance while visiting the doctor. What happens to those with college degrees when their temperatures soar over 100 degrees? Are they able to understand and follow every bit of instructions coming at them. . . .?

The Everyday Consumers viewed many of the Social Justice issues as one of power. It was often seen as giving Power to the consumer through allowing them to control their medical records. This Power should be utilized Ethically for the protection of medical records through HIE. Because the codes for Resources, Ethics, and Power also inherently relate to Equity, these were integrated into Equity. For example, there is an inequity in Resources such as Technology access which relates to the Digital Divide, and the paternalistic nature of healthcare results in a perception of inequity in Power. The quote from the Everyday Consumer involving Ethics was "If someone has my records for purposes other than helping me, I would like to be able to take it away from them." Within this quote, it can be interpreted that the consumer feels a lack of Equity regarding the control of his records. Because Equity will be preserved as a code to represent Ethics, Power, and Resources, these three codes are italicized in Table 17.

Reconciling Information Privacy and Rights between Legal and Institutional Provisions and Social Justice

Information Privacy and Rights were two codes which fell into different axial codes (Legal and Institutional Provisions and Social Justice) between the three data sources. This surfaced another dimension of the same construct in which there is a legal dimension and social dimension. Rights were framed in terms of the Right to Control/Own one's medical record (from AHIC) and the Right to Information Privacy.

Everyday Consumers and AHIC members viewed Information Privacy as an inherent Right that people hold, whereas the CACHI group members discussed Privacy and Rights in terms of HIPAA regulation. HIPAA is considered the minimal level of Privacy Rights protection, and the Everyday Consumers and members of AHIC didn't always view this as being adequate. The Everyday Consumers felt that Ethical considerations were sometimes more compelling than legal implications because of this. While this is an area ripe for further investigation, this study will view Information Privacy and Rights as innate beliefs which are supported by Legal and Institutional Provisions.

Information Privacy as a Right is placed under the Social Justice axial code because the sensitive nature of health information is seen by society as something that should be protected. Therefore, it is inherent as a human being

that one's medical records should be kept Private as an innate Right. These were not placed under Legal and Institutional Provisions since, if viewing Information Privacy as an innate Right, Legal and Institutional Provisions should support this Right with fundamental policy, law, and enforcement.

Consumer Confidence in HIE

The final selective coding category for Consumer Confidence in HIE was fairly consistent in its meaning across the groups. Table 18 shows a side-by-side comparison of the open and axial coding for each group.

Consumer Assurance

To provide Consumer Assurance, varying levels of Trust should be considered. This complex concept is viewed on a continuum, which is a focus for future research. Based on all three data sources, consumers want to trust their providers, employees, their processes, and the secure exchange of health information. A member of AHIC (from the Markle Foundation) stated:

> Because I think public trust is a critical outcome of this process. . .If there is a weak link in the network, then we are all at risk, and therefore, it becomes a public policy question. So, some of you know, health has spent 4 years working on these issues and they are very hard. . . . (Transcript, February 21, 2006).

Table 18. Original Open and Axial Coding for Each Group for Consumer Confidence in HIE

AHIC		CACHI		EVERYDAY CONSUMER	
Axial Coding	**Open Coding**	**Axial Coding**	**Open Coding**	**Axial Coding**	**Open Coding**
Consumer Assurance	*Consumer Trust*		Level of Distrust		*Trust in Provider Competence*
	Information Integrity		Accountability		*Distrust in Non-Provider Stakeholders*
Consent Management		Consent Management		Consent Management	*Authorization*
	Access		Control		Access
	Control		Access		*Consent*
	Information Ownership				*Disclosure*
					Control
Conventions in HIE	Data Elements	Conventions in HIE	Processes		
	Information Sources		Standardization		
	Standards				
Information Technology	Value of PHR	Technology Mediation	Information Technology	Security	*Protection*
	Information Security		Information Security		*Records/ Information*
					Processes

However, consumers also display a level of distrust in HIE due to the number of unauthorized disclosures that they have heard about in the news. The CACHI members often discussed Assurance in terms of the Level of Distrust rather than Trust, using terms such as “suspicious” and “technical skepticism” to describe their feelings. The Everyday Consumers felt that there was a Level of

Trust in Provider Competence between themselves and the providers. For the Everyday Consumers, there was also a level of Distrust in Non-Provider Stakeholders such as the government and insurance companies. However, if they trusted their physician, they trusted the HIE technology that the physician may have implemented. Therefore, the Trust of the physician may be a proxy for Trust of HIE according to the Everyday Consumer.

Regarding the continuum of Trust and Distrust, which could be considered two separate constructs, it seems that Trust is a necessary foundation for Consumer Assurance and Distrust could be a factor in motivating a consumer to become Engaged. This would need additional research to investigate, and, for the purposes of this study, Level of Distrust will be utilized under the selective code for Consumer Confidence to portray that there is a continuum of Trust and that Distrust may also affect the level of Consumer Confidence. Therefore, the other codes relating to Trust are italicized in Table 18 due to their integration into Level of Distrust.

Closely associated with the Level of Distrust is Accountability. CACHI felt that Accountability could reinforce a level of Assurance and Confidence in HIE. This is also related to Enforcement of Policy and Regulation since healthcare providers and others who hold sensitive medical information should be held Accountable for the appropriate stewardship of that information. One CACHI

council member felt that there was no Accountability to protect the records by following appropriate and fair consent management procedures: "There needs to be accountability throughout the information chain for privacy and security, regardless of where the information is. People need to be responsible for the breach and the protection needs to follow the data." This relates closely to the notion of Enforcement which was previously discussed.

According to AHIC members, Information Integrity is also important to Consumer Assurance that medical information, as it is shared among healthcare providers and among PHRs, will be accurate upon which to make medical decisions. This is also a concern of providers, who feel there could be a legal liability for basing a medical decision on information from either a consumer's PHR or from the medical record of another physician, when the original information could be incorrect or incomplete. Ultimately, the goal is to improve quality of consumer health based on the efficient and effective use of HIE, and Information Integrity is critical to achieve this goal.

Conventions in HIE

Conventions in HIE supports consistency in Processes so that consumers can be Confident in their expectations. For example, standardized forms for HIPAA privacy policies would affect Consumer Confidence since consumers would know what the form would ask no matter which physician's office they

were visiting. Everyday Consumers did not discuss Conventions in HIE in the context defined in this section, therefore there are no codes for them in this concept. However they did discuss Processes from a different perspective which will be discussed in the Technology Mediation section.

AHIC and CACHI members wanted Standardization in HIE Processes to ensure that medical information be handled consistently among providers' offices. AHIC's group also focused on Standardization of PHR interoperability, portability, and through Certification of PHR features. In essence, the way that data is gathered, transmitted, and accessed should be performed in a consistent, Standardized method. Data Elements should be gathered from different Information Sources, such as various doctors or hospitals and stored in consistent formats. Therefore the Data Elements would be Standardized and portable such that they could travel with the patient across numerous providers' offices. Consistency in how health information is gathered, stored, and transmitted seems to be important in building Consumer Confidence in HIE so that they know what to expect even when visiting various physician offices.

Consent Management

Consent Management is the idea of Controlling Access to medical information. To determine who has Control over Access to medical information, one needs to understand who Owns the information. This was discussed

primarily at AHIC, and the following conversation is representative of their perspective on Ownership of medical information (the quotes are taken directly from the transcript):

> Member from Pharmaceutical company: ". . . .I guess this gets into this issue that we haven't fully addressed in this, there was a question I stuck on the bottom of the draft a while back about have we really defined who owns the PHR data itself?"
>
> Member from the Department of Health and Human Services: "It depends, ownership is a really complicated issue. Ownership of data. And it's something, I know, that when we -- when the department dropped at HIPAA we'd stay very far away from, because – "
>
> >> [Multiple speakers]: (Laughing.)
>
> Member from the Department of Health and Human Services (continued): "To be honest. Because, they're, typically at least where there is State law on ownership of health information, that usually resides with the provider who is creating the medical record, although there is certain laws on rights with certain information I don't think there's any laws that I've seen on personal health records and how and whether there's ownership rights or not that –"
>
> Member from the American Medical Informatics Association: "That's exactly right. Which is the personally entered health information, so stuff that you contribute yourself, there's very little framework for that, but I think that's -- that's the -- that's why this is such a timely issue to try to readdress. "
>
> Member from the Veteran's Health Administration: "I think a number of people point out when there's electrons involved the issue of ownership is an interesting one. And before you get a little bit different about it, the word "ownership" has a very different meaning. This provider certainly has a copy of what they generate. We seem to endorse the patient also has a right to a copy of that.

> The interesting thing then is who has the right to [relief] that. Does it remain the patient's right as to when the provider can or cannot release that and under HIPAA there is the control that there so if you have differentiate the roles the patient has a right to a copy, the provider has the copy." (Transcript, April 25, 2006)

While Ownership has traditionally been in the hands of the provider since they create the medical records, PHRs may transform the way that healthcare stakeholders view ownership. Even at a granular level, when a patient uses their Own personal PHR and information could be transmitted to it from the physician's office, there is confusion as to who Owns that information.

In the data analysis of the three groups, both Control and Access were consistently discussed. For the Everyday Consumers and AHIC group, they discussed Controlling someone's Access to medical records through consent options, and also to Control the Disclosure of their information. The open codes for Control and Access will be preserved since they encompass Authorization, Disclosure, and Consent. Therefore, Authorization, Disclosure and Consent are italicized in Table 18.

Technology Mediation

Although the Everyday Consumers recognized that Technology supports HIE, they were not as concerned about the details of the Technology. As long as they felt confident that the Technology was secure, they seemed comfortable with HIE. They spoke of Technology Security in the context of the Processes

which Protect their Records and Information. CACHI discussed Information Technology and Security in similar terms, where Technology can provide Information Technology, and they often discussed specific technology such as encryption which could support Information Security. AHIC's Consumer Empowerment Group did focus on PHR Technology as part of their charge. They were interested in the Value of the PHR for consumers and Information Security. The AHIC group talked about communicating the Value of PHRs to consumers so that they would be adopted by consumers, who would ultimately have Confidence in a product they felt would be of use. If a PHR contains features that the consumer will use and will Value, it is logical to assume that the consumer would be Confident in the use of HIE Technology. In this case, the axial coding term for Technology Mediation is preserved since HIE will utilize Technological foundations such as PHRs and security features to share, yet protect access to medical information. Because Information Security implies a Process to Protect Records and Information, it is preserved as a code to encompass these terms (thus they are italicized in Table 17).

Integrated Theoretical Model for the Dimensions of Consumer Empowerment in HIE

Figure 13 shows all of the open, axial, and selective codes for Consumer Empowerment in HIE. In this Integrated Theoretical Model for the Dimensions of

Consumer Empowerment In HIE, there are 27 open codes, 8 axial codes, and 3 selective codes. These were generated by a data analysis of three data sources, one from a U. S. federal government organization (AHIC), one from a state-level group (NCHIC CACHI), and one from a group of "everyday consumers." Examining the phenomena of Consumer Empowerment in HIE through these data sources allowed for theoretical models to be built for each perspective, and also for an integrated model to be generated which encompasses each of the three viewpoints. It is proposed that three dimensions: Fairness in HIE, Consumer Commitment and Engagement in HIE, and Consumer Confidence in HIE, are necessary to build a foundation for Consumer Empowerment in HIE. Consumers need to be Confident, Committed, and Engaged in HIE, and also need to feel that HIE is Fairly performed in order to experience a level of Consumer Empowerment. These Dimensions will be discussed next, with previous literature woven through, in support of the emergent categories.

In a grounded theory study, the literature may be briefly investigated in the beginning to ensure that there is no existing literature which examines a researcher's topic in the same manner (Heath, 2006). However, grounded theory states that in-depth literature review is delayed until theory emerges

(Heath, 2006). The creators of grounded theory have different views on literature's role in a study. While Strauss and Corbin (1990) believe that

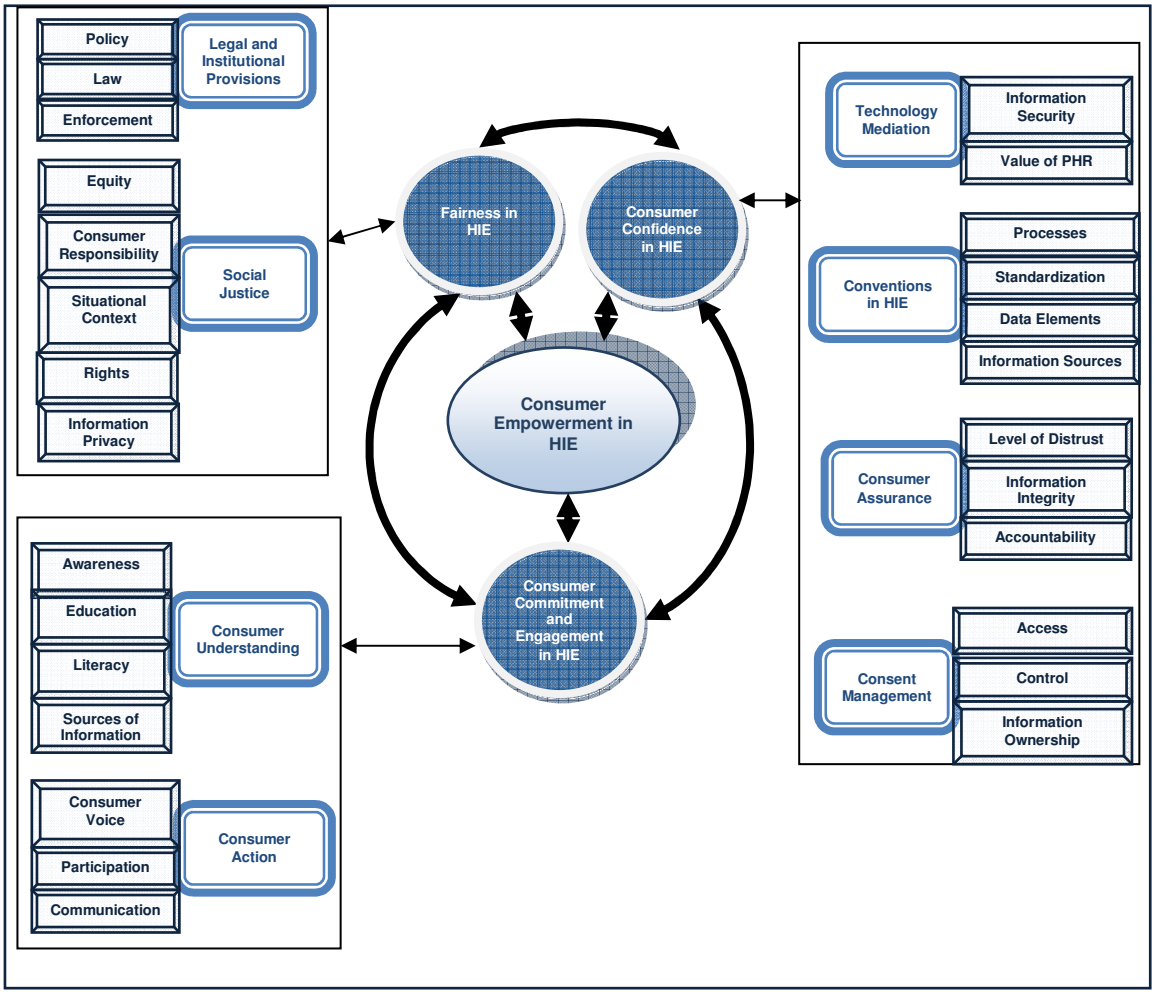

Figure 13. Integrated Theoretical Model for Consumer Empowerment in HIE

literature can be incorporated throughout the research in a key role, Glaser feels that literature review should primarily be delayed until theory emerges. This is because the purpose of grounded theory is to allow the theory to evolve from the data being analyzed. (Heath, 2006). Glaser believes that it is important that the researcher avoids imposing predetermined frameworks on the study in progress. At that point, the previous literature can be incorporated on equal footing as data (Heath, 2006). For this research, Glaser's perspective on literature review was upheld, with a brief review performed at the beginning of research to ensure that this was a novel study. Some areas of literature were examined as the theory was built with confidence that it had reached a developed stage which wouldn't be biased with literature as it emerged. Therefore, literature will be woven into the discussion of the Integrated Theoretical Model of Consumer Empowerment in HIE, as shown in Figure 13 . Each of the three selective codes: Fairness in HIE, Consumer Commitment and Engagement in HIE, and Consumer Confidence in HIE will be described.

Fairness in HIE

Fairness in HIE involves Legal and Institutional Provisions (Law, Policy, and Enforcement) and Social Justice (Equity, Consumer Responsibility, Situational Context, Rights, and Information Privacy). Fairness is "necessary because it is often difficult for employees to evaluate whether a leader's request

is legitimate. To resolve this dilemma, employees often use the apparent fairness of the authority as an indicator of whether the authority's orders are legitimate" (Konovsky, 2000, p. 490). Fairness, then, could be said to determine whether consumers feel that HIE is legitimate based on how HIE is implemented by the 'powers that be"—the healthcare stakeholders. Therefore, Fairness is determined by interactions and conflict in relationships between consumers and healthcare stakeholders. The notion of pseudo-Fairness which "superficially resembles fair behavior, but it stems from tactical motives unrelated to Fairness" (Leventhal et al, 1980) is reflected when healthcare stakeholders superficially utilize the term consumer empowerment as a persuasive strategy, for example, to adopt HIE technology.

Fairness in HIE consists of Legal and Institutional Provisions for the Enforcement of Law and organizational Policy. This is to ensure that HIE does not allow for sensitive health information to be disclosed in an unauthorized manner and that Law and Policy will be enforced in the event of violations. In their study of individuals' concerns about the privacy practices of organizations, Smith and colleagues (1996) state that "perceptions of organizational privacy policies and practices may be related to levels of employee concern and levels of concern may also be associated with different cultural values and regulatory structures." They suggest that if managers take a proactive stance to create

organization privacy policies, they could reduce the possibility that "onerous regulatory options will be pursued" (Smith et al, 1996, p. 190-191). In HIE, this translates to healthcare providers creating privacy policies which are compliant with federal and state law, but also generating practices which support those policies. These practices are what the data sources referred to as Processes (which is included in the dimension for Consumer Confidence in HIE). Social justice reflects the belief systems of actors, which are affected by larger social structures such as the legal system, laws, and practices (Pozzuto, 2006, p. 89), which are encompassed in the Legal and Institutional Provisions facet of Fairness in HIE.

Therefore, a related component of Fairness in HIE is Social Justice. This is a complex dimension of Consumer Empowerment in HIE. "Believing in the importance of justice is one thing. Acting justly is another, and saying what justice really is, is quite another" (Pozzuto, 2006, p. 83). Social Justice is a term often used in the fields of social work and education. Social justice has been stated to be a "social process of inquiry, critique, sustenance, and creation" (Pozzuto, 2006, p. 95). It can be said that social justice "results from purposeful actions that then form the fabric of the social world. . .which is informed by Berger and Luckman's seminal work, *The Social Construction of Reality"* (Pozzuto, 2006, p. 90). Berger and Luckman's work suggests that the

reality of an individual is socially constructed by institutions (such as the government) through the internalization of roles, socialization processes, and a "social stock of knowledge" (1967, p. 43). Therefore, a consumer's perspective of HIE is determined by this social construction of reality. Each consumer's reality is based on Equitable treatment and distribution of resources and their Situational Contexts.

Justice in terms of Consumer Empowerment in HIE emerged through the codes for Equity, Situational Contexts, and Rights to HIE and Information Privacy. In healthcare, it can be said that "more equitable a society is—the more fairly its wealth, land, housing, access to health care and education, other basic resources and services are distributed—the healthier its people are likely to be. In short, there is a strong correlation between health and social equity" (Werner & Saunders, 1997, p. 108). Thus, if HIE is to become a widely adopted technology and process for exchanging information, patients should have Equitable access to HIE resources, for example, kiosks in physician offices which allow access to their medical records. One facet of Equity is the Digital Divide, which is "the patterns of unequal access to information technology based on income, race, ethnicity, gender, age, and geography" (Mossberger et al, 2003, p. 1). In their study on the Digital Divide, Mossberger and colleagues found that their respondents were willing to go to a variety of places to have Internet

access, including recreation centers, senior centers, churches, schools, and public libraries. Those who were most willing to use public access were the affluent, better educated and African American groups. This is ironic, because those who typically need public access are those who are in the low-income, less-educated brackets. While people who have no home computers were most likely to use public access at libraries, they were also less likely to use that access than those who have home computers. Even more disconcerting is that older and low-income individuals were found to be less willing to use public access sites, and less willing to learn new skills (Mossberger et al, 2003). Equity in HIE resources can increase as HIE technology is adopted, for example, PHRs can cost a monthly fee to maintain, and not everyone will have computer access, funds, or motivation to learn and use this technology due to these factors.

Different Situational Contexts also present concerns of Social Justice. Smith and his colleagues' study on organizational privacy policies suggested that "concerns may be context-sensitive based on either the type of information being managed or the type of organization collecting and storing the data" (2006, p. 190) Thus, as suggested by this study of consumer empowerment in HIE, there are Situational Contexts in which patients may have stigmatizing conditions or chronic illnesses. "Security violations could lead to blaming patients for their health conditions—like the cardiac patient who, . . .has been smoking and eating

excessively for the last 20 years—resulting in differential treatment for them. Or violations could result in marketplace prejudice—by a health insurer, for example, who learns that someone applying for coverage has HIV" (Gearon, 2007, p. 9). In these cases, consumers want to ensure that there is Equity in how they are able to provide and give access to sensitive information. The point is that, for example, patients with cancer or substance abuse history may be treated differently if employers or insurance companies find that they have conditions that are socially constructed as stigmatizing. They may hold different views of Information Privacy than consumers who do not have stigmatizing conditions.

"The word 'privacy' does not appear in the Constitution of the United States, yet most people in the U.S. consider it to be one of their fundamental rights, one from which many of their other constitutionally protected rights derive" (Nakra, 2001, p. 278). According to Malhotra and colleagues, "information privacy concerns refer to an individual's subjective views of fairness within the context of information privacy" and are based on how an individual defines Justice (2004, p. 337). Nakra (2001) suggests that with technological advances and the sharing of information online, "consumers are losing their right to privacy one mouse-click at a time" (p. 278). Nakra (2001) states that customer Privacy Rights are fundamental human Rights. One such Right is to review and correct

data, and to be informed of fair information practices through opt in and opt out decisions.

From the social contract theory perspective, Information Privacy concerns can be mediated through “an equitable exchange involving a long-term relationship. . .” in which Fairness may be perceived when the “consumer is granted control over the information and the consumer is informed about the firm’s intended use of the information” (Malhotra, 2004, p. 338). Beyond the concepts of inequity in HIE resources, the digital divide, and Situational Contexts, there is a process of inquiry which is encompassed in the dimension of Consumer Commitment and Engagement in HIE.

Associated with the Right to Information Privacy and to review and correct data, is the Consumer Responsibility to understand how to use HIE to manage their health records. For example, if consumers manage their own PHRs, they also need to be Responsible to keep the medications and treatments up-to-date so that the information is accurate. “When does an individual’s responsibility begin and when does it end” in the realm of sharing information (Wang et al, 1998)? Consumers will vary in their levels of interest and motivation to be Responsible for the delegation of medical record management from the provider. In their research on the public services and the consumer, Gilliatt and colleagues state that “many aspects of the move to the ‘responsible consumer’ are already

evident in the market for private sector goods where it is often left to the consumer to help assemble the product, to take a part in its production, and thereby feel empowered" (Gilliatt et al, 2000, p. 336). In the context of HIE, this means that the movement to 'empower consumers' through the use of technology such as PHRs means that they will be Responsible in understanding and selecting a PHR, for example, and being able to take part in the management and sharing of their medical records.

Fairness in HIE is the culmination of Legal and Institutional Provisions and Social Justice incorporated into HIE efforts. Organizational Policy and Laws should be Enforced to help build a sense of Fairness in HIE. There should be Equity in resources and an understanding of the different Situational Contexts for HIE to occur in a Fair environment. Rights to Information Privacy should be considered when building HIE technology and forming processes to support the secure exchange of health information. Associated with those Rights is the Responsibility of the Consumer to understand and use HIE appropriately. To do so requires a level of Commitment and Engagement in HIE.

Consumer Commitment and Engagement in HIE

Consumer Commitment and Engagement entails a level of Consumer Understanding (Awareness, Understanding, Education, Literacy, Sources of Information) of HIE and Consumer Action (Participation, Communication,

Consumer Voice) to Participate in and learn about HIE. Commitment has been studied in organizational research in terms of employee and employer commitment to one another. The "concept of empowerment has emerged as the key means of mobilising and maintaining worker commitment" (Collins, 1999, p. 210). Empowerment of employees has been suggested in research to build commitment (Cunningham & Hyman, 1999). However, it can be proposed that in healthcare, a patient must be committed to participating in her own healthcare to become empowered. In her article on *Health: A Personal Commitment*, Parse states that "when one becomes reflectively aware of the meaning of a situation, a light is shed on the personal commitment. One can choose to stay with the commitment or change the commitment by changing the meaning of a situation, thus, changing health" (1990, p. 138). A consumer can Act to change the meaning of a situation by using Sources of Information to Become Educated. Participation and Communication through the Consumer Voice and through seeking Sources of Information are important to move the consumer through the process of being Aware to becoming Educated in HIE. How Committed a consumer is to HIE can determine how Engaged she wants to be within Participation and Communication efforts.

According to Dewey, "to learn to be human is to develop through the give-and-take of communication" (Dewey, 1984, p. 154). Consumers may

Communicate with others about HIE and perhaps through this Communication, they may feel a sense of growth as an individual. Within this notion, according to Dewey, who was a noted researcher in the field of education, is a sense of democracy. "The process of democracy—that is the including of varying voices, each with their own significance—to reach a common conclusion of the reweaving of the social fabric" (Pozzuto, 2006, p. 93). It is important to examine how new information which evolves with innovations such as HIE will be distributed so that consumers are able to commit and become Engaged in their healthcare if they wish.

For a person to seek information, they first need a level of Awareness to decide what information they need to find. For example, Malhotra and colleagues state that awareness is a passive dimension of information privacy, and it refers to the degree to which a consumer is concerned about [her] awareness of organizational information privacy practices" (2004, p. 339) This suggests that Awareness is passively discovered by a healthcare consumer. An example may be hearing a story on the news about a case of identity theft made possible by retrieving information on a stolen laptop, and gaining an Awareness that laptops may not be secure. After a consumer becomes Aware of a concern of interest in HIE, they may then decide to seek further information on it. Because HIE is relatively new, Awareness is at a basic, foundational level.

In order for a consumer to navigate the health system, they should have a level of Literacy, which encompasses several facets: Functional Literacy, Technical Literacy, Information Literacy, and Health Literacy. In the United States, one in five adults is functionally illiterate (they cannot perform reading tasks above the level of first or second grade) (Kingsley, 2008, p. 12). The struggle to perform everyday tasks is apparent. "Adults without basic literacy skills find ways to get by. . . .Before the advent of the information age, the hustle was easier. . . [It meant] asking for directions instead of relying of maps and committing to memory the shapes of words absolutely essential for work." People who have a low level of literacy are very aware of their lack of education. They watch others to learn: "I learn by watching people. . . If I can see what you're doing, then I can do it" Robert Wilson, who is working with Reading Connections, says. Toni Cordell, patient advocate, stated, "I've spent my life facing challenge after challenge and attempting to gain enough knowledge so I can feel normal" (Cordell, 2007, pg. 331).

Technical literacy is the "ability to operate a computerized or electronic device," such as using a mouse, typing, and giving instructions to the computer (Mossberger et al, 2003, p. 40). Due to the pervasiveness of computers and the Internet, especially within the innovation of HIE, it may become necessary for consumers to also be Technically Literate to navigate the health system.

Functional literacy is “a prerequisite for information literacy” (Mossberger et al, 2003, p. 42). Information literacy is “the ability to recognize when information is needed and to locate, evaluate, and use effectively the needed information while adhering to principles of social responsibility” (Mossberger et al, 2003, p. 42) This is closely related to health literacy, which is necessary to be able to navigate the health system. Health Literacy is the “degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions” (North Carolina Institute of Medicine, 2007, p. 11).

Because of the push to adopt HIE technology such as PHRs, it will be important for consumers to understand this technology, policies, and the processes which support it. Part of the emerging health system seems to be towards PHRs, online EHRs (Patient Portals), and different types of consent management options. Therefore, consumers need to become Aware and Educated in the area of what I propose to be HIE Literacy. A member of the AHIC group stated that

> as I think we looked into the health literacy issues back in I guess late March and April, the literature is very weak and there's really not a whole lot known around HIT and health literacy in combination so that strikes me as an area that might help with a little bit more definition and maybe prioritizing some of the important things we need to be mindful with, you know, people with low [inaudible] or certain ethnicities. You know, we can say that

> certainly these tools need to be sensitive to a variety of people and a variety of different backgrounds and what we do we really need to do to make it happen.

There is a “transience” nature to a consumer’s healthcare, with patients often moving from one family doctor to different physicians, and utilizing different physicians due to the managed care system as they change jobs. Because of this, it will be important to involve consumers in the management of their own records so that physicians have a comprehensive knowledge of their health history (Roth, 1994). Therefore, consumers need to be HIE Literate. However, patients may have “little access to information and knowledge that can help them participate in, let alone guide, their own care” (Tang & Lansky, 2005, p. 1290).

Berger and Luckman state that “knowledge is socially distributed” (1967, p. 16) and that there is a “social stock of knowledge” (p. 43) which “consists of recipes for the mastery of routine problems.” The Digital Divide can create an inequitable social distribution of the stock of knowledge pertaining to HIE. Granted, there are other Sources of Information, but the Internet offers a variety of sources within one access point (rather than going to the library to search for books or magazines, or asking the physician). In order to increase one’s individual stock of knowledge, they need to become more Educated. In relation to healthcare in general, Roth states that “consumers often have limited knowledge and technical expertise with which to identify and evaluate medical

conditions, problems, and treatments" (1994, p. 117). Since HIE is a new phenomena, it is logical to propose that consumers have limited knowledge of HIE. If consumers want to become more Educated in HIE, they need to utilize different Sources of Information to do so.

Roth found that social marketing campaigns could be helpful to support consumer involvement in health care (1994). "Although research has shown that information access and awareness can affect health behavior positively, many social marketing programs produce weak communication and behavioral effects" (Roth, 1994, p. 117). The Sources of Information primarily used by the respondents in his interviews were physicians, print media (newspapers and magazines), word-of-mouth (friends, relatives), books and articles, TV and radio, and other medical professionals. The reasons that consumers used these Sources of Information were to have peace of mind, better quality of life, support, control, and empowerment. While this study is in the context of treatment and healthcare, it can be asked if these would also hold true for HIE. To support empowerment, consumers should have information that is "personally relevant in both content and delivery" (Roth, 1994, p. 125). It was found by Roth that more complicated information should be Communicated by physicians. The best setting for Communication between the provider and patient is one where the provider is "accessible, attentive, personable, non-authoritative, and candid. In

this environment, the consumer can relate information to their own knowledge and experiences, thereby gaining the confidence to engage in self-motivated or directed action. By becoming empowered, consumers view health care issues as Active participants. . . ." (Roth, 1994, p. 126).

Communication involves seeking Sources of Information to become Educated, as well as using one's Voice to talk with providers and to Participate in HIE efforts. The concept of Voice is often found in educational literature. In a study on student self-empowerment, Maldonado and colleagues found that students saw "education as a process of developing one's own voice" (2005, p. 622). The idea of Voice in this study of HIE has also been at the individual level. Whether asking questions of the physician or Participating in HIE efforts, an individual Consumer's Voice is important to Communication and becoming Educated in HIE. In summary, Commitment and Engagement in HIE can be supported by an initial level of Awareness and Consumer Action to Participate and Communicate using the Consumer Voice to become Educated and HIE Literate using a variety of Sources of Information.

Consumer Confidence in HIE

Consumer Confidence involves Consumer Assurance (Level of Distrust, Information Integrity, and Accountability), Conventions in HIE (Processes, Standardization, Data Elements, Information Sources), Technology Mediation

(Information Security, Value of the PHR), Consent Management (Access, Control, Information Ownership). Research from the marketing, management, and psychology literature can be applied to Consumer Confidence in HIE.

Technology is a mediating factor in Consumer Confidence in HIE since information can be gathered, stored, and transmitted electronically. Although new HIE technology such as EHRs and PHRs are being developed and offered in the marketplace, there hasn't been widespread adoption of either (Ball et al, 2007). Wang and colleagues state in their study on Internet marketing that "one of the major impediments against full-scale integration of the Internet marketplace with modern business is the lack of confidence Internet consumers have in the newly developed marketing machinery. The most crucial issue that Internet consumers have identified is fear and distrust regarding loss of personal privacy associated with the emerging electronic commerce marketplace" (Wang et al, 1998).

According to a survey by the California Health Care Foundation, the respondents felt that they could use PHR Technology to help manage their healthcare (Lakewood Research, 2006). For consumers to adopt HIE technology such as PHRs, it is critical for them to understand what could be potential Value of PHRs (or HIE technology in general). The Value of the PHR to the respondents included improving quality of care, avoid medical errors, improving

communication between the physician and patient (and being able to see what their providers write down), and avoiding repeated procedures. Many respondents were concerned about their medical Information Security, though. Approximately 80% of the respondents said they were worried about their information being disclosed for identity theft purposes and 77% were very concerned about marketing firms having Access to the information. Technology such as PHRs can help to improve Information Security, and can provide give Control and Access features for authorized disclosure of the information.

It is necessary to provide Information Security through Technology Mediation to increase the level of Consumer Confidence in HIE. One of the biggest concerns about HIE technology such as PHRs is that of Information Security and the distributed nature of health information (California Health Care Foundation, 2007). Mercuri (2005) states that when providing Security assurances, transparency and trust are inherently intertwined concepts. One of the Seven Patient and Consumer Principles endorsed by the Markle Foundation's Personal Health Technology Council is that "electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information" (Ball et al, 2007, p. 78). Information Security can be provided through Technology such as encryption and middleware which contains

rules for Access and Control (Mercuri, 2005, Gearon, 2007, Evered & Bogeholz, 2004).

Consent Management is the capability for a person to Control the Access to one's medical record. Consent Management topics have often fallen under the realm of database security in literature (Smith et al, 1996) because it often relies on technological features to provide Access and Control to records. According to social contract theory and the foundations of procedural justice, individuals perceive procedures as fair when they have Control of the procedures (Malhotra et al, 2004, p. 338). Control of one's medical record is important in the perspective of social contract theory, since there is a level of risk involved with sharing one's health information. Consent Management features can provide Access and Control of HIE procedures. "Privacy, which depends on security systems, involves complex social issues that concern our right to know what information about is collected, who might see it, and how it might be used" (Karat, 2006, p. 56). Because an electronically stored medical record holds sensitive information and could be vulnerable to unauthorized disclosure, it is important that Security measures are in place as well as Consent Management features such as Opt In and Opt Out choices. The Opt Out model is for a consumer to be informed by a physician that their records will be automatically shared with other providers unless the patient states that they do not want to do

so (they must choose to Opt Out of the HIE). The Opt In model states that the records will not be shared unless the patient chooses to do so (the patient chooses to Opt In to HIE) (Watson & Halamka, 2006). However, these are broad consent features. For example, what if a patient wants his cardiologist to see the entire primary care doctor's record, but doesn't want him to Access his behavioral health records? There are technological options which do exist for granular level control such as at the file, record, or field levels, but these haven't been incorporated into HIE technology (Smith et al, 1996).

Another aspect of Consent Management was being able to Access audit trails. If the consumer wants to view who has Accessed which portions of her medical record, audit trails could be utilized. "Since decision making often relies on collections of data that must be accurate and reliable, additional Confidence is typically provided through redundancy and auditability" (Mercuri, 2005, p. 16). Providing levels of Consent Management for Access and Control can provide Confidence, but could also be confusing to consumers if they don't have a high level of HIE Literacy.

Control of the medical record often implies Ownership of the record. Ownership of the information has not been determined, and could be challenged through the use of HIE technology. "Fundamental to PHRs is the notion that health information is a personal commodity rather than an institutional asset"

(Gearon, 2007, p. 9). Therefore, by the shifting of information Control from the physician to the patient, "PHRs could shift the balance of power between clinicians and patients" (Gearon, 2007, p. 9). If the consumer is to gain more Control of the medical record, there needs to be Conventions in HIE to make it more consistent and Standardized across entities.

Conventions in HIE are important to support Consumer Confidence in HIE. If Processes, Data Elements, and Standards are utilized to provide consistency throughout different healthcare providers, the consumer may then be more Confident because she knows what to expect from each provider's office. Because of the many Information Sources which could populate medical records for a comprehensive history, the need for consistency is high.

Information Sources which could be used to populate HIE technology such as EHRs and PHRs could be from the patients, the providers' offices, pharmacists, insurance companies, and caregivers. However, with the capability to transmit and Access Information from various Sources comes the possibility that the information may be Accessed in an inappropriate way. Other entities such as marketing firms, employers, or the government may seek Access to this data for advertising purposes, insurance coverage purposes, or biosurveillance purposes. With data mining techniques, privacy protection involves more than protecting individual Data Elements. General Data Elements in the PHR include

patient demographics, medications, decision logics from a person's insurance plan, a consumer's rules regarding privacy and access to information, medical procedures, and diagnoses. (Gearon, 2007, p. 7). "Data aggregation techniques are changing the playing field. Research demonstrates that minimal amounts of information believed to be anonymous can be used to personally identify an individual" (Karat et al, 2007). Therefore, "the balancing of beneficial uses of data sources with the privacy rights of individuals is truly one of the most challenging public policy issues of the information age" (Wang et al, 1998, p. 69).

Having interoperable, portable records is fundamental to the concept of HIE. The sharing of medical information is expected to improve the health of patients. "Data integration, systems interoperability, and standards implementation are additional issues that must be resolved for PHRs to achieve their full potential. In particular, standards development must focus on . . . user authentication, communication to and from EMR systems, mapping medical jargon to consumer-oriented information and terms, and the enabling of consumer controlled access" (Krohn, 2007, p. 22). The "holy grail of the PHR is the ability to collect and collate data from all points of the healthcare compass. . This data typically comes in different formats and using different vocabularies, and it must be normalized within a single, common nomenclature" (Krohn, 2007,

p. 22). Since healthcare providers have disparate systems to gather, store and transmit medical information, having Standards for these Processes is important. There should be Standards for storing the Data Elements, transmitting, and sharing the information. Data Elements could be named differently at each location and in PHR software, depending on the health record system utilized. For the patient to understand the HIE process and even the types of information stored in HIE technology, it is important that they be Standardized. One way of Standardization was through the use of certification. Organizations such as National Institute of Standards and Technology (NIST) and Health Information Technology Standards Panel (HITSP) have been integral to the creation of standards for HIE (Mercuri, 2005). Even beyond Standardization of technology, there should be Standardization of Processes, for example, the Process of providing consent and signing privacy policies should be consistent across providers or should be a one-time decision which could be stored in the rules for the medical record. These Conventions can provide consistency in expectations so that Consumer Confidence is improved.

Consumer Assurance can be gained through Levels of Trust/Distrust, Information Integrity, and a sense of Accountability in HIE. “Trust comes into play when there is risk” (Cook, 2005, p. 9). How does a consumer know which healthcare stakeholders she will trust? The decision to trust can be based on

'likely' trustworthiness (Cook, 2005). Trust is the "subjective expression of one actor's expectations regarding the behavior of another actor" (Baba, 1999, p. 333). Because HIE is relatively new, consumers will need to base their expectations for Trust on prior similar circumstances. In general, consumers tend to trust their providers because they have an expert stock of knowledge which allows them to treat patients. "If we trust in the competence of another, we expect that he or she has the requisite knowledge, skill, and personal characteristics needed to perform an action in a way that results in a positive outcome for us (Baba, 1999, p. 333). Fudiciary Trust suggests that consumers would expect providers to behave in a way that enables appropriate healthcare treatment, while avoiding opportunism. For example, they would be expected not to sell medical records to marketing companies. Because consumers may believe the healthcare provider is competent, this may lead to an expectation that the provider will perform his duties with Fudiciary Trust, meaning that he will protect our sensitive health information. An example would be that a consumer Trusts her healthcare provider because she thinks he is competent, therefore she believes that the provider will implement technology that will Secure her medical information. Distrust can be thought of as the opposite on a continuum of Trust; the expectation that the provider will behave in a way that does not protect the consumer. Distrust can "consume a great deal of energy. . . " impeding adaptive

behavior (Baba, 1999, p. 334). While the literature suggests that "it is possible for the party at risk to therefore choose not to participate," healthcare may be a different situation. A patient may choose to avoid care, certainly, but in this study, it was found that a certain Level of Distrust was appropriate. It often seemed that some of the consumers felt a Level of Distrust, therefore, they were more likely to ask questions and seek additional information to mitigate their feelings of risk. What Level of Distrust is appropriate is another topic of interest for future research because it was out of the scope for this study. The term Level of Distrust is utilized for the code because it signifies that there may be a Level of Distrust which is appropriate for consumers to be Committed and Engaged in their healthcare, as well.

Consumers also need to feel that the information in their medical records is accurate. In their study on information privacy, Smith and colleagues state that "many individuals believe that organizations are not taking enough steps to minimize problems from errors in personal data" (1996, p. 173). Because there could be many Information Sources for the PHR, the consumer should be aware that the information could be incorrect (whether out-of-date, accidentally entered incorrectly, or possibly the inclusion of medical information from another patient with a similar name). Providers also worry about the possible legal liabilities and who will be Accountable for making medical decisions based on incorrect

information. This is also where audit trails will be effective. The patient or provider could examine the audit trail to determine from path the data were generated. The audit trail could also provide a method for the consumer to enter notes which don't edit the original record, but allow the consumer an avenue for corrections.

In summary, ensuring Security and the Value of the PHR to consumers while providing Conventions in HIE and Consent Management features will support improved Consumer Confidence in HIE. A sense of Accountability, Information Integrity, and Level of Distrust will form a level of Consumer Assurance, and, in turn, improved Consumer Confidence. Figure 13 is a diagram showing the results of the coding process which provide the dimensions of consumer empowerment in HIE from the data sources utilized. Figure 14 displays the parsimonious integrated model of consumer empowerment in HIE.

Figure 14 shows the final parsimonious model for the three main dimensions of Consumer Empowerment in HIE as found from the three data sources analyzed in this study. Consumers need to feel a sense of Commitment and Engagement in HIE to have an understanding about HIE topics and to act upon their needs to learn more from different sources of information as they are motivated. The participants in this study also felt that Legal and Institutional Provisions and Social Justice components would provide a sense of Fairness in

HIE. This is important so that consumers feel their sensitive medical information is protected in a Fair manner and that they are treated Equitably in regards to access to HIE technology. The third facet of Consumer Empowerment in HIE is the necessity to build Consumer Confidence in HIE through levels of Trust, Assurance of Information Integrity and Standards for gathering, storing, and transmitting medical information. The Value of the PHRs and HIE in general should be communicated to consumers for adoption and use of HIE. When consumers feel that their medical information is Secure using HIE Technology and Processes, this builds Confidence to use HIE.

It is important to note that these are proposed Dimensions of Consumer Empowerment in HIE according to the data sources analyzed in this study. What is not known is at what level these different Dimensions can interact to produce a landscape that is ideally conducive to build Consumer Empowerment. While all of these Dimensions were found to be important to the data sources in this study, some Dimensions may be more important than others depending on the individual consumer and her background and experiences. It also should be noted that it may not be necessary for all of these dimensions to occur for consumer empowerment to be experienced. The multitude of possible interactions of these dimensions and their relationships may affect empowerment at different levels.

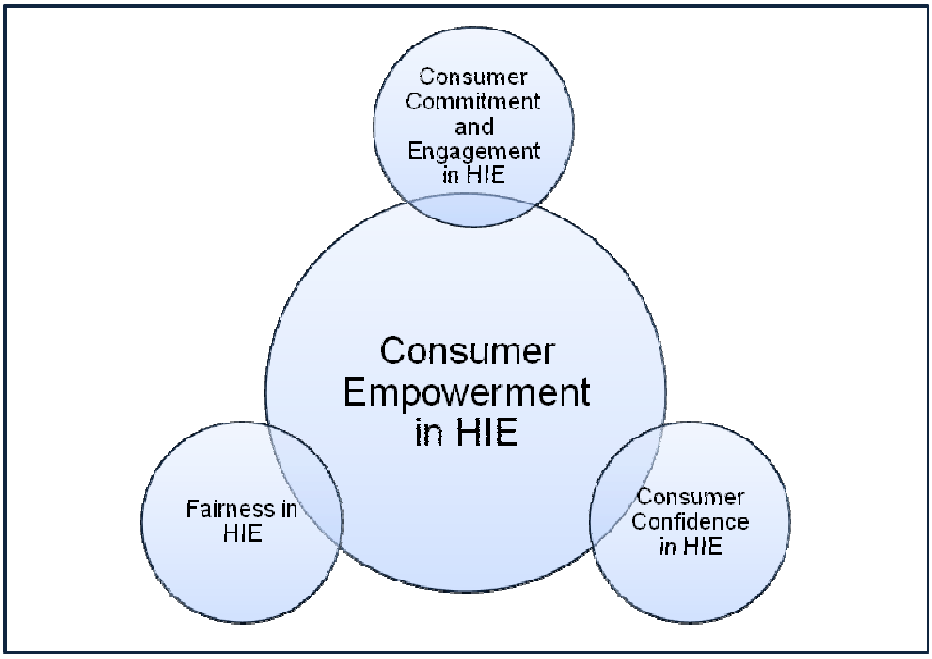

Figure 14. Parsimonious Integrated Theoretical Model for the Dimensions of Consumer Empowerment in HIE

Another point to be made is that just because a consumer feels empowered does not mean that she will make the best decisions regarding her information. For example, a patient may choose to withhold information from the physician and it may be critical for the physician to know that information to make an appropriate medical decision. This can happen without electronic medical records, but in the case that many providers may access the same information, and inaccurate or incomplete information could be multiplied. In the next

chapter, I will investigate ways that Consumer Empowerment may be achieved in HIE, with the understanding that it is a very complex phenomena.

CHAPTER X

PROCESS MODEL OF CONSUMER EMPOWERMENT IN HIE

(HOW TO ACHIEVE CONSUMER EMPOWERMENT IN HIE)

The two research questions for this study are: "What are the dimensions of consumer empowerment in Health Information Exchange?" and "How can consumer empowerment be achieved in Health Information Exchange?" Examining the dimensions of consumer empowerment is the first research question provided the foundation for understanding consumer empowerment in HIE and supplied concepts for which to suggest ways that consumers could be empowered in HIE. To apply the findings of the first research question, ways that consumer empowerment can be achieved in HIE will be examined.

The working definition utilized for empowerment for this study was:

> an intentional, ongoing process, centered in the local community, involving mutual respect, critical reflection, caring and group participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources (Rappaport, 1995, p. 802)

It was found that empowerment in HIE has many of these same facets, including that empowerment is a process, often taking place in the community through participation to gain access to the valuable resource of medical records. There does need to be a level of mutual respect and critical reflection in which to provide a foundation for empowerment. This means that consumers will be able to provide a voice which will be heard by healthcare stakeholders. As part of the resources mentioned in this working definition, there is no mention of literacy or education, both of which are critical for building a mutual understanding of HIE.

Because "a grounded substantive theory that corresponds closely to the realities of an area will make sense and be understandable to the people working in the substantive area" (Glaser & Strauss, 1967), this chapter will examine how consumer empowerment can be achieved in HIE. Based primarily on the activities of CACHI and AHIC, and supporting information from previous literature, recommendations will be made which could facilitate achieving consumer empowerment in HIE. These will be discussed within the context of the theoretical coding generated from each data source.

"These concepts provide a necessary bridge between the theoretical thinking of sociologists and the practical thinking of people concerned with" HIE so that both may understand and apply theory (Glaser & Strauss, 1967, p. 241). The concepts presented "must be abstract enough to make [the researcher's]

theory a general guide to multi-conditional, every changing daily situations. . . being general enough to be applicable to the whole picture" (Glaser & Strauss, 1967, p. 242). Before discussing these approaches to achieve Consumer Empowerment in HIE, it is important to note the role of literature review in the grounded theory approach.

Through the process of conducting a study using the grounded theory methodology, "a grounded theorist starts with gathering focused data and stays close to the data, while developing concepts that synthesize and explain the collected data" (Charmaz, 2003, p. 82). The methods utilized in this study closely follows this approach. I chose to follow the data to discover emerging theory, and have presented the findings directly from the three data sources. Previous literature was not examined in-depth until later in the process so that it did not bias the findings from the emerging data It is important to note that literature review is not required as part of the grounded theory approach (Charmaz, 2003), but it can be used as a source of data in which to incorporate with the resulting theory. In essence, the literature is considered data which can be presented to support the proposed theory.

From incorporating the findings from the three data sources and prior literature for a synergistic approach, ways to achieve consumer empowerment in HIE will be recommended. The following is not an all-inclusive discussion of

recommendations, but rather a presentation of ideas which seem to evolve from emerging theory to enable consumer empowerment in HIE to be achieved. An important note to make is that there are levels of empowerment. It is difficult to "know enough about measuring or maintaining empowerment" (Perkins, 1995, p. 790). Therefore, the following are recommendations which may enable relative changes or improvements of empowerment, but this is determined by the individual and the situation in which one is immersed.

Consumer Commitment and Engagement in HIE

Because all three data sources relayed the importance of being able to understand and be active in HIE, Consumer Commitment and Engagement in HIE is examined in much more detail than the other areas (Fairness and Consumer Confidence). There is a large amount of supporting literature in this area, which will be examined in depth. Literature from sociology, education, psychology, and other fields will be woven through the discussion.

In their briefings papers on ways to spur consumer engagement in health care, AcademyHealth and Robert Wood Johnson Foundation state that "Consumer Engagement must not be viewed as a silver bullet; consumers have neither the power nor the skills to transform health care systems on their own. . . Change will require a joint effort on the part of consumers, providers, payers, insurers and policy-makers" (2007, website). Because HIE is based on the

foundation that providers traditionally control medical records, it will be a transformation for both providers and consumers to understand how HIE can be appropriately used to improve the quality of health.

Through an initial level of Awareness, the consumer can learn more about HIE by Communicating and Participating (asking questions of the provider or searching the Internet). As the consumer becomes more Educated, she may find that there are other areas of HIE which she was not aware of (such as encryption or levels of consent management) and then decide to Communicate and Participate more to be better Educated. The Role of Consumer Understanding is discussed first.

The Role of Functional Literacy and Health Literacy

Because the state group NCHICA CACHI is a data source from North Carolina, statistics and stories will be presented from this state, as an example for comparison. In the North Carolina town in which I was born, High Point, and the nearby town in which I was raised, Thomasville, there are many people who work in the furniture industry. In her article on "Why Can't High Point Read," Amy Kingsley writes about illiteracy in High Point and how laying off of factory workers has affected employees who are trying to find another job and integrate into society in a way with which they may be unfamiliar. "[The furniture industry] has a lot of uneducated people in the workforce, and deliberately so, because it

serves the businessmen to keep the labor force uneducated" (King, 2008, p. 13) Part of the problem is that parents who have low literacy skills tend to have few resources and a lower expectation level for how their children perform in school. To provide resources for those with low levels of literacy, Reading Connections was set up in Greensboro, North Carolina to offer literacy services. Of their High Point clients, around 40% are non-native English speakers. One quarter of the High Point population is functionally illiterate, and in United States one in five adults is functionally illiterate (they cannot perform reading tasks above the level of first or second grade) (Kingsley, 2008, p. 12). The struggle to perform everyday tasks is apparent.

"Adults without basic literacy skills find ways to get by. . . .Before the advent of the information age, the hustle was easier. . . [It meant] asking for directions instead of relying of maps and committing to memory the shapes of words absolutely essential for work." People who have a low level of literacy are very aware of their lack of education. They watch others to learn: "I learn by watching people. . . If I can see what you're doing, then I can do it" Robert Wilson, who is working with Reading Connections, says (King, 2008, p. 14). Toni Cordell, patient advocate, stated, "I've spent my life facing challenge after challenge and attempting to gain enough knowledge so I can feel normal"

(Cordell, 2007, pg. 331). This level of Awareness will be important as a motivation for one to begin the process to become health literate.

Health Literacy is the "degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate health decisions" (North Carolina Institute of Medicine, 2007, p. 11). Because the health care system in the United States focuses on emerging HIE technology and processes to share information, the role of the patient can be that of managing their own health, resulting in a patient-centered system. With this focus, "patient activation" and "patient empowerment" are phrases used to describe the new patient-centered system (North Carolina Institute of Medicine, 2007, p. 11). In essence, health literacy will be more important for consumers to understand how to navigate HIE to manage their own healthcare. Health literacy includes the capability to navigate the healthcare system, including communicating with healthcare providers and their staff, how to read prescription labels, and understanding physician's recommendations and options for treatment and care. "In North Carolina, approximately 34% of the population performs at or below the basic health literacy skill levels and would have difficulty understanding basic health information" (North Carolina Institute of Medicine, 2007, p. 16). On average, those who have lower health literacy scores are those who are over 65 years old, in certain minority groups such as

Black and Hispanic, and have lower educational achievement (less than or some high school).

"Inadequate knowledge is a barrier to appropriate self-care" (North Carolina Institute of Medicine, 2007, p. 23) and can hinder efforts to communicate with health care providers. It is important that patients understand the healthcare system so that they can better manage their own care. Part of the emerging health system seems to be towards PHRs, online EHRs, and different types of consent management options. This is an addition to the traditional concept of Health Literacy. The concept of Health Literacy was discussed in the AHIC meetings as a necessary component of consumer empowerment. The following is an excerpt from a discussion at the June 16, 2006 meeting (the names of the speakers were not identified in the transcription, and it was difficult to determine who the members were from the audio file):

> Member 1: . . . But in terms of what you think our main contribution could be to try to better on an organized deliberative efforts around consumer education in this area, would it be better identifying the health literacy issues and how to act on them-- you think that there's a role for this group to consider based upon what others are doing-- how we might be able to encourage better public private deliberation around consumer education, or is there a unique role for any given organization that should be recognized to create more of an organized process? I mean as I think we looked into the health literacy issues back in I guess late March and April, the literature is very weak and there's really not a whole lot known around HIT and health literacy in combination so that strikes me as an area that might help with a little bit more definition and maybe prioritizing some of the important things we need to be mindful with, you know, people with low [inaudible] or certain ethnicities. You

> know, we can say that certainly these tools need to be sensitive to a variety of people and a variety of different backgrounds and what we do we really need to do to make it happen.
>
> Member 2: Well, for me it's not really that much different from all the efforts that have been going on related to written documents and also, you know, CMS I think has had tremendous amount of experience with trying to deal with, you know, all of the health literacy issues with its web site and communications to Medicaid beneficiaries, so I just I do really struggle.

What is important to note from this conversation is Member 1's statement that the literature is very weak around the concept of HIT (Health Information Technology) and health literacy. This is an area ripe for future research because understanding how one's medical information can be managed, accessed and disclosed will be necessary for consumers to understand as HIE is integrated into the health system on a wider scale. Another member of AHIC from the National Health Council stated during the same meeting that

> We here, again, I think have done quite a bit of research as well as others done research on what the core components, how people perceive them. We deal with health literacy all the time and our role is to reach out to health educate and create awareness among patients and consumers and to learn from them what works and doesn't and what they value and how they use it and then create the message to go out and create hopefully at the graduate level a real patient/consumer demand for these.

Therefore, basic functional literacy, health literacy, and perhaps HIE literacy will be core for consumers to become Aware and Educated in HIE.

It should be emphasized that through the process to become Aware and Educated, it is the choice of the consumer whether to become more educated in HIE. This choice can be affected by factors such as level of resources, lack of interest, type of illnesses or health status. It is expected that consumers will be comfortable at different levels on the continuum of being Educated; furthermore, it is expected that not all consumers will have the resources to become more Educated. "The four pillars of empowerment are awareness, freedom, choice, and responsibility. Awareness is an aid to making informed choices. People are both free to choose how they will live their lives and responsible for their choices" (Feste & Anderson, 1995). This should be incorporated into any interpretations from the Process to become Educated in HIE, since the assumption emphasized for the purpose of this study is that consumers will want to become more Educated.

Defining Awareness and Educated

Awareness, according to the Encarta World English Dictionary[37] can mean "noticing or realizing something**:** knowing that something exists because you notice it or realize that it is happening." In the context of HIE, Awareness is an initial level of discovery. For example, when someone reads a newspaper story

[37] See www.encarta.msn.com

about a disclosure of medical information because a laptop was stolen, she may become Aware that a situation like that could occur. Perhaps before reading the story she did not know that health providers used laptops to carry medical information; therefore, she became Aware of that after reading the story.

For the purposes of this study, the terms Educated and Informed are used interchangeably. According to the Encarta World English Dictionary educated means “knowledgeable: having the benefit of experience or knowledge” and being informed means “having enough information to understand something**:** having sufficient and sufficiently reliable information or knowledge to be able to understand a subject or situation and make appropriate judgments or decisions regarding it.” When using the terms Educated or Informed for this study, the meaning reflects someone having enough reliable knowledge or experience to be able to understand a subject or situation to make appropriate decisions.

There are different levels and contexts of Education. For example, a consumer may be more Educated in the area of privacy rights than in technological security. As the consumer learns more and external forces such as new regulations occur, there is a cyclical effect in which the consumer becomes aware of new issues or perspectives and then may communicate and participate to learn more. One concern with this approach is whether all people will

communicate and participate at the same level. There are certainly differences in motivations and resources that people have which result in some consumers being more aware and educated than others. While this is an important consideration, it involves a much deeper level of discussion than is feasible for the purposes and scope of this study and will not be examined in more depth at this point.

Because HIE is relatively new, Awareness is at a basic, foundational level. For example, the Everyday Consumers had not generally heard of PHRs, EHRs, or the NHIN, which are basic technologies involved in HIE Consumers will travel through a process to become Educated at a level in which they are comfortable. As they move from this basic level of Awareness, they will learn more about other HIE concepts which they were not previously aware (such as what PHRs are). Consumers also form a sense of self-Awareness based on their feelings about HIE. "We believe that the purpose of health education is to provide a combination of knowledge, skills, and a heightened self-awareness regarding values and needs, so that patients can define and achieve their own goals" (Feste & Anderson, 1995, p. 140). So, Awareness, then is a combination of self-Awareness and one's feelings and an Awareness of HIE components (such as technology or the processes involved in HIE). Thus, a consumer can choose

whether to follow-up on their Awareness to act, by, for example, seeking information.

HIE is a complicated issue. During her presentation to the NCHICA CACHI group in 2007, Dr. Peel from Patient Privacy Rights stated that there is a wide variety of people involved in these HIE issues, and even the experts aren't as knowledgeable as one may think. As she suggests, it is a very complex issue: "IT people don't get healthcare. Healthcare reporters don't understand the issues; legal reporters don't know about health or IT. This issue sits right in the middle. Conceptually, very few people have all of the pieces. It's hard to talk about policy at a level people can understand." While not everyone will be Educated in all aspects of HIE, what is important is the use of Communication and Participation between healthcare stakeholders and consumers to become comfortable with their personal level of Awareness and Education in HIE.

As a speaker to CACHI stated "no one knows all of the parts" of HIE components, it is also critical that policymakers, vendors, insurance companies, and other stakeholders become educated in HIE. This will provide an environment for communication that is open and accurate upon which to build a trusting relationship for HIE to evolve.

From both literature and from the three data sources in this study, consumers trust their providers over any other stakeholder (AHIC, April 25th

Transcript; e-Health Initiative, May 29, 2007) to be a Source of Information about HIE. Therefore, there will be a need to ensure that providers are appropriately informed about HIE and have educational materials available to give patients. As stated in a 2005 National Consumer Health Privacy Survey, "consumers and their advocates should gain a deeper understanding of privacy rights—and act on them by only selecting providers or health insurers that actively support personal privacy rights, or by insisting that adequate security measures be present in any new ehealth initiatives put forth by industry" (California HealthCare Foundation, 2005, p. 5). Providers should have education on HIE incorporated into their medical education continuum (Marion et al, 2007), and through required workshops.

HIE Literacy can be incorporated into Adult Basic Education and in the general high school curriculum in the United States (Diehl, 2007). The faith community in North Carolina has also been engaged, for example, the Black Churches United for Better Health project[38] and Project Direct[39] have been involved in health literacy and communication efforts. This was a suggestion by

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[38] North Carolina Department of Health and Human Services. *Black Churches United for Better Health: 5 A Day Project*. Retrieved May 2008 at http://www.communityhealth.dhhs.state.nc.us/PAN/fiveaday.htm

[39] North Carolina Diabetes Prevention and Control Branch. Retrieved May 2008 at http://www.ncdiabetes.org/programs/projectDirect/index.asp

one of the CACHI members, as well, because the church is an important social structure which provides support and community leadership (Plescia & Newton-Ward, 2007). In these groups, consumers can share information and stories, therefore creating a common framework for discussion. These "overlearned stories communicated through . . . .mass-media or social institutions" are known as dominant cultural narratives and provide a common ground for groups of people to discuss their concerns (Rappaport, 1995, p. 803). Public-campaigns can be utilized, such as AHRQ's new website for Health Literacy and Cultural Competency.[40] Figure 15 shows a billboard advertising the AHRQ website. It is interesting that the AHRQ website covers areas of Health Literacy and Cultural Competence. For patients who are of different ethnicities and speak English as a second language, it can be especially difficult to navigate the United States' health system. Imagine not being able to speak or read English very well and being presented with privacy policies written at the 17th grade level to read. Martinez (2007) says that the immigrant population in North Carolina grew 58% within 2000-2005, and projects such as the University of North Carolina at

[40] United States Department of Health and Human Services. Agency for Healthcare Research and Quality. *Health Literacy and Cultural Competency*. Retrieved May 2008 at http://www.ahrq.gov/browse/hlitix.htm.

Greensboro Center for New North Carolinians Immigrant Health ACCESS Project can aid those residents to acclimate into the health system.

Figure 15. AHRQ Public-Campaign Billboard as seen in Thomasville, North Carolina

"Public messages that link information technology, privacy, and resulting health benefits are not reaching consumers effectively—particularly the chronically ill, aging consumers, ethnic minority groups, and the less educated segments of the U.S. population" (California HealthCare Foundation, 2005, p. 5). Because providers are the trusted source of information about HIE, there are

ways that they can help support the achievement of consumer empowerment in HIE. Providers have

> missed an opportunity to reassure a concerned public about the health care privacy safeguards that are in place. Health care organizations should simplify and enhance their communications to consumers about organizational measures taken to increase the privacy and security of consumers' PHI—understanding that the resulting consumer loyalty will exceed the costs of taking on this educational burden. Employers should bolster internal practices to maintain information privacy, and, like health plans, should ensure they communicate this adherence to privacy regulations to employees (California HealthCare Foundation, 2005, p. 5).

Suggestions for appropriate communications from the North Carolina Institute of Medicine include (2007, p. 31-37):

1. Providers should avoid using jargon and complicated medical technology; use plain language.
2. Providers should be aware at the speed in which they speak and emphasize key messages.
3. Providers should use visual materials.
4. Providers should use techniques such as teach-back in which they ask the patient to repeat the information the provider just stated. The lets the provider know whether the patient understood and retained the information.
5. Motivate consumers to take action, such as using the AskMe method (developed by the Partnership for Clear Health Communication) which encourages patients to ask the following three questions: What is my main problem? What should I do about this problem? Why is this important to me?
6. Utilize group medical visits where appropriate. These are conducted by a team, including a nurse, physician, and other providers.
7. Emphasize the use of community health workers to provide information to consumers.

8. Provide written information which is at an appropriate reading level, includes images, and sufficient labels, white space and margins. The reading level should be appropriate since "almost half of the population reads at or below an eighth grade reading level" (pg. 34)
9. Communication with patients should emphasize desired behaviors rather than medical facts.
10. Ensure that communication is culturally sensitive.
11. Use a variety of tools, such as web sites, videotapes, DVDs, audiotapes, and CDs.

The consent process should also be clear to the patient, with appropriate readability for policies and forms. A recent study found that the Iowa Health System consent forms were written at 17th grade level (college) or above (Abrams, 2007).

It is difficult to achieve Consumer Understanding without some level of Consumer Action. "Exercise of observation, is, then, one condition of transformation of impulse into a purpose" (Dewey, 1938, p. 79). Recall the statement of Robert Wilson, who was functionally illiterate when he said he learned by watching others (King, 2008). In this way, Robert is participating in his own education by observing. "But observation alone is not enough. We have to understand the significance of what we see, hear, and touch" (Dewey, 1938, p. 79) If I am in the line at the doctor's office and see the patient in front of me signing the consent forms, feeling that it is the right thing to do by signing the forms when it is my turn is not a true form of understanding. The purpose of the action is to sign the form, but there is no understanding behind what I have

signed if I do not read the form. Futhermore, if I read the form and sign it, although I don't understand some of the terminology, there is a lack of education.

> Questions move people along their journey through life. 'Answers' stop the process of searching. Philosophically, then, we come to understand that questions bring lessons and that lessons can change or be expanded. Unlike answers, lessons do not stop progress but rather serve as points of momentary respite as people continue their journey (Feste & Anderson, 1995, p. 142).

Communication such as asking questions is important to find those answers, which only temporarily stop the process of searching. Often, asking questions prompts additional questions, thus the cyclical nature of becoming Educated. In the context of our situation, a consumer may ask the receptionist what the form means to become educated. However, as Toni Cordell mentioned from her experience, often the receptionist will say she doesn't understand the forms either. Freire suggests the importance of Communication when he states "Only through Communication can human life hold meaning" (1970, p. 77). Ironically, it seemed that after CACHI members were willing to Communicate and reveal their weaknesses in what they didn't understand by asking questions, they felt more empowered. Thus, questions bring lessons. So, as part of being empowered, one would need to be comfortable in revealing those weaknesses and in taking action to correct the weakness (by looking for more information, for example) and turning the weaknesses into opportunities for lessons. These

statements highlights two points: that there are different levels of Education through increased Participation and Communication and that providers and other healthcare stakeholders also need to participate in the process of HIE Education so that they can better inform their patients.

Consumer Voice should be incorporated in a meaningful way in HIE initiatives. This could be the consumer voice of people similar to those in CACHI or even Everyday Consumers. The integration of both voices can provide a comprehensive voice. The consumer voice are sometimes “small voices with limited access to the public legitimation” (Rappaport, 1995, p. 799) such as that of Toni Cordell. But she had the courage to become a patient advocate so that she could provide others similar to her (with low levels of literacy) with legitimation through sharing her stories. “The goals of empowerment are enhanced when people discover, or create and give voice to, a collective narrative that sustains their own personal life story in positive ways” (Rappaport, 1995, p. 796). Consumer Voice should be more than token, and, as one of the speakers to the CACHI group stated, “should be on equal footing” as the others involved in HIE initiatives, such as vendors and insurance companies. Instead of using the term consumer empowerment because it seems to be a trend in the “empowerment social agenda” (Rappaport, 1995, p. 801), it should be used to represent a true quest to involve the consumer perspective into HIE initiatives.

"People often find their unique inner strength when they connect with stories that reflect what they value and believe" (Feste & Anderson, 1995, p.142). For the members of CACHI, this was important. One member felt that the discussions they had increased his level of understanding and made him feel more comfortable since all members experienced the same types of problems in HIE and shared their own lack of knowledge in some areas of HIE. The North Carolina Institute of Medicine suggests group medical visits, which "foster group discussion and information sharing. In a group setting, patients may get answers to questions they did not think of themselves or were too embarrassed to ask" (2007, p. 33). Empowerment is:

> at once a personal and group process. It is part of a process of building collective self-confidence. This is needed for people to shed the feelings of powerlessness and resignation which result, at least in part, from the lack of skills and confidence required to change their condition. Frequently this confidence is forged in a common struggle.(Werner & Sanders, 1997, p. 131).

Communication and Participation can be seen at different levels. It can be passive (such as listening to a speaker) or more active (searching for information on the Internet and asking questions of the provider). While it is ideal to have consumers participate in HIE initiatives such as AHIC or CACHI, representatives of those groups may be appropriate. It is a difference between individual empowerment and organizational empowerment. While the CACHI group feels

empowered by their efforts, the goal is to ultimately empower individual consumers who may be unable to participate in such efforts. "It may be more accurate to think of Participation as a cause and effect of empowerment" (Perkins, 1995, p. 768). Groups such as CACHI are "interventions that "act" small and locally, even as they "think" more globally, are most effective" (Weick, 1984). This view is called the "collectivist" classification of empowerment (Wilkinson, 1997). "Recognizing the importance of such [grassroots] popular participation is a key to successful health care initiatives" (Werner & Sanders, 1997, p. 129).

One of the problems that the members of CACHI experienced was in the difficulty to find members that could Participate consistently. Inherent in the process of being able to Commit time to the group was that the person had the capability to take time from work to Participate. The Executive Director of NCHICA felt that this was a particular challenge of the council, "The biggest challenge is building the membership of the Council and balancing the need to obtain input from the Council with the understanding that these are unpaid volunteers." Even those who could take time from work still experienced work responsibilities which prevented them from attending some of the meetings. As stated by a CACHI member, "the problem is to reach out and get people involved with time commitment to come" suggests that consumers who work hourly jobs

would experience difficulty getting time from work than those at higher-paying salaried jobs. This creates a disparity in the types of people who could participate. One solution for this is for groups such as CACHI to hold town hall or focus group discussions at the locations convenient to the consumers, such as libraries or coffee shops.[41] This results in a more collaborative approach and relies on CACHI reaching out to others for voice and Participation.

"The ideal aim of education is creation of power and self-control" (Dewey, 1938, p. 75), and has "long been used for the purpose of promoting equal opportunity and empowerment, especially to compensate for poverty, disability, and other disadvantages" (Perkins, 1995, p. 775). As consumers learn more about HIE and are placed in situations where they experience HIE, they should become more educated. Therefore, Education is a cyclical process, which should be a collaboration between healthcare stakeholders and providers, which was mentioned by a member of AHIC who was affiliated with the Medical Group Management Association:

> . . . . that you think about the effectiveness of a PHR, it's really going to be a tandem between the patient and the provider, and I think what we have to do is develop a workplan which would not only educate the provider on PHR, the technical side of it, but also

[41] At the writing of this paper, NCHICA is holding town hall meetings to gain input from a variety of stakeholders.

> the philosophical side, how can this improve the care they deliver to patients, what are they going to expect from patients as we walk through the door. . . . .So I think outreach materials that we could develop that could be given out to medical specialty societies, to government agencies that are working with both type community health centers, Indian health services and all those folks, the more consistent the message I think probably the better for providers (6-19-2006).

Werner and Sanders (1997) discuss Education in the same perspective of Paulo Freire (1970). It is noted that these authors wrote in the realms of childhood survival and the advocacy of peasants and urban laborers (respectively). Their writings reflect a notion of social change that is on a larger and more global scale of oppression and social inequity than that of HIE. However, their concepts of Education as being vital to the process of social change is also applicable to HIE. According to Werner and Sanders, "A more empowering approach is to help people improve their understanding of health problems and build on their skills for dealing with them" (1997, p. 130).

Having a variety of Sources of Information upon which to build a stock of knowledge can be important. Roth (1994) found that social marketing campaigns can be helpful to support consumer involvement in health care. The Sources of Information primarily used by the respondents in his interviews were physicians, print media (newspapers and magazines), word-of-mouth (friends, relatives), books and articles, TV and radio, and other medical professionals. To support empowerment, consumers should have information that is "personally

relevant in both content and delivery" (Roth, 1994, p. 125). It was found by Roth (1994) that more complicated information should be Communicated by physicians. The best setting for Communication between the provider and patient is one where the provider is "accessible, attentive, personable, non-authoritative, and candid. In this environment, the consumer can relate information to their own knowledge and experiences, thereby gaining the confidence to engage in self-motivated or directed action. By becoming empowered, consumers view health care issues as Active participants. . . ." (Roth, 1994, p. 126). The capability of a consumer to learn through group discussions, whether with family members, friends, or with groups such as CACHI, is important. However, it is the collaborative efforts, such as CACHI and AHIC which can "create fundamental change" (Werner & Sanders, 1997, p. 130) geared towards providing consumer voice in HIE efforts and to ultimately help inform individual consumers. "In this guided awareness-raising process. . .the group moves from discussion of problems, to analysis of the problems' underlying social causes, and then to collective action to remove those causes. . . After a pause for reflection, the sequence is repeated" (Werner & Sanders, 1997, p. 130). Although in HIE, it may not be feasible to expect groups such as CACHI to "remove the underlying social causes" of inequity and lack of empowerment in HIE, they may be able to bring light to those issues.

This cycle of Education continues and is iterative because, as a consumer learns more about HIE, she becomes more aware of facets she did not previously know about, and then she may decide to learn more about HIE. It is important to understand that it does take a level of commitment on the consumer's part to make the decision to become more educated. Reflection and dialectical thought are also important to the cyclical process. After a consumer becomes Aware of HIE concepts (such as consent management options), she may choose to reflect upon what she has become Aware of and then determine if she wants to take further action and perhaps become more Educated on that topic. Freire considers this process to be "committed involvement" (1970, p. 69). However, it remains that not all consumers have the resources or interest to become fully educated in HIE, and this is where actions on the part of the providers will be important to reach out to the consumer for mutual understanding.

CACHI sought several ways in which to support Consumer Commitment and Engagement in HIE. The wanted to become more Educated so that they could provide an informed Voice, and they wanted to help Educate other consumers. Several important events occurred during the course of CACHI meetings (even after data collection ceased in January 2008) which seemed to

empower the consumers on the council. These are discussed in more detail in Appendix G.

During the course of time, the consumers began to realize that they didn't fully understand HIE, although they were educated in healthcare and/or information technology. This realization seemed to result in a yearning for more information and action to be taken to make a difference in HIE initiatives. They found information from various Sources such as presenters, the Internet, and collaboration with other groups such as HISPC. They felt that their own council members should become more Educated to be able to provide a Consumer voice in HIE efforts, and they had speakers who gave presentations at the meetings. As a group, CACHI was able to be Engaged through Participation in HIE efforts to provide a Consumer Voice in the design of HIE technology, processes, and policy (throughout the meetings). The council has representation on the NC Governance Council and the NCHICA NHIN Project, Phase II, and provides feedback on these projects. One of the CACHI members attended the HISPC Privacy and Security Solutions National Conference to give a presentation on CACHI efforts. The purpose was to provide information to representatives of other states so that they could form similar consumer advisory councils.

The writing from this research was also incorporated into the HISPC Final Solutions Report and the Consumer Toolkit (HISPC, 2007). This is also a

foundational aspect of the grounded theory approach; the application of the theory to practice in a way that is "readily understandable by laymen concerned with this area [HIE]" (Glaser & Strauss, 1967, p. 237). "Relevance for grounded theorists means bringing tangible benefits to the experts" (Fernandez & Lehmann, 2005). In this case, the experts reading the Consumer Toolkit and the HISPC Final Solutions Report were those involved in the HISPC project who examined security and privacy concerns in HIE, and groups like CACHI who wanted to provide a voice to HIE initiatives.

To help Educate other consumers, CACHI gave input on a Consumer Toolkit and plan to create a Consumer's Guide to HIE in North Carolina, which will include HIE acronyms. This was suggested by CACHI members who attended the NCHICA Annual Conference, in response to the confusing terminology and jargon used in the presentations. CACHI also created a website[42] including information about the group, their minutes, agendas, and a page of Internet resources about HIE topics such as privacy, laws, and technology. The web site documents the evolving nature of the group, including minutes, agendas, speaker presentation slides, and a Resources page. However the group wanted to engage others proactively, rather than expect

[42] North Carolina Healthcare Information and Communications Alliance. Retrieved May 2008 at www.nchica.org/cachi/main.htm.

consumers to search out their web site. One member suggested that "We need outreach tools, beyond a web page; something more interactive. There is a limit to the time we can spend going out to reach consumers." It was agreed by council members that "it will take more than one strategy" to realize empowerment in HIE initiatives.

A variety of strategies were discussed, including education for the council members through speakers and the creation of the Resources web page, a glossary of healthcare IT terms and acronyms. Education and engagement of other consumers was another goal, including the possibility of town meetings, council members speaking to organizations in the community about HIE topics and creating surveys and a Consumer Toolkit. Town hall meetings were of interest to the council members, but again lack of resources was the issue for one member who said, "the audience is so diverse. Other states are doing town hall meetings. We don't have structure for that. We wouldn't know how to do that or how to make it happen." From these efforts it is hoped that Consumer Commitment and Engagement will aid in creating a satisfactory level of Consumer Empowerment in HIE.

Fairness in HIE

Fairness can be supported through Legal and Institutional Provisions (Law, Policy, and Enforcement) and considerations of Social Justice concerns

(Equity, Consumer Responsibility, Situational Context, Rights, Information Privacy). Fairness in HIE can be achieved by introducing organizational policy along with federal and state laws related to HIE. These laws and policies should be enforced so that a sense of Fairness in HIE is formed. Social Justice considerations for equal access to computers and HIE resources need to be incorporated into HIE efforts. Also, different Situational Contexts such as stigmatizing conditions and Information Privacy Rights should be integrated into HIE policy, regulation, technology and processes so that consumers feel their sensitive information is Fairly protected.

Laws such as HIPAA have been passed to allow for standards to transmit health information and to provide privacy policies. Organizations should adopt policies which incorporate state and federal privacy laws. HIE technology should include features which support legal provisions for privacy and security of health information. One of the goals of AHIC was to examine the policy issues and barriers which affect adoption of PHRs. The deliverables from the national HISPC project also described the barriers to health information exchange. One of the HISPC findings was that state and federal privacy policies should be reconciled. It was found that HIPAA is weaker than some state privacy laws and that stronger laws should be adopted and enforced (NC HISPC, 2007, *Privacy and Security Solutions*).

Policymakers should examine state and federal laws to determine which is more stringent and at what level they are comfortable protecting medical records and allowing secure HIE, while also providing strong enforcement, which is expected especially by the Everyday Consumers who were interviewed. "Political advocates should recognize that privacy issues are not a hurdle" (California HealthCare Foundation, 2005, p. 5), and should "speed the spread of health IT with increased funding and political support [including] addressing privacy issues by broadening the scope of federal protections and more vigorously enforce current federal laws" (California Healthcare Foundation, 2005, p. 5). It is often difficult to frame health IT issues for legislators. Legislators seem to understand these issues when framed in terms of improving healthcare, so it is wise to "turn the social policy problem into a personal story" (Perkins, 1995, p. 786) by integrating the voices of consumers such as those in CACHI or Toni Cordell. When seeking legislator help in forming health IT bills, it is important to set the agenda, provide "data on the dimensions and relative standing of the issue, the number of people affected, and the interests of those involved," with personal stories incorporated (Perkins, 1995, p. 786). To suggest specific policy, advocates should understand what variables are likely to affect the people to which the policy applies and suggest alternatives which are socially acceptable.

The CACHI group was able to provide feedback to a North Carolina legislator on a pending bill regarding health information trusts, which he felt was valuable. "Our current system is not sustainable. Two of the toughest issues are cost containment and shifting the population towards health maintenance and lifestyle changes," said the legislator. "In the coming months, I look forward to talking with this group about how consumers could be affected by proposed federal health policy changes. We've got to get back to quality care and affordability. We shouldn't lose that focus." The legislator also stated that NC CACHI offers helpful perspectives on health care and health IT topics because members evaluate topics from the standpoint of users of the system (NCHICA Website). This led him to meet with the group to discuss policy-related concerns with healthcare IT. "Laws and policies must give patients confidence that caregivers will heed not only the personal information in PHRs, but also patient preferences for treatment, such as life support" (Gearon, 2007, pg. 8). Deciding on how to provide Rights in these policies and laws can be based on socially constructed norms and expectations.

Social Justice in terms of Consumer Empowerment in HIE emerged from the data in the context of Equity, Situational Contexts, and Rights to HIE and Information Privacy. Because it does rely on norms of society in general, Social Justice can be difficult to achieve. Consumer advocacy organizations such as

Patient Privacy Rights should continue to represent consumers because group efforts provide a stronger Voice than individuals can. Consumers may not have the literacy levels, motivation, or money to access HIE resources (including the technology or resources for information). CACHI members were provided with economic funding to attend the NCHICA Annual conference. However, for everyday consumers, it is difficult to find time from work or even for the money for gas or travel to go to presentations or Participate in HIE efforts. These problems will not be solved any time soon in society, but consumer organizations, legislators, and HIE vendors should be Aware and consider these inequities in their work to implement HIE technology and associated policy.

The Digital Divide also needs to be addressed. States should also look toward ways such as e-NC Authority (North Carolinians online) to provide affordable and convenient methods to access technology so that they can participate in HIE, by accessing their providers' medical record portals and managing their own PHRs. Providers should also provide kiosks in their offices for patient access. Providers could also Communicate to patients the local areas for public access to the Internet so they will be Aware that other options are available. However, public access areas may be a security risk to sensitive medical information access, so consumers will need to be Educated on these

problems, as well. Perhaps public access sites could work with providers to Educate consumers on ways that the access points are kept secure.

AHIC examined the ways that needs of different populations of people could be incorporated into the features of PHRs through the inclusion of certain data elements and Privacy protections. For example, there should be granular levels of consent management so that substance abuse patients can disclose only the information that they feel is needed to specific providers. The AHIC members were also charged with considering the Privacy issues which result from the sharing of data through registration summaries and medication histories. There are a few different organizations which have compiled privacy principles upon which vendors can integrate in the HIE technology they develop. For the CACHI group, an aggregated list of these Principles was compiled so that they could guide their priorities. They also want to ensure that consumers are Educated in these Principles because they are closely aligned with what they feel are their Privacy Rights. What also needs to be communicated to consumers is that the implementation of HIE technology and increased consumer control is the associated Responsibility to understand and use HIE in an informed manner.

In summary, Fairness in HIE is subjective and based on societal expectations while enforced by policy and law. The Social Justice aspects of Fairness in HIE will be the most difficult to achieve because societal values are

complex and social change doesn't occur easily or naturally without the help of advocates or groups such as CACHI.

Consumer Confidence in HIE

Consumer Confidence can be provided through Technology Mediation (Information Security, Value of the PHR), Consumer Assurance (Level of Distrust, Accountability, Information Integrity), Conventions in HIE (Processes, Standardization, Data Elements, Information Sources), and Consent Management (Access, Control, and Information Ownership).

Technology plays a foundational role in the capability to provide HIE. Vendors should implement technology which has components of Value to the consumer, offers Information Security features, Consent Management controls, Standardized processes and means for gathering, transmitting, and storing medical information, and avenues to ensure that Information Integrity exists. The broad charge for AHIC was to make a recommendation to AHIC so that within one year, a pre-populated, consumer-directed and secure electronic registration summary is available to targeted populations. To examine the current technology and what could be offered of value to consumers, AHIC members developed a matrix for the Inventory of Tools in which features of the current tools can be assessed based on affordability, consumer friendliness, and longitudinal effectiveness. This allowed them to see what the current landscape

included so that they could build from there and incorporate features of value to consumers. They also discussed ways in which the market can be urged to adopt these tools and incorporate features that the consumer will value.

It is not clear that PHRs and HIE technology will provide clarity to the notion of Information Ownership. If the consumer has total Control over other people's Access to the medical record, who Owns the data? There are questions such as this that need to be investigated within HIE efforts. If the patient's PHR is updated with information from the provider's EHR system, who owns that information and can it then be forwarded to other providers? AHIC members felt that consumers should be able to Control their medical records and provide different Consent Management levels. For example, a patient should be able to disclose only information that they think is necessary to specific providers. Therefore, clear granular-level Consent Management options should be offered so that patients can Control the Access to their medical records as they feel appropriate.

Standards and benchmarks should be provided for which consumers can become confident in their expectations of HIE. Providing standard forms, policies, and ways to store and transfer medical information will enable the consumer to become more confident in what to expect with HIE. Certifications for HIE technology, such as PHRs will allow consumers to examine the product

for features that they prefer, and be confident that certain security features are included. As Wathieu et al (2002) suggested, consumers can be more confident when they are able to look at what other consumers' choices are, and can periodically determine if they have made the correct decision as they use HIE. This would entail web sites, perhaps, or brochures at the provider's office, which compare HIE products, such as PHRs in a simple, matrix-style format that is easy to understand. Vendors of this technology could employ 'wizards' on their websites to help the consumer determine what type of PHR they prefer. This is similar to consumers going online to purchase computers based on their needs (graphics, games, business needs, etc.).

As part of the recommendations to the main AHIC community, the AHIC Consumer Empowerment Group found that they needed to determine the data sources for the data elements which would populate the registration summary and medication history. They wanted to ensure that they were consistent and used common standards across HIE technologies so that the records were portable and interoperable. This capability to use portable and interoperable PHRs can support Consumer Confidence in HIE.

In summary, because there are many facets of consumer empowerment in HIE, the strategies to address and achieve consumer empowerment in HIE are varied. There is no ranking or ordering of which ways may be more helpful or

important than others, although educational components were mentioned frequently. It will take time to determine how the future of HIE will evolve, and thus how best to achieve consumer empowerment within this context.

CHAPTER XI

CONCLUSIONS

This study applied the grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1990) to the data from three sources at the federal, state, and individual levels in the U.S. to examine the dimensions of consumer empowerment in HIE. The result is a theoretical model that shows how the dimensions and components relate to each other. The main dimensions of Consumer Empowerment in HIE which emerged from these data sources were Fairness in HIE, Consumer Confidence in HIE, and Consumer Commitment and Engagement in HIE. Fairness in HIE can be achieved through legal and institutional provisions and a sense of social justice. To feel a level of Consumer Confidence, consumers should be provided with appropriate consent management, conventions in HIE, consumer assurance, and technology mediation. Finally, Consumer Commitment and Engagement can be realized through Consumer Understanding and Consumer Action.

Ways that Consumer Empowerment in HIE could be achieved were proposed in a previous chapter. The examples provided for achieving Consumer

Empowerment in HIE are examples of what emerged from the data sources. The suggestions provided are not all-inclusive, and other ways are possible. The avenues to reach a level of Consumer Empowerment in HIE are discussed within the realm of the three dimensions discovered from the data sources. Consumer Commitment and Engagement in HIE can be realized through efforts such as educational programs offered by providers, since consumers trust providers more than other stakeholders. Educational information should be clear and at an appropriate reading level. Patients can choose to be committed at a variety of levels, from being encouraged to ask more questions of their providers to providing input in HIE initiatives.

To realize a sense of Fairness in HIE, state and federal privacy laws should be reconciled so that consumers feel they are fair in protecting their information privacy rights and in the enforcement of such laws. If the effect of HIE on those with stigmatizing conditions is considered within HIE efforts, consumers may feel that their needs have been addressed fairly. Also, there needs to be equity in resources for HIE, such as Internet access to medical records. Therefore, more avenues for access to medical records, such as kiosks in providers' offices, should be implemented.

Consumer Confidence in HIE could be attained through granular consent management features and audit trails which reveal who has accessed one's

medical record. Lastly, patients are not likely to accept HIE unless they see a value to their healthcare. In the data from AHIC, it was suggested that the value of PHRs be communicated to consumers so that they are more confident in adopting this technology.

The concept of consumer empowerment is a complex one and a methodical and rigorous analysis of the data helped identify the multifaceted dimensions of consumer empowerment and its relationships in the HIE context. What is not known is at what level these different Dimensions can interact to produce a landscape that is ideally conducive to build Consumer Empowerment. While all of these Dimensions were found to be important to the data sources in this study, some Dimensions may be more important than others depending on the individual consumer and her background and experiences. It also should be noted that it may not be necessary for all of these Dimensions to occur for consumer empowerment to be experienced. The multitude of possible interactions of these dimensions and their relationships may affect empowerment at different levels. The methods utilized to perform such a rigorous analysis provide credibility to the study.

Credibility of the Study

There are many ways in which the credibility of a grounded theory study can be ensured. The credibility is also referred to the trustworthiness of the

study. For this study, the following verification procedures were utilized: prolonged engagement/persistent observation, triangulation, member checking, and using rich, thick description where appropriate (Creswell, 1998).

Verification through prolonged engagement/persistent observation

The researcher was engaged in the Consumer Advisory Council on Health Information for 18 months (approximately 64 hours of meetings plus individual interviews with the council members). This should ensure that there is enough time spent with the participants to investigate the research questions. AHIC transcripts were analyzed until the data were saturated; this was approximately 18 hours of meeting time. The AHIC group moved more quickly through their process than CACHI because they already had a broad charge given to them and they had resources available that CACHI did not. Also, the AHIC group had to move quickly because their deliverables were due basically within a one-year time frame. The Everyday Consumers were interviewed until the data were saturated. Although the Everyday Consumer interviews revealed a basic knowledge of HIE, in order to capture additional facets, the researcher would need to help the consumers become more informed about HIE to be able to provide answers at a more detailed level.

Trustworthiness through rich, thick description

The best attempt was made to collect, transcribe, and communicate to the reader a rich, thick description of the contexts of the AHIC, CACHI, and the Everyday Consumers. Numerous quotes and stories were provided throughout the data analysis explanations to reveal how the theory emerged from the data.

Triangulation

Triangulation was achieved primarily by using different sources and methods. The sources of data allow for evidence to be confirmed or disconfirmed between the resulting coding for each group. The methods utilized were interviews, document analysis, and attending meetings. These various perspectives helped shed light on emerging themes for theory-building.

Member checking

Member checks were performed with the NCHICA CACHI members by periodically asking their verification on interpretations or any documents written for the Council. Follow-up interviews were also performed with some of the Everyday Consumers to reveal additional information if needed.

Clarifying Bias through Memoing

The researcher wrote memos to reflect upon emerging themes in the data as well as concerns or issues that arose regarding potential biases. These notes were used extensively in the analysis and write-up of the results.

One area of possible bias was coding three data sources and the importance of being aware that each data source should be coded independently of the others. The quotes for each data source were reviewed and analyzed independently of other data sources. Although the AHIC and CACHI data were analyzed prior to the Everyday Consumer data, there was some level of prior knowledge and perhaps bias in the everyday consumer data analysis. However, when generating codes from open coding, it was important to be aware of how the codes were worded according to the context of the interviewee's quotes. While some of the same terms were utilized in the everyday consumer data analysis as the AHIC and/or CACHI analysis, this is only because those terms were appearing in the same context within the everyday consumer analysis. As the data was coded for each of the sources, I was also aware that some of the concepts that emerged were not exactly used in the same context, and in these cases, code names were used that preserved the context from the everyday consumer data. So, while it is impossible to remove all researcher bias from the coding names, it was also possible to be aware of this bias and to appropriately code according to what emerged from the data while also being aware of some level of coding consistency between data sources.

Tie the study to existing literature

Previous literature was utilized to discuss the results of this study for both research questions. Literature from psychology, education, and marketing were woven into the discussions for the integrated theoretical model and the chapter on how to achieve consumer empowerment in HIE.

Limitations

The analysis and findings from this study have been within the perspectives of an individual researcher. While it is expected that someone else conducting the same study with the same sources would generate similar findings, interpretation entails a level of researcher bias, as in any study.

The data sources for this analysis were performed with a North Carolina Gathering group (CACHI), a United States federal effort, and Everyday Consumers from North Carolina. Therefore, the dimensions of consumer empowerment which are proposed (Confidence in HIE, Fairness in HIE, and Consumer Commitment and Engagement in HIE) were driven by data saturation of these sources. If additional transcripts from AHIC, for example had been analyzed, new dimensions may evolve. Sources outside of North Carolina would be helpful to examine, as well as other federal efforts, such as AHRQ and its

consumer website.[43] Also, the group of Everyday Consumers represented those who were not in healthcare or IT work. There are other groups (such as those with stigmatizing conditions, certain ethnicities, etc) which should be examined outside of the non-healthcare/non-IT group that was examined for this study. Examination of other data sources may also lead to other dimensions of Consumer Empowerment in HIE. The findings for this study are tied to the data which was analyzed, therefore, generalizability to other groups should be performed with caution.

People may not want to divulge personal information, especially when it pertains to behavioral health issues or other stigmatizing conditions such as AIDS. Cold-calling methods may not be as effective, thus using snowball sampling techniques are valuable. Inherently using such snowball techniques means that the data sources may be from similar groups of people. Therefore, gathering data sources in this manner can result in a less diverse group. For this study, consumer empowerment is a fairly recent concept in HIE and thus, increases the difficulty in both finding people to participate and in employing common terminology for discussion and interviewing purposes. It is suggested that, for future research purposes, more diverse groups should be utilized for

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[43] United States Department of Health and Human Services. Agency for Healthcare Research and Quality. *Consumers and Patients.* Retrieved May 2008 at http://www.ahrq.gov/consumer/.

study. For example, to gain the perspectives of Everyday Consumers, perhaps studies could be conducted through physician's offices or patient advocacy organizations.

During the course of the CACHI meetings, and also seen through the AHIC group, it is apparent that the limited involvement of consumers is through representatives of consumer groups. Although the CACHI group was often stated as being a diverse group, it could be argued that it was a fairly homogeneous group since the members were educated in healthcare and/or IT issues. The definition of consumer has many connotations, and while everyone has at some point been a consumer of healthcare, the members of CACHI have a broader background in HIE issues which give them a possible advantage for understanding security and privacy issues than consumers who do not work in healthcare or IT. Is it the same to have representatives or advocates of consumer groups, or do those from the 'everyday consumer' group have different perspectives which would be more valuable to include? From this research, it appears that the CACHI group has enough awareness of the issues and a level of education that enables them to gain a better understanding of HIE. Given this interpretation, it seemed that CACHI members were aware of their position as representatives of consumer populations. With both of these traits, CACHI allowed for the members to be at the heart of consumer empowerment in HIE by

giving them an avenue for voice and participation which made a difference. They have since met with a legislator from North Carolina and influenced his decisions on HIE legislation. This type of impact is at the core of consumer empowerment and can be achieved at this state level easier than at the individual, everyday consumer level. Although a consumer could email her legislators regarding HIE legislation, the capability for a group to influence opinion is more likely.

While the educated consumers of AHIC and especially CACHI are advantageous, there is an inherent inequity of participation levels for consumer engagement and involvement in HIE initiatives. The more educated, informed consumers are typically the people who are able to take time from work to participate. Whereas those consumers who work hourly jobs such as in manufacturing, retail, or food industry have difficulty in taking time off of work to participate in HIE initiatives.

A variety of possible solutions to this were discussed because engaging 'everyday consumers' by asking them to attend meetings in a boardroom in Raleigh may be daunting. It is likely that participating in a group with consumers who have been employed in security, privacy, or public health could be intimidating to the 'everyday consumer.' Even finding Everyday Consumers to participate in this study was difficult because discussing HIE can involve sensitive information. At the National HISPC meeting in Washington, DC in

November 2007, several of the states involved in the HISPC project created initiatives to involve the consumers such as educational videos and town hall meetings. Libraries are also another feasible meeting venue. This is an effort to reach out to consumers rather than burdening consumers to have a long-term commitment to be involved in an organization or initiative. In light of this, a feasible solution is to have advocates and 'informed' consumers representing 'everyday consumers' in long-term projects while reaching out to the 'everyday consumer' through town hall meetings and focus groups at local establishments such as coffee shops.

For future studies, organizations and groups which represent diverse groups should be approached for participation. Because there were many facets of Consumer Empowerment discovered in this study, it was difficult to integrate literature into every category and code in the final integrated model. The literature which seemed most pertinent was included in this study, and additional literature can be integrated within future research possibilities.

Implications for Research and Practice

As stated earlier, to the author's knowledge, there is no theory in literature that examines consumer empowerment in HIE. This study provides a theory of Consumer Empowerment in HIE. This study could serve as a foundation to stimulate more research in this important area to make HIE more efficient and

effective. It provides a foundation for future research to better understand or add to consumer empowerment in HIE. One could build on this research either using positivist or interpretive research. This theory can facilitate further research into better management and electronic sharing of information among participants in the healthcare system. Examples of future research topics are provided in the next section.

For practice, an improved understanding of the facets of consumer empowerment in HIE can influence other organizations at the local, state or federal level to consider these factors as they develop policies for HIE. Findings of this study may be useful to patient advocacy groups that bring together the providers, stakeholders, legislators, and patients to discuss HIE issues and determine where gaps and misconceptions exist. Understanding the dimensions of consumer empowerment ultimately can affect HIE policy and regulation, as well as how HIE technology is developed. ". . .A partnership among empowerment researchers, citizen/clients, and practitioner/administrators can improve the quality of the research, enhance its use, encourage greater public support for empowerment research, and ultimately improve empowerment applications in the community" (Perkins, 1995, p. 784).

The Implications for practice are numerous, and it is anticipated that this research will be utilized as part of practitioner responses to the calls for

consumer empowerment in HIE. The facets of consumer empowerment are not fully understood in the healthcare field. With studies such as this, an improved understanding of these facets and how to achieve consumer empowerment should be realized. A portion of the findings from this research study was used in both the Consumer Toolkit and the HISPC Final Solutions Report.

Future Research

Because this is an emerging area of research, there are many opportunities rich for further study. For example, although the dimension of consumer education was identified as part of consumer engagement, which methods work best to enable learning and education for HIE will be examined further. Likewise, it would be important to develop a process to increase consumer confidence in HIE if the objective is to get customer buy-in for HIE. While it is generally assumed that consumer empowerment is positive, what circumstances in HIE would entail consumer empowerment as a negative concept? There may be negative consequences of empowerment which have not been examined. Another question of interest is: What are the motivating factors for consumers to become empowered? Are there certain features of PHRs which would motivate consumers to see value? If so, these factors should be considered throughout the systems analysis and design process for PHR and HIE technology.

In general, future studies could be conducted to examine Consumer Empowerment in HIE in other federal efforts such as AHRQ (Agency for Healthcare Research and Quality) and in other states. Other groups outside of the categorization for non-healthcare and non-IT work experience should be investigated to see if the same theoretical concepts emerge. These groups could be different ethnic groups, groups of patients based on geographic location, or consumers with different stigmatizing conditions or literacy levels. Research in how the Digital Divide inequities would affect the adoption and use of HIE would be important. If patients are not provided with equitable access to HIE technology, it seems that they will be less likely to adopt the technology, and may not feel as empowered.

The following is a list of the researcher's possible future research studies.

1. The role of trust is of interest for future research. At what point does the level of distrust become a barrier to consumer empowerment in HIE? Does a level of distrust prompt a consumer to become engaged, and if so, under what circumstances?
2. A variety of perspectives from Davidson and Reardon's (2005) concept of Organizing Visions:
    a. Organizing Visions in Consumer Empowerment-- To examine different perspectives of providers, insurance companies, vendors, legislators, etc. with respect to consumer empowerment
    b. Organizing Visions in HIT Legislation--Analysis of HIT legal framework and how the testimonies of stakeholders has influenced HIT
    c. Organizing Visions in Consumer Advocacy Efforts in HIE

    d. The Influence of Collaborative Networks—An Examination of how grassroots efforts such as NCHICA have been able to influence change in the field
3. Investigation of AHIC Consumer Empowerment Group efforts since the first six months. This will provide a comprehensive examination of what goals they were able to achieve and the change toward AHIC's successor to a public/private collaborative organization.
4. Where does the role of rights and responsibilities fall within the realm of consumer empowerment in HIE? What is the associated responsibility with the right to control and access one's medical information?
5. Is the knowledge of HIE more difficult to gain/learn about than other types of knowledge? There is no current field of HIE Literacy, as mentioned in the AHIC meetings, and this requires further investigation to determine what methods to use to educate consumers and other healthcare stakeholders.
6. How does one move from being an unaware consumer to aware to informed? This process seems to be iterative, but there is research that could be utilized to explain this from the fields of Education, Psychology, and perhaps Sociology.
7. Knowledge Management in HIE Collaborative Efforts—An Examination of the notion of knowledge management within the HISPC and NCHICA projects; how is this information shared across projects for efficiency
8. How do you assess consumer empowerment efforts to see which activities work the best? While activities to educate and involve consumers are foundational to achieve consumer empowerment, how will the level of consumer empowerment be assessed to determine which methods are most appropriate?
9. Do "empowered consumers" reach an outcome that is more satisfactory? Wathieu et al (2002) suggest that when consumers make choices, they may sometimes have an "impoverished understanding of what they will enjoy more at the time of consumption" (p. 301). A consumer, for example, may originally want a PHR with many features, bells, and whistles. However, when the consumer actually uses the PHR, will she become annoyed with those additional features?
10. Examine global perspectives of consumer empowerment in HIE.
11. Case study of the implementation of a Patient Portal in a North Carolina physician's office to determine how patients use the Portal and what their perceptions are of consumer empowerment within this situation.

12. Examine previous literature such as Procedural Fairness, Equity, Social Exchange, Conflict theory can be incorporated into Consumer Empowerment in HIE.

Since consumer empowerment has been discussed by AHIC and CACHI as important to HIE efforts, it is important to investigate this phenomena in more detail. While it is still unclear how the technology will be implemented, it is critical for consumers to be empowered to ask questions and learn more about HIE technology and processes. It is also vital that consumer perspectives be incorporated in HIE initiatives, including technology features, security, policy and laws and the enforcement of those to protect the information privacy rights for individuals to feel confident that HIE has been implemented and utilized in a fair and equitable manner.

In conclusion, the three dimensions of Consumer Empowerment in HIE are Consumer Confidence in HIE, Consumer Fairness in HIE, and Consumer Commitment and Engagement in HIE. Ways to achieve Consumer Empowerment in HIE were examined. Because the technology, processes, and policies related to HIE are evolving rapidly, consumer empowerment should be incorporated into HIE efforts. It will be more difficult to integrate consumer empowerment facets after momentum has increased and technology and policy have been created. If consumer empowerment in HIE will ultimately improve the

quality of healthcare, it is vital that healthcare stakeholders be aware of these dimensions and possible ways that it could be achieved.

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APPENDIX A. CHARTER FOR NCHICA CONSUMER ADVISORY COUNCIL

NCHICA North Carolina Consumer Advisory Council on Health Information

NORTH CAROLINA CONSUMER ADVISORY COUNCIL ON HEALTH INFORMATION (CACHI)

CHARTER

PURPOSE: The purpose of the CACHI is to engage patients (health care consumers) in providing input and feedback on topics related to health information.

CACHI is a unique health care consumer group formed for grassroots input and participation to explore ideas and issues surrounding health information, such as privacy and electronic health records. CACHI will provide an opportunity to influence both state and national policy with regard to health care consumers' ideas and concerns about health information and technology, and will participate in trying to find a balance between a patient's need for privacy and the health care system's need for access to personal health information.

MEMBERSHIP: In order to achieve a diverse representation of North Carolina healthcare consumers, it is essential that the individuals chosen to be the members of CACHI have varied backgrounds including gender, age, race, education, geography, health status, recent experience with the health care system, etc. The 15-member panel will have rotating membership with five members serving 1-year terms, five serving 2-year terms, and five serving 3-year terms. CACHI will be supported and assisted by a group of experts who will serve on a resource panel.

RESPONSIBILITIES: CACHI members will be expected to attend monthly meetings. They should participate in CACHI activities in order to raise awareness on the affects of the health information technology to the consumer.

ACTIVITIES: Activities include participation in consumer focus groups and research studies to find ways to educate and empower North Carolina health care consumers.

MEETINGS: CACHI members will meet the third Thursday of each month from 2:30-4:30 at the NCHICA office (see directions on back). There may be opportunities for optional special topic meetings outside of the regular meetings.

NORTH CAROLINA HEALTHCARE INFORMATION & COMMUNICATIONS ALLIANCE, INC.
3200 Chapel Hill/Nelson Boulevard, Cape Fear Building, Suite 200
P.O. Box 13048, Research Triangle Park, NC 27709-3048
Voice: 919.558.9258 Fax: 919.558.2198 www.nchica.org

APPENDIX B. INITIAL CALL FOR PARTICIPATION FOR CACHI

The North Carolina Healthcare Information and Communications Alliance, Inc. (http://nchica.org) is seeking fifteen North Carolina volunteers to serve on a Consumer Advisory Council (CAC) that will assist with exploration of ideas and issues related to health information technology, such as privacy and electronic health records. The CAC will be supported and assisted by a group of NCHICA volunteers who will serve as a resource panel.

The Consumer Advisory Council will be selected from those who complete the online nomination form. We anticipate many more than fifteen nominations. NCHICA will review those who are nominated and select the final fifteen members. Council members will be chosen to represent North Carolina citizens across various criteria including gender, age, race, education, geography, health status, recent experience with the health care system, etc. Council members will be asked to represent the citizens of North Carolina (and not a particular organization). Plans are for appointment of a 15 member panel with 5 serving 1 year terms, 5 serving 2 year terms, and 5 serving 3 year terms. Once appointed, the group will identify their "rules of engagement" within the Council, and develop plans for meeting locations and agendas. Current plans are for the CAC to meet on a monthly basis with each meeting providing a presentation on a topic of interest as well as time to discuss relevant issues where the Council will help NCHICA explore health information technology issues from a consumer's perspective. The CAC will normally meet from 11am-3pm the 3rd Thursday of each month, with lunch provided. The first CAC meeting will be held on **August 28** (11-3, NCHICA offices in Research Triangle Park NC, lunch provided).

Some of the topics that are being considered for presentation to the Consumer Advisory Council include those bulleted below. The CAC may also identify topics of interest to them.

- What does it mean to be an informed healthcare consumer in this age of technology?
- Opt in / Opt out: Identify the effects of opting in or out of a health data exchange.
- Review the latest NC consumer opinion profile from recent privacy and security research surveys.
- Explore how information regarding stigmatizing conditions (such as HIV or alcoholism) is handled, used, and disclosed.

If you know of someone you would like to nominate, or have someone who might volunteer, please ask them to complete the online nomination form. The first 100 responders will be considered for Council membership. The nomination form can be completed at http://www.surveymonkey.com/s.asp?u=907342384346 and should be submitted not later than **Aug 6**, 2006. People who are nominated but are not selected for the 15 member council may still participate as a volunteer for the resource group to the CAC.

Questions or comments may be sent to me at the email address below. Thank you for your consideration and assistance in this important project.

W. Holt Anderson, Executive Director holt@nchica.org
North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA)
PO Box 13048
3200 Chapel Hill / Nelson Blvd. Suite 200 Cape Fear Building,
Research Triangle Park, NC 27709-3048

APPENDIX C. LETTER OF SUPPORT FROM NCHICA EXECUTIVE DIRECTOR, HOLT ANDERSON

NCHICA

North Carolina Healthcare Information and Communications Alliance, Inc.

November 19, 2006

To Whom It May Concern:

This letter is written in support of Sherrie Cannoy's dissertation research project to examine patient security and privacy perceptions of healthcare information that is collected, stored, and exchanged in electronic form. The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA – www.nchica.org) formed the North Carolina Consumer Advisory Council on Health Information Technology (CAC), which is a unique health care consumer group formed for grassroots input and participation to explore ideas and issues surrounding health information technology, such as privacy and electronic health records. The CAC will provide an opportunity to influence both state and national policy with regard to health care consumers' ideas and concerns about health information technology, and will participate in trying to find a balance between a patient's need for privacy and the health care system's need for access to personal health information.

The CAC is being formed with individuals who are representative of residents of North Carolina, and it is essential that the individuals chosen to be members have varied backgrounds, including gender, age, race, education, geography, health status, and experience with the health system. Our goal is to achieve a membership of 15 members for the CAC, with a supporting group of experts who will serve on a resource panel. The members will meet on a monthly basis at the NCHICA office in Research Triangle Park to discuss relevant issues and explore health information technology issues from a consumer's perspective. Some of the topics that are being considered as background presentations to the CAC include:

- What does it mean to be an informed healthcare consumer in this age of technology?
- Opt in / Opt out: Identify the effects of opting in or out of a health data exchange.
- Review the latest NC consumer opinion profile from recent privacy and security research surveys.
- Explore how information regarding stigmatizing conditions (such as HIV or alcoholism) is handled, used and disclosed.

CAC members will brainstorm and prioritize a list of consumer concerns and issues where health information technology is concerned. From that list, the group will identify specific projects and products of value. Some ideas being considered include conducting consumer focus groups and web surveys, conducting research on compliance and/or patient satisfaction and the impact of technology, analyzing issues of accuracy in patient-entered data, finding ways to advocate for a level technology playing field in rural and urban health care, exploring technology strategies to help resolve disparity in health care services, developing a white paper, generating a list of resources for patients, and finding practical ways to reach out and help educate and empower North Carolina health care consumers. Many additional ideas are expected as the group gains momentum.

The CAC has agreed to allow Sherrie Cannoy to utilize its discussions and efforts for data collection in her dissertation. They feel that her dissertation topic aligns well with the mission of the CAC and welcome her to sit in on the meetings as a project co-chair with Professor Linda Goodwin, RN, PhD from the Duke University School of Nursing. The Council understands that Sherrie will protect the confidentiality of the Council members as she states in the IRB Informed Consent form that each member will sign. The hope is that Sherrie's research will help to communicate the CAC's privacy and security concerns to policy makers and those involved in the health care community, as well as to help educate and empower North Carolina health care consumers. Please let me know if you have questions.

Sincerely,

Holt Anderson,
Executive Director, NCHICA

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APPENDIX D. LIST OF AHIC (AMERICAN HEALTHCARE INFORMATION COMMUNITY) CONSUMER EMPOWERMENT GROUP MEMBERS

- National Patient Advocate Foundation
- American Heart Association
- Office of the National Coordinator/Department of Health and Human Services (ONC/DHHS)
- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Medicare and Medicaid Services
- Surescripts
- Veterans Health Administration
- Markle Foundation
- Pfizer
- OCR/DHHS
- RxHub
- Tri-Service Infrastructure Management Program Office
- American Medical Association (AMA)
- Blue Cross Blue Shield Association
- Microsoft
- Office of Personnel Management
- Palo Alto Medical Foundation
- Medical Group Management Association
- National Health Council

APPENDIX E. LIST OF ACRONYMS

AHIC—American Healthcare Information Community

AHRQ—Agency for Healthcare Research and Quality

AMA—American Medical Association

AMIA—American Medical Informatics Association

CACHI—Consumer Advisory Council on Health Information

CEG—Consumer Empowerment Group

CFR—Code of Federal Regulations

CHCF—California HealthCare Foundation

DHHS—U.S. Department of Health and Human Services

EMR—Electronic Medical Record

EHR—Electronic Health Record

FTC—Federal Trade Commission

HIE—Health Information Exchange

HIMSS—Health Information Management Systems Society

HIPAA—Healthcare Insurance Portability and Accountability Act

HISPC—Healthcare Information Security and Privacy Council

HIT—Health Information Technology

HITSP—Health Information Technology Standards Panel

HL7—Health Level 7 (a standard for transmitting health information)

HON—Health on the Net

IS—Information Systems

IT—Information Technology

NC CACHI—North Carolina Consumer Advisory Council on Health Information

NCHICA—North Carolina Healthcare Information and Communications Alliance

NCGS—North Carolina General Statute

NHIN—Nationwide Health Information Network

OMB—Office of Management and Budget (in the U.S. White House)

ONC—Office of the National Coordinator for Health IT

PHI—Personal Health Information

PHR—Personal Health Record

RHIO—Regional Health Information Organization

RTI—Research Triangle Institute

APPENDIX F. INFORMATION ABOUT HIPAA

There are many state privacy and security-related laws which give additional protection for sensitive medical information such as HIV/AIDS status, mental health, and genetic testing results (Congress, Sept. 29, 2005). Many of these state laws have been aligned with the federal law HIPAA (Healthcare Insurance Portability and Accountability Act). Because some of the state laws require more stringent protection than HIPAA, HIPAA is considered by many to be the floor, or the minimum standard by which privacy and security policies are set. There are many issues which are discussed in the next sections which prohibit consumers and even healthcare providers from understanding HIPAA regulation. This undermines power that consumers could achieve through knowledge of how they are giving consent to share their medical information.

HIPAA was enacted in 1996, and covers insurance reform for ensuring preexisting coverage when changing jobs, as well as the standardization of electronic transmissions. It consists of two components, the Security Rule and the Privacy Rule. If the rules are not enacted, organizations could face financial penalties imposed by the government (Mercuri, 2004). One suggestion for allowing appropriate disclosures of medical information according to Lo and colleagues (2005) is to determine if risks of breaching confidentiality are proportional to the likely benefits. However, federal HIPAA guidelines do not

specify how to determine these risks and benefits consistently. HIPAA also was originally legislated for the sharing of information for those involved with the patient's care and the payment for that care. Because of the widespread secondary use of data, HIPAA rules are not clear because they apply to the 'covered entities' such as providers, insurance companies, and clearinghouses (for billing and insurance claim filing).

Security Rule

The Security Rule requires that PHI be protected specifically in electronic storage and transmissions. Implications for HIPAA compliance have been intense. Developing standards and security encryptions for existing software, as well as ensuring that third-party partners are compliant, has been time-consuming and costly. In essence the Security Rule can be thought of as the technological aspects that can support the protection of PHI.

HIPAA Privacy Policies

Studies have shown that patients do not have a clear understanding of HIPAA and the privacy policies that they sign. This is due in part to the complexity of the law and the nature of business practices for giving patients the notices. One study found that black Americans were less likely to receive HIPAA consent forms when visiting medical offices (Broder, 2006). Dr. Alan Westin,

Director of the Program on Information Technology, Health, and Privacy, testified at the Hearing on Health Privacy and Health Information Technology for the NCVHS Subcommittee on Privacy (2005) to discuss the results of a privacy study he performed. He stated that studying public attitudes towards healthcare was important to the success of technology such as electronic medical records. The core results of his study on public health privacy perceptions revealed that one-third of the respondents replied that they never received a HIPAA (Healthcare Insurance Portability and Accountability Act) privacy notice, yet two-thirds said that HIPAA regulation and the privacy notices had increased their confidence in the way that their medical information had been handled. Westin focused primarily on electronic medical records for his survey, and only 29% of the respondents stated that they had heard about a national EMR program, yet, in response to a question asking if the technology benefits outweigh the risks of privacy, the respondents were divided—47% felt that privacy risks outweigh the benefits of the technology and 48% felt that the technology benefits outweigh the privacy risks. It seems questionable that only 29% knew of EMR efforts, but 48% felt the technology benefits outweigh the risks. These issues need further explanation to determine why respondents feel the way they do

The high level of readability of HIPAA privacy policies used by organizations also prevents understanding of the policy. Within the

institutionalized notion of control over patient information, the wording of HIPAA Privacy Notices can be even more confusing to patients. In light of a study on the readability of HIPAA privacy notices (Hochhauser, 2003), patients may not understand HIPAA privacy notices since many are written at a 2nd-3rd level college reading level. It was found that, of the 31 privacy notices analyzed, all were written at a 2nd-3rd year college reading level. Of the US population, approximately 25% have at least a college degree, and many read several grades lower than their highest level of grade completed (Hochhauser, 2003). This readability level also makes it difficult for the elderly (who earned less education historically) and those who speak English as a second language. Another study (Breese and Burman, 2005) revealed comparable readability levels for privacy notices of the 2004 US News and World Reports' Best Hospitals and other publications. The Flesch Reading Ease scale was used, with a score of 0 being very difficult to read and 100 being easy to read. Comic strips were the easiest to read (between 90-100), *Huckleberry Finn* by Mark Twain was Easy to read (score of 80-89), and professional medical literature difficult to read (score of 30-49). Privacy notices were the most difficult to read (0-29 score), with most being in small font size (10 point) and approximately 6 pages long. Hochhauser (2003) suggests that HIPAA privacy notices are often given to patients along with other documents (Patient Bill of Rights, etc.) and

recommends that less information in a layered approach (having an initial Privacy Rights document which refers to other detailed documents), written in a simple style, would be more appropriate.

HIPAA Compliance Issues

According to a survey performed by the American Health Information Management Association, one of the largest American healthcare IS associations, *". . .fewer hospitals and health care facilities are complying with federal laws to protect patient privacy, and more patients are refusing to sign forms to release health information."* (Baker, 2006). Ten percent of the respondents reported difficulty gaining protected information from other providers because patients had not granted consent (Baker, 2006). If patients do not trust that their personal medical information will be kept confidential, they may withhold important medical information from healthcare providers, or worse, avoid seeking healthcare (Rindfleisch, 1997).

What is of interest to note that of the 15,000 HIPAA-related complaints filed since 2003, none has resulted in a civil prosecution (Broder, 2005). Of the 19,420 complaints of HIPAA violations lodged by consumers since 2003, 73% of the cases were found to be non-violations or either found providers to be negligent. Those providers were allowed to promise to correct the problems instead of being fined (Stein, 2006). Privacy advocates feel that such voluntary

compliance measures make the law meaningless while representatives and organizations of the providers appreciate the ability to correct issues related to a new and complicated law. In either case, Privacy and Security Rule compliance and understanding may be revealed in this study as dimensions which affect consumer empowerment in HIE through consent to share medical information.

APPENDIX G. IMPORTANT CACHI ACTIVITIES

NCHICA CACHI Timeline and Major Events

Meetings. The first official meeting of the CACHI group was in August 2006. The Resource Panel members met in July 2006 to prepare for the initial meeting with the council members. During the July 2006 meeting, the discussion was primarily in regards to recruitment of council members. The initial announcement for nominations to take part in the council was sent to the members of NCHICA through email. The email requested that interested people go to an online Survey Monkey and nominate either themselves or others to be on the council. The announcement and survey were generated by the Executive Director of NCHICA and the founding co-chair of the Resource Panel. (See APPENDIX B. Initial Call for Participation for CACHI). While it was expected that around 100 nominations could be received through this recruitment process, only about a dozen were completed. This was the beginning of a primary concern which the council struggled with throughout its establishment since finding members who could contribute and travel to Raleigh, North Carolina once a month for a two-hour meeting was a challenge.

The first meeting of the council was in August 2006. There were four council members and three Resource Panel members in attendance. The members discussed the council vision, mission, goals, draft charter (created by

the Executive Director of NCHICA), as well as recruiting strategies, rules of engagement, and possible funding ideas. Some of the ideas for consumer priorities to discuss were (from CACHI agenda, Sept. 2006):

- Consumer Empowerment
- Consumer Informed Choice for Choosing Providers (standard of care outcomes)
- Consumer Access to Medical Records
- Protecting Privacy and Security of Information through technology and business processes—Risk vs Benefit
- Accuracy and Timeliness of Data for Decision Making
- Affordability of Health Benefits
- Role of Technology In Healthcare Quality
- Perspectives of Special Populations
- Provider and Patient Perceptions of How to Handle Sensitive/Stigmatizing Information
- How to Influence HIT and Practice through NCHICA, Policy, Publicity, Promotion

The draft charter included what later was felt to be a set of lofty deliverables such as "CAC members will brainstorm and prioritize a list of consumer concerns and issues where health information technology is concerned. From that list, the group will identify specific projects and products of value and focus on 1-2 deliverables that are agreed upon within the group. Some ideas being considered include conducting consumer focus groups and web surveys, conducting research on compliance and/or patient satisfaction and the impact of technology, analyzing issues of accuracy in patient-entered data, finding ways to advocate for a level technology playing field in rural and urban health care,

exploring technology strategies to help resolve disparity in health care services, developing a white paper, generating a list of resources for patients, and finding practical ways to reach out and help educate and empower North Carolina health care consumers. Many additional ideas are expected as the group gains momentum" (draft charter, October 2006). In March of 2007, the minutes state that the "ultimate goals of the CAC included disseminating information, raising public awareness of health information issues, identify the impact of HIT on the consumers and also to accelerate information regarding healthcare information technology. The information disseminated would represent the members' concerns and perspectives." These challenging goals emphasize the complicated nature of consumer empowerment and HIE issues, but often also seemed to be overwhelming to the council. Finding which issue to tackle first and how to go about achieving the goals was cumbersome even for these 'informed consumers.'

The development of a web site[44] for the CACHI group was initiated in February 2007 and was also funded as part of the NC HISPC project to engage consumers. It was agreed by the council members that their names could be posted on the site, but no email addresses or quotes would be associated with

[44] North Carolina Healthcare Information and Communications Alliance. Retrieve May 2008 at http://www.nchica.org/CACHI/main.htm.

their names. The purpose of the web site is to post minutes, agendas, and other supporting documents from the meetings so that other interested parties would understand what the council was achieving.

In March 2007 an important decision was made by the council members. The members revisited the initial draft charter for the council. During this conversation, the council members decided that instead of calling the council the "Consumer Advisory Council on Healthcare Information Technology" as originally given by the NCHICA Executive Director. There was consensus to change the name to the "Consumer Advisory Council on Healthcare Information." The purpose in doing so was because they did not want to focus on technology as a solution to issues of sharing, storing, and manipulating health information, but felt rather that the primary concern was the information itself that needed to be kept private and secure when flowing through the system. This was a distinction that the council members felt strongly to make. It was also a way for them to participate in the naming of their own council to signify to others what they feel is at the heart of the HIE subject matter.

During the time between July 2006 and the summer of 2007, the Resource Panel members were primarily responsible for generating the minutes, agenda, and arranging speakers for the CACHI. Over the course of this time the council members primarily discussed what issues were of interest to them as well

as what they could achieve as council members. The Resource Panel felt that over the course of time, it was important for the members of the CACHI group to become more independent and to be responsible for setting their own agendas based on their interests for being engaged in healthcare IT issues. The Executive Director of NCHICA, who attended most of the CACHI meetings as a Resource Panel member, urged the council members to lead the meetings and particularly to set the agenda items based on their interests and goals.

Speakers. The first speaker for the CACHI was in January 2007. The goal of the group was to investigate PHRs for senior citizens in North Carolina since one of the council members was actively involved in a senior citizens group and was especially interested in helping the elderly with PHRs during times of crisis or disaster. Therefore, the speaker from the vendor CapMed demonstrated their PHR software.

In June 2007 Alison Rein, a Senior Associate at AcademyHealth[45] was the speaker (she is also a member of the AHIC Confidentiality, Privacy & Security workgroup and a member of the Health Information Protection Taskforce of the State Alliance for e-Health). There were approximately a dozen people in attendance (including council members, Resource Panelists, and visitors) at this

[45]AcademyHealth. Retrieved May 2008 at http://www.academyhealth.org/.

meeting. Ms. Rein talked about the difficulty in understanding health IT issues because of the "alphabet soup" and jargon utilized. What was ironic in her discussion was that she stated the privacy and security issues of health information aren't "really about the technology; otherwise the technology dictates what we do." This reinforced the council members' previous decision to omit the word "Technology" from the council name in March, 2007. Much of what Ms. Rein emphasized was that consumers aren't actively involved in health IT initiatives and that there is reason "for consumer advocates to be engaged better." The council members asked questions and became engaged in her presentation through discussion. From this, Ms. Rein formed a positive opinion of the CACHI group. She stated that it "actually has consumer engagement which is actually rare. . . it is in a meaningful way and not enough to have a token person. The CAC is adept and has an appreciation for sophistication at the IT level, but also look at it [HIE issues] from a consumer perspective."

Carol Diamond, the Chair of Connecting for Health[46] , emphasized the need for synchronizing technology with policy as well as the need for "participation on equal footing" for consumers at the July 2007 meeting. Although this was an entirely different presentation than that of Ms. Rein, there

[46] Connecting for Health. Retrieved May 2008 at http://www.connectingforhealth.org/.

was a common theme that technology could "enforce privacy and security aspects of the system." In essence, technology was not a solution entirely on its own, but needed appropriate policy as part of the implementation. "Technology design decisions that are made in synch with policies and rules foster trust and transparency." As part of the policy concern, Ms. Diamond suggested that implementing technology with appropriate policy is better "in lieu of retrofitting. . . .which turns [the issue] into a debate about consent." This was the first instance where I heard privacy and security of health information referred to as a civil liberty. In exercising this civil liberty, Ms. Diamond felt strongly that there should be participation on equal footing and that trust of consumers is the "essential ingredient." In order to participate, "the consumer needs to understand [the issues] to make informed decisions." To Ms. Diamond, the question of informed consent was not opt in or opt out, but opt into WHAT. The council members asked Ms. Diamond to elaborate on how to make consumers aware that HIE initiatives exist, to which she emphasized ease of use to participate as being essential and that consumers must be informed, have equal footing (equal participation), and trust in the system. One question from a council member was if any other states were good examples of how to engage consumers. At that time, there weren't many successful initiatives truly engaging consumers.

At the same meeting in July 2007, after Ms. Diamond's presentation, there was also a presentation by three people (from Intel) regarding the Dossia PHR.[47] According to the website, the Dossia Foundation is "consortium of large employers united in their goal of providing employees, their dependents, retirees and others in their communities with an independent, lifelong health record. . . funding Dossia, an independent secure, non-profit infrastructure for gathering and securely storing information for lifelong health records. At the request of employees and other eligible individuals, Dossia gathers health data from multiple sources. Employee participation as a Dossia user is completely voluntary and individuals have complete control over who sees their information. Once gathered and securely stored in a decentralized database, the health information is continually updated and is available to individuals for life even if they change employers, insurers, or doctors. The Dossia Founders Group includes AT&T, Applied Materials, BP America, Inc., Cardinal Health, Intel Corporation, Pitney Bowes, sanofi-aventis and Wal-Mart." The presentation on Dossia was focused on the consumer trusting the people who hold data so that employees would put information into the PHR. The security and privacy policies for Dossia were being generated based on best practices from industry. Another

[47] Dossia (2006-2008) Retrieved May 2008 at http://www.dossia.org/home.

topic of concern was consent management which the presenters said should be understandable to the patient.

One of the council members who was involved with the elderly population stated “I consume healthcare very well, what if they [either senior citizens or physicians] made a mistake in the record?” The representative of Dossia stated that the patient can annotate the record, not change the original information. Another point that he also made was that wherever the original source of that data is stored should be updated as well. For example, if the information was sent from the primary physician to a specialist and was found to be incorrect, the information should also be changed in the primary physician’s record. Two questions were asked during this presentation by the council members. One related to the governance of Dossia, since it was a collaborative effort. The council member asked if consumer advocacy group members were included or if the best practice security and privacy policies were at least sent back to consumer organizations for feedback. The representative replied that there were workgroups within the Dossia collaboration which included consumer representatives which gave feedback on policies and technological features.

The other question was in regards to the troubles that Dossia had experienced. The problem was that the nonprofit organization which had been hired to develop the software was not paid by the Dossia organization, who

stated that the developer had not produced the required deliverables (McGee, 2007). When asked by the council member how Dossia could guarantee the privilege of health information when they were not paying the developer, the representative responded that the early technological capabilities lie where the information already is in the existing infrastructure. The answer was fairly short and ambiguous; however, the council members did not follow up with additional questions on that topic.

What came to be the most controversial and discussion-provoking presentation for the council to this date was in August of 2007. Dr. Deborah Peel, founder of the Patient Privacy Rights Organization and a Freudian psychologist, shared her thoughts regarding patient privacy and security issues. This was an important event, and took place during a daylong meeting. The first portion of the day was a luncheon and presentation by Dr. Peel to the CACHI members, Resource Panel members, and visitors such as people invited from NCHICA's membership list. There were almost two dozen attendees at this special meeting (about half of these were CACHI members and Resource Panel members). The second part of the day was devoted to the monthly meeting of the CACHI for which Dr. Peel stayed to answer further questions about her presentation.

From her opening slide content, it was apparent that Dr. Peel was a steadfast patient advocate: "Today health privacy does not exist—secondary uses are the primary uses of Americans' personal health information." To further reinforce this, Dr. Peel discussed how consent privileges for American health consumers have actually been eliminated and that the HIPAA Privacy Rule (see Appendix for more information on HIPAA) is only a disclosure rule which creates people being in classes of uninsurable and unemployable. The effects of "NO Health Privacy" according to Dr. Peel are denial of promotions or job loss, insurance discrimination, credit denial, and denial of admission to schools. A discussion with the CACHI members led to the question of whether people who need the money would be the ones to sell their health data in a quid pro quo situation.

Dr. Peel posed the question "It's 11:00 at night, who's got your data?" to emphasize the secondary use of health information for unauthorized purposes. Such secondary users/sellers are: the insurance industry, data miners and aggregators, the hospital industry, the transcription industry, self-insured employers, quality assurance and improvement hospital-based studies, research without consent, state and federal databases and registries, and the technology industry. The "whole point of the health record is to provide better care for the patient." Since consent is given at the point of care, Dr. Peel suggested that

patient's don't often think about the secondary use issues since they may be feeling poorly at the point of care. What happens, as a council member emphasized, when a breach occurs, but the patient is still sick and needs treatment? A council member made the point that "as long as the record exists, there are people who will want it. . ." and try to combine it with other data to identify and target specific consumers. The discussion with the CACHI regarding consent was whether consent management policies would motivate people to think through those issues.

Dr. Peel, like Ms. Diamond, referred to privacy as a civil liberty and that it is "essence of freedom and liberty to be left alone." The incarcerated consumer was discussed, and it was suggested that privacy and security issues "are not on their radar." Stigmatized populations are worried about healthcare access, domestic violence, jobs, and, in general, are still experiencing life at the bottom of Maslow's hierarchy of needs. When the conversation turned to the use of health information to discriminate against people with stigmatizing conditions, the notion of civil rights was again mentioned. "It's civil rights violations in those cases." The use of behavioral health records to discriminate against people in employment cases was the focus, with stories disclosed regarding protection of children who have had behavioral health treatment so that they would not face discrimination in the future. "School is part of getting a job," stated Dr. Peel, and

there have been cases where parents withheld information and the child committed suicide. Not everyone, like professional athletes, has the money to go to other states or countries to receive 'black market care' so that they don't have to file insurance claims. "If we don't have privacy about the most fundamental information about us, we don't have privacy at all," Dr. Peel declared.

A controversial point made by Dr. Peel was that PHRs are actually designed for data mining because the financial model for funding is selling the data and that laws, ethics, and security/privacy protections are inadequate. In essence, the healthcare industry is creating the technology before there are appropriate policies in place. Although technology can make data more vulnerable, protections can be stronger with technology, according to Dr. Peel. Dr. Peel stated that, similar to the proliferating trend for companies to 'go green', "if we can get the technology companies to do the right thing with security, it may drive the legislation." However, a council member point out that "no one gives up power" when it's their advantage. While many of the council members didn't seem to relish the idea of a central warehouse for health information, one council member said "I'm intrigued by the notion of a central warehouse. . . .the advantage is tremendous for research and public health issues. It seems that we're almost too far gone. . .because there is a proprietary interest in keeping information in separate silos." According to Dr. Peel and recent consumer polls

that she references, the public does not want the industry to lead the way, but rather wants the government to set the rules. As one of the CACHI members asked "We see the benefit—what kind of business/cost model gives the patient the privacy rights that are accessible and useful?" Another CACHI member suggested that "accountability throughout the information chain for the privacy and security" of health information is necessary and that "regardless of where the information is. . . there needs to be responsibility for the breach. . .and that protection needs to follow the data."

Consumers want to participate and want to decide how to protect their information and "we don't need to be paternalistic, [but rather] we should let people decide where [information] should be disclosed." "There is NO other stakeholder. It is YOUR data. Quality control should be the responsibility of the patient," Dr. Peel avowed. In reference to organizations such as AHIC, Dr. Peel declared that "none of those people should be serving because they have conflicted interests." Consumers should not be compelled to share information to obtain employment, insurance, credit, or admission to schools. As a solution, Congress should set national privacy policies so that consumers can "take control back of personal data in health." Currently, Dr. Peel stated, 60% of HIPAA complaints filed are not found to be violations because HIPAA allows so much to be shared. According to an Editorial in The Philadelphia Inquirer which

Dr. Peel referenced, “With an Orwellian turn of phrase, the ‘privacy rule’ has little to do with patient confidentiality. In fact, it permits the widespread sharing of medical data among 800,000 or so health, business, and government entities” (Medical Privacy, 2006). She suggested that there should be “compliance through monetary consequences” and that the Attorney Generals in each state should be able to defend consumers. “Shouldn’t there be someone to defend the consumer who can afford lawyers?” Dr. Peel felt that it should be a crime to keep secret databases and to re-identify health information. This includes segmenting information to control who accesses what data and requiring audit trails. This can be enabled by smart technology which provides protections to “ensure privacy and security, while ensuring access to the right data, at the right time and place.”

Yet, “how can we inform consumers relative to privacy and security so they can become a mass voice for what they want? It’s like power to the masses.” A CACHI member asked how to involve and educate consumers on these issues. “There are professional representatives to speak on behalf of other people” who have enough information. “I’m fairly educated and it’s still hard enough to understand laws and rights to know what kinds of information to ask.” Part of the problem for informing people, according to Dr. Peel, is that “IT people don’t get healthcare; healthcare reporters don’t know IT; legal reporters don’t

know about health or IT. This issue sits right in the middle. Conceptually, very few people have all of the pieces and it's hard to talk about policy at a level that people understand." Healthcare IT is a bipartisan issue, however, although people use the term consumer-centric, there are no consumers involved in most HIE efforts. Dr. Peel revealed that "you have to know a lot to know what to do to have hope."

Dr. Peel's presentation also had a lasting impact on the discussions of the Council members. One member later stated: "The best thing that happened to us was Deborah Peel. . . I will remember her until my dying days because it was a stunning presentation." However, her presentation was viewed as a more radical approach than other perspectives on patient privacy, as one Resource Panel member stated, "Deborah Peel presented the edge/extreme of the issues. . .[this council should] know where the edges are and [not] get into one extreme or the other."

NCHICA Annual Conference Attendance. The notion for the council to be self-sustaining became an issue at the forefront of the council during October to December of 2007. I believe this was primarily due to the fact that several of the council members attended the NCHICA Annual Conference. As part of the NC HISPC project, several of the CACHI members were paid (and expenses were reimbursed) to attend the NCHICA Annual Conference in Asheville, NC

during September 25-27, 2007. The purpose of the attendance by the council members was to: "provide CACHI members the opportunity to see and hear what is being proposed in the areas of health care and health information technology, and [to] interact with public policymakers, physicians, and vendors to develop their own views of how of these changes may affect themselves and their families" (from PowerPoint slides presented at the National HISPC Conference in November 2007). The council members were to attend at least five presentations at the NCHICA Annual Conference. These presentations were:

1. The Opening Plenary session by Dr. Robert Kolodner, National Coordinator for Health Information Technology, U.S. Department of Health and Human Services

2. Either the session on "Duke University Affiliated Physicians: A New IT-Focused Culture for Healthcare Providers" or "NGA State Alliance for eHealth & the NC HISPC Project: Potential Impact on NC"

3. POC3: Plan of Care at the Point of Care Brings the Power to Change

4. eHealth Initiative Washington Update and the Impact on Sustainability for HIEs

5. Closing Plenary Session: Connecting Patients, Providers, and Payers by Dr. John Halamka

Outside of these, the council members had the opportunity to eat lunch with Dr. Kolodner and had an informal discussion with Mr. Halamka. In return

for being reimbursed for attending the conference, those attending agreed to assist in the compilation of a HISPC CACHI report on the conference from a consumer's perspective. The council members were identified by a CACHI ribbon on their name tag. Once each day, the council members were involved in a debriefing in which they discussed their reactions to each of the presentations they attended. The council members saw opportunities where they felt that providers and vendors discussed consumer empowerment in healthcare IT, but only at a superficial level. The council members who attended felt that consumers could have a more prominent voice in HIE projects. It seemed that through their attendance at the NCHICA conference and especially through their discussions of the presentations, the council members discovered that they overall felt that consumers were not as involved in HIE initiatives as they believed they should be. During the debriefing sessions when the council members openly discussed their feelings and reactions, there was an obvious change in the depth of their perceptions. Because they discovered that others in their group also felt similarly regarding the lack of consumer contribution, the council members seemed to become more confident and adamant in expressing their discontent with some of the presentations. It became a watershed event for which the consumers could later discuss references to the presentations and the context of their concerns. Although they did feel that some of the presenters

were genuine in expressing their commitment to engage consumers in HIE initiatives, the council members were concerned with two issues: that the presenters were using the terms of consumer empowerment, engagement, and involvement in a superficial manner; and that the consumers really have not been able to participate in initiatives.

Consumer Empowerment Toolkit Generation. Another opportunity for the CACHI to provide input into the NC HISPC project was in the development of the Consumer Empowerment Toolkit. The purpose of the Toolkit was to develop a guide for other states to follow, based on the efforts of the CACHI group. No states participating in the National HISPC project were including the consumer perspective in their solutions to the sharing of healthcare information. The participation of the council members was to agree to include their documentation, policies, and procedures as samples for other states to utilize.

The members of the council came to a consensus that, instead of having someone outside of the group to write the sections of the Toolkit for them that they preferred to split the Toolkit into sections and write the sections themselves. This would serve two purposes for them: to document what they conceived for their policies, procedures, and objectives; and to participate in the NC HISPC project by providing other states with a sample toolkit for forming their own advisory councils. The Toolkit sections were divided and sent to the council

members to write, as discussed in the meeting. However, the Project Manager for NC HISPC, who had not been present at the meeting, felt that this was not appropriate, given that the Toolkit was actually a deliverable of the NC HISPC project. Therefore, the council members were asked not to write the toolkit themselves. The final Toolkit was developed from my own contributions from this research study as well as sections written by the NC HISPC Project Manager. While the end deliverable was good, the council members felt somewhat disconcerted and possibly betrayed that they did not have the level of participation they would like by writing the sections themselves. Although they were informed in the beginning that the Toolkit was a deliverable of the NC HISPC project and would provide examples from CACHI's efforts, some of the council members seemed to be disappointed that the project had been, in essence, taken from their control, since they were unable to write the sections.