Consumer Empowerment in E-Healthcare: An Investigation Using the Grounded Theory Approach

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Abstract

Technological innovations such as electronic health records (EHRs), regional health information organizations (RHIOs), and the nationwide health information network (NHIN) have enabled increased sharing of medical records in the healthcare community. Recent studies have shown that patients do not trust healthcare providers to keep medical records safe from unauthorized release and want more control over their medical records. Patients seem to have focused attention on negative media stories of information disclosures. Therefore, the notion of patient/consumer empowerment has emerged within the healthcare community's discussions regarding sharing of medical information. In this research, facets of patient empowerment in e-Healthcare will be investigated through a Grounded theory approach to analyze both United States federal and state patient empowerment groups. It is the first phase of a longitudinal study which will generate theory and enable practitioners to better understand the concept of consumer empowerment in e-Healthcare to develop appropriate e-Healthcare policy and technology.

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 and the nationwide health information network, 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 your 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) (Ferris, 2006; Rindfleisch, 1997). 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).

Patients are more aware now of these negative consequences of sharing medical information. However, patients lack empowerment to control the disclosure of their sensitive health information through new technological innovations. U.S. states such as North Carolina have found that their citizens top 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) 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).

Ultimately, a patient's trust in the security and privacy of their medical data will 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 and Lansky, 2005). 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 with other entities. "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). Consumer empowerment, in this context, would enable self-determination of how and what medical information the patient feels the need to share.

The Need for Health Information Exchange

Many reasons have been given for the necessity to share medical information across entities. One is that health information exchange (HIE) improves the quality of healthcare, thus the quality of human health. *"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. . "* (U.S. Senator Kennedy, HIMSS, 2007). Stakeholders in the healthcare pursuit to share information include the physicians, hospitals, pharmacies, insurance companies, legislators, government organizations, and patients/consumers. Here, 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.

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 parents, of which 82% wanted access to track their children's health records for information such as immunization dates. The majority (80%) also felt that an advantage of accessing their records would aid in managing 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 is the unauthorized sharing of their information, many Americans also felt it necessary to share information under certain circumstances. These included: 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. One advantage of e-Healthcare is that the capability to provide audit trails of access to data by individuals or organizations is available (Joch, 2007).

In his article on Health-e Connections, Slone (2007) discusses the primary advantages of sharing medical information electronically. Slone 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, e-Healthcare 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. E-Healthcare Information Technology (IT) can provide these benefits through several types of technological innovations, which will be discussed next.

Technological Innovations for e-Healthcare

There are generally three different types of e-Health technology which are used to store patient health information—the EMR, EHR, and PHR. The Electronic Medical Record (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), 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 Personal Health Record (PHR) is 'an electronic application through which individuals can maintain and manage their health information. . .in a private, secure, and confidential environment' (ONR, 2004, pg). "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) 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).

Due to privacy and security concerns, there is a rising concern to address how patients can become more involved in what, when, and where their medical information may be shared through e-Healthcare technology. 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" 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 EHRs, some patients have become savvier and want not only access, but the ability to change information in the EHR and the capability to carry a smart card or flash drive containing the EHR data (Chan et al, 2001). 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.

Issues In Disclosing Personal Health Information

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, pg. *). 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 for improper disclosure.

Another hurdle is the potential conflict in state and federal privacy law. There are variations in state and federal privacy regulations (Slone, 2007, NC HISPC (Healthcare Information Security and Privacy Council), 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).

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, pg. 37). This means that confidential medical information should be "furnished only on the authorization of the patient" or caregiver (pg. 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, "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, 38).

Other reasons stated as challenges of sharing medical information include:

1. *Unauthorized disclosure of sensitive information* (Clemens and Hitt, 2004; Botkin, 2001; Ferris, 2006; AMIA, 2006)
2. *Lack of security and policy standardization across entities* (NC HISPC, 2007)

3. *Accurately matching patient search to the correct patient* (Ferris, 2007)
4. *Quality of the data and liability for 'dirty data'* (Ferris, 2007)
5. *Confusion as to ownership of and access privileges to the information* (American Medical Association website)
6. *Lack of definition for consumer empowerment in e-Healthcare and how to include it in system design* (NC HISPC, 2007)
7. *Lack of consumer understanding and awareness of e-Healthcare technology; therefore less consumer input* (Broder, 2005; Broder, 2006; NC HISPC, 2007)

Significance of the Study

Due to emerging technologies in the health care 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 health care. The recent concerns among healthcare stakeholders in sharing sensitive medical records have been the access and control the 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).

Research is needed to examine the variety of perspectives involved in these 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 e-Healthcare so that an understanding of consumer empowerment dimensions in e-Healthcare will aid in implementing appropriate policy and technology to ultimately improve human health.

Research Questions

Examining consumer empowerment in e-Healthcare is necessary since the technological innovations allow for the sharing of a person's medical information between people in organizations. Because the technology creates new relationships between people and entities, the sociological aspects and technology intermingle to create a phenomenon of consumer empowerment in e-Healthcare. In order to investigate the phenomenon of consumer empowerment dimensions in e-Healthcare, the research questions will be broad since this area is emerging. Lee (2001) 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. 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."

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 e-Healthcare?
2. How can consumer empowerment be achieved in e-Healthcare?

This study will investigate the dimensions that emerge when information technology in e-Healthcare interacts with consumer empowerment foundational issues. The first question examines the dimensions and facets of consumer empowerment in e-Healthcare 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 e-Healthcare.

Literature Review

"Empowerment is a construct that links individual strengths and competencies, natural helping systems, and proactive behaviors to social policy and change" (Perkins and Zimmerman, 1995). 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 and 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.

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 focuses primarily on the concept that consumers can enforce their power through marketplace economics (Shaw, Newholm, and 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, et al (2006), this type of influential purchasing is very similar to citizens casting votes in elections. This political comparison is also interesting 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, pg. 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 et al (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 weaknesses in the marketing research are that it 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). There also has been no determination of a model for government or organizations to provide funding and resources for consumer empowerment in e-Healthcare, 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 e-Healthcare is needed to examine whether these weaknesses are experienced in the quest for consumer empowerment in e-Healthcare 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 e-Healthcare 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 e-Healthcare will be important to investigate power issues and how they affect the adoption and implementation of e-Healthcare 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, pg. 118-119) such as biosurveillance. Ultimately, empowerment is socially constructed (Berger and Luckman, 1966) and is "an outcome of changes in fundamental structures and relations of power" (Anderson, 1996), 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). Because of this inherent difference in power in institutional structures; patients have not been able to seek empowerment through e-Healthcare technology.

Empowerment in e-Healthcare

Literature expresses empowerment as 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 e-Healthcare web sites and the availability of patients to access treatment on the web regarding their treatments, diagnoses, and support group options (Luo and 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).

The difference is that empowerment in healthcare literature currently focuses primarily on 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, http://www.hon.ch/HONcode/HON_CCE_en.htm). E-Healthcare empowerment focuses on the sharing of sensitive, personal medical information, and is likely to contain different dimensions than healthcare empowerment based on the type of information being utilized. For e-Healthcare, this involves analyzing patient access and control of ***their own medical records*** for self-determination of who the information will be shared with and for what purpose, based on the technology utilized.

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 e-Healthcare because traditionally the healthcare provider has held power, especially in the doctor/patient relationship. 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 predominately states 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 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 e-Healthcare, it has not been determined how the technology and access to electronic medical records would be provided and who would be responsible for the costs, maintenance, and education to implement such technology.

Because there is no existing theory for consumer empowerment in e-Healthcare, 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). 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 e-Healthcare primarily by analyzing meeting transcripts of a U.S. government-led Consumer Empowerment Group and a grassroots state-level effort.

Methodology

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 and Biklen, 2003). Glaser and Strauss (1967) suggest that the grounded theory approach is the purposeful “discovery of theory from data systematically obtained” (pg. 2). 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. 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) Open coding--incidents are compared to other incidents to develop concepts; 2) Axial coding--concepts are compared to incidents to determine if the particular incident should be aggregated with the concept; and 3) Selective coding--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. In essence, the researcher performs joint coding and analysis at the same time by using systematic coding and analysis procedures (Glaser and Strauss, 1967, pg. 102).

Application of Grounded Theory Methodology

The grounded theory approach will be utilized to propose a theory for consumer empowerment in e-Healthcare since no such theory currently exists. It is an appropriate approach to use because it provides rigor and relevance (Fernandez and 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 purpose of this research is to investigate the dimensions of consumer empowerment in e-Healthcare by studying organizations which focus on consumer empowerment as a goal in implementing e-Healthcare technology and policy. For grounded theory studies, the purpose is to discover theory from concepts in data analysis.

Data Sources

There will be two primary sources of data for this study: American Health Information Community Consumer Empowerment Group (AHIC CEG), and the North Carolina Healthcare Information and Communications Alliance Consumer Advisory Council on Health Information (NCHICA CACHI). The focus for both groups is on consumer empowerment in e-Healthcare; however, the investigation for this study is to determine how each group, from a federal and a state perspective, view consumer empowerment. The initial source of data for this phase of research will be 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" (http://www.hhs.gov/healthit/). 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 efforts, such as AHIC, which study consumer empowerment in the context of e-Healthcare. 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 an initial data source for this study.

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" (Transcript, 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. Currently, there are over 500 pages of documentation from their meetings, which began in January of 2006 and have been held monthly since that time. 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. For this preliminary analysis phase, only the meeting transcriptions will be analyzed. Other documents such as presentation slides and articles supplied by AHIC members for supporting evidence will be included in the next phase of this study. It is anticipated that the content of these meetings will provide a conceptual foundation for the factors driving consumer empowerment in e-Healthcare.

Preliminary Analysis

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

Using the grounded theory approach, the AHIC CEG (American Healthcare Information Community Consumer Empowerment Group) data has been analyzed by examining the source documents carefully, and using the constant comparative method to begin generating concepts for theory. For the current study, an initial analysis was performed on one year of AHIC meeting transcripts (Jan. 2006 to Jan. 2007), which included 495 pages of meeting notes. The documents were reviewed for content and context so that codes generated are grounded in the data. The transcripts were entered into the qualitative software package, QSR NVIVO 7.0 to make the management of the data and analysis and coding 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 analyzed manually for content, NVIVO was utilized to hold open codes generated during the analysis. A constant comparative analysis was performed between the transcript data and the open codes to determine the context of the open codes being generated. As the analysis progressed, the open codes were grouped into similar concepts. For example, consumers and patients were grouped together as the concept Consumer. From this analysis, six initial concepts were generated.

Initial Research Findings

Based upon the context of the documents and the concepts that emerged frequently during the meetings and were emphasized by AHIC CEG members as being important, the following open coding map (Figure 3) was generated. It includes the initial open coding concepts in shaded blocks—Consumers (here it is used interchangeably with patients), Record, Policy, Stakeholders, Technology-Related, and Action-Related. Underneath each concept block are the associated terms which were aggregated underneath each concept. For example, the concept for Record also was associated with the concepts of information and data included in a patient's medical record. Underneath each concept and its associated items are the preliminary attributes associated with each concept. For example, for the information included in the patient's medical record, the transcripts often referred to it as being sensitive, or shared for primary or secondary purposes, as well as being portable for the patient to transfer to each healthcare provider's office.

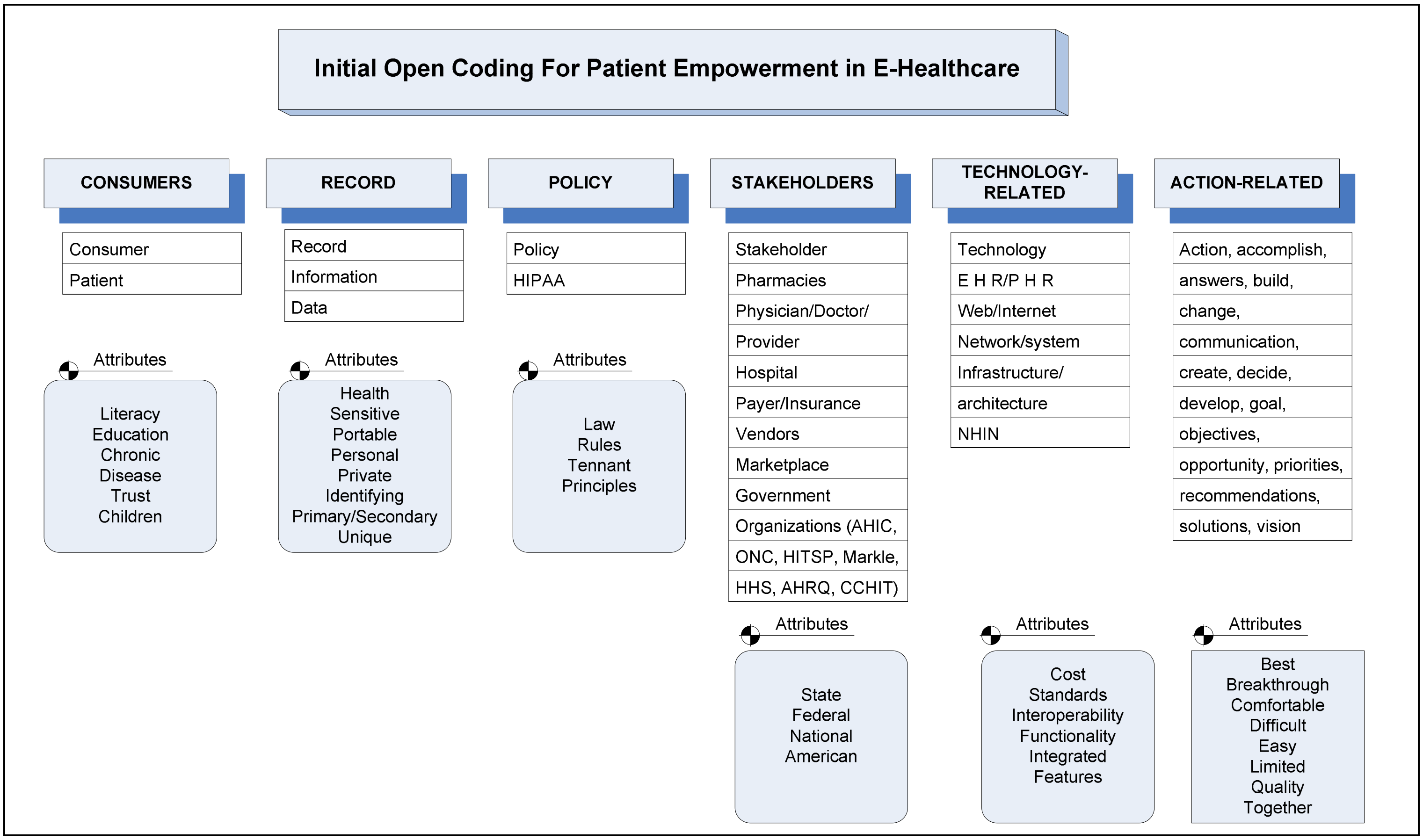
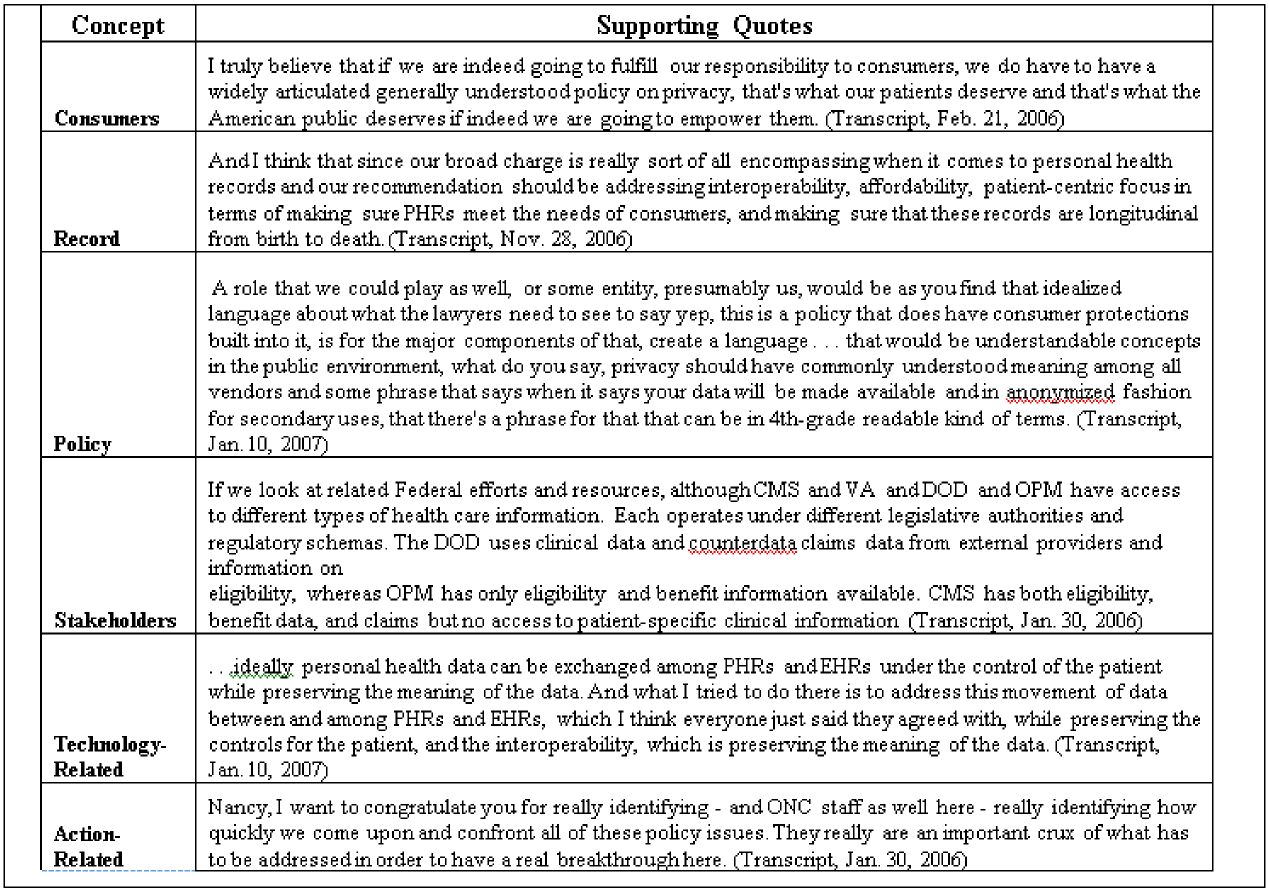


Figure 1--Open Coding from Data with Associated Terms and Attributes

These concepts reveal that empowerment for patients in sharing their healthcare information between stakeholders may be related to the type of medical information in the record, trust between the patient and other stakeholders, privacy and security policies such as HIPAA, and to the features of technology such as the personal health record (PHR) and the Nationwide Health Information Network (NHIN). From the frequently discussed proposed actions, the Consumer Empowerment Workgroup seems to be dedicated to the cause of encouraging empowerment issues and making recommendations to the AHIC Community Group. Since qualitative approaches such as grounded theory should be rich in description, quotes from the AHIC minutes are given in Table 1 to support the reasoning for these conceptual categories.



Concept	Supporting Quotes
Consumers	I truly believe that if we are indeed going to fulfill our responsibility to consumers, we do have to have a widely articulated generally understood policy on privacy, that's what our patients deserve and that's what the American public deserves if indeed we are going to empower them. (Transcript, Feb. 21, 2006)
Record	And I think that since our broad charge is really sort of all encompassing when it comes to personal health records and our recommendation should be addressing interoperability, affordability, patient-centric focus in terms of making sure PHRs meet the needs of consumers, and making sure that these records are longitudinal from birth to death. (Transcript, Nov. 28, 2006)
Policy	A role that we could play as well, or some entity, presumably us, would be as you find that idealized language about what the lawyers need to see to say yep, this is a policy that does have consumer protections built into it, is for the major components of that, create a language . . . that would be understandable concepts in the public environment, what do you say, privacy should have commonly understood meaning among all vendors and some phrase that says when it says your data will be made available and in anonymized fashion for secondary uses, that there's a phrase for that that can be in 4th-grade readable kind of terms. (Transcript, Jan. 10, 2007)
Stakeholders	If we look at related Federal efforts and resources, although CMS and VA and DOD and OPM have access to different types of health care information. Each operates under different legislative authorities and regulatory schemas. The DOD uses clinical data and counterdata claims data from external providers and information on eligibility, whereas OPM has only eligibility and benefit information available. CMS has both eligibility, benefit data, and claims but no access to patient-specific clinical information (Transcript, Jan. 30, 2006)
Technology-Related	. . . ideally personal health data can be exchanged among PHRs and EHRs under the control of the patient while preserving the meaning of the data. And what I tried to do there is to address this movement of data between and among PHRs and EHRs, which I think everyone just said they agreed with, while preserving the controls for the patient, and the interoperability, which is preserving the meaning of the data. (Transcript, Jan. 10, 2007)
Action-Related	Nancy, I want to congratulate you for really identifying - and ONC staff as well here - really identifying how quickly we come upon and confront all of these policy issues. They really are an important crux of what has to be addressed in order to have a real breakthrough here. (Transcript, Jan. 30, 2006)

Table 1—Foundational Quotes from the Data for Each Open Coded Concept

Proposed Initial Theoretical Model of Consumer Empowerment

One aspect that seems to unfold from this initial analysis is that empowerment is a multi-dimensional and complex concept. Also, some of the concepts at this point may be inter-related, such as trust of the consumer and the stakeholders. For example, one member suggested that "o*ne of the other points we learned is that people want their information -- this information to be conveyed by a trusted source. They viewed their providers as trusted sources. They view the voluntary health agencies, the patient advocacy organizations as well as some that represent clinicians, as the trusted sources to deliver this information. So we know what messages can identify the problems, the solution, who needs to deliver the information as a credible caring source*" (Transcript, Sept. 18, 2006). There are most likely other concepts that may emerge through additional coding, such as barriers, which may overlap with other concepts because policy and technology, for example, could each create barriers to the sharing of medical information. The next steps of clarifying the initial coding and then conducting axial coding for the relationships help generate theory for the relationships between the concepts.

In the model, it is proposed that federal and state policy enacted through active participation of patient/consumer advocacy groups have a direct bearing on consumer empowerment. For example, HIPAA itself is not sufficient to empower patients in e-Healthcare and either modification or additional regulations are needed to truly empower patients and make them active participants in the healthcare system (Stein, 2006). Patient/consumer awareness and self-determination construct is also critical for consumer empowerment. Without patients being aware and fully educated in terms of the level of control that they have on their own healthcare information, it is difficult to conceive of effective consumer empowerment. The initial analysis suggests that effective education, awareness, and programs be initiated so that patients begin to become aware and feel more self-determined in their healthcare information as participants in the healthcare system. Additionally, the concept of record, which incorporates sensitive healthcare information of patients, integrates with information technology as a delivery for healthcare information exchange to enable consumer empowerment. It is difficult to imagine an efficient e-Healthcare system that does not employ information, data and web-based information technologies. The four interdependent concepts of patient/consumer awareness, record, information technology, and policy combine to represent tools in the hands of the stakeholders to achieve consumer empowerment in e-Healthcare through specific actions, goals, communication to reach for a solution that truly empowers the patients. As a member of the AHIC CEG stated, ". . . .*you know, generally thinking we need to be building to a sustainable value based system, that will encourage the integration of care, and consistent communication and coordination, then we need to be thinking that sort of how to build on -- you know, over time, to enable the most important functional areas, or what a PHR could do, that really does deliver value to the patient. So that they get the evidence-based health information that they need that's specific to their conditions, and that they can, you know, talk -- or communicate with their clinicians or their health care team about the decisions that would best meet their needs based on their preferences*" (Transcript, Sept. 18, 2006).

From the AHIC CEG meeting notes, the PHR (Personal Health Record) technology was discussed quite often, in terms of getting people educated and informed about PHRs and the technological capability so that they are willing to use the technology self-sufficiently. A member of AHIC stated that for their future plans, there are "*a number of critical success factors. One is getting the patient-consumers involved and educated, and advocating for this. Two is getting the docs on to EHRs [Electronic Health Records].. Three is having the whole system integrated, because that work flow issue, and the shared information, is what we're after. . . And it's really about the connectivity with the physicians, the patients, the health care team, and the caregivers who is going to be really an important force in the not too distant future. It's really about the relationship, not a product, not software, not a technology*" (Transcript, Sept. 18, 2006). This supports the proposed states of consumer empowerment in e-Healthcare.

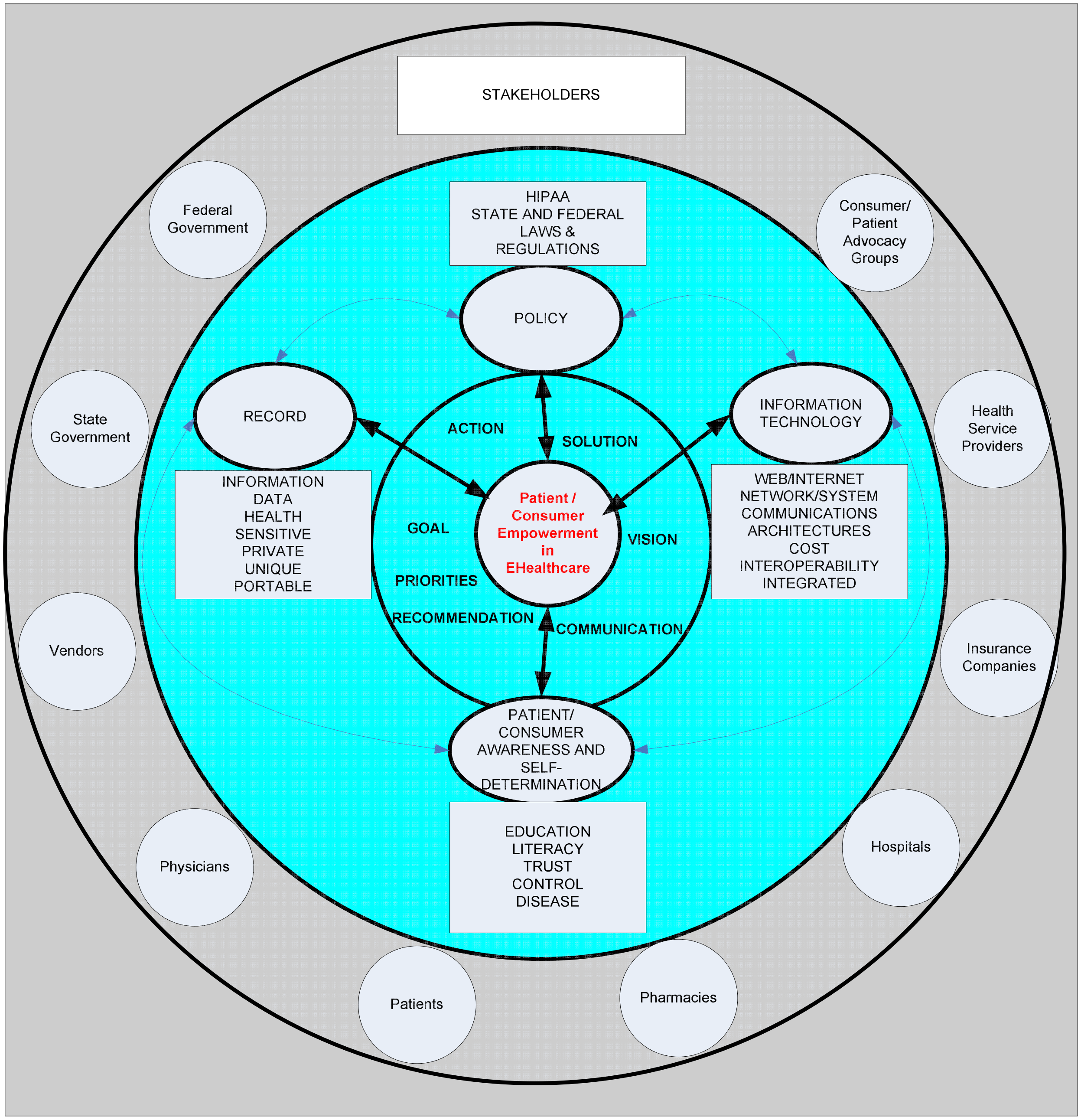


Figure 2--Theoretical Model for Consumer empowerment in e-Healthcare

In analyzing the transcripts from AHIC's Consumer Empowerment Group, there were moments where the AHIC group members realized that focusing on empowerment entailed many issues and the need to emphasize consumer empowerment was their main charge. One member stated that "*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). At a meeting on a different date, the conversation returned to the notion of understanding consumer empowerment and ensuring that their deliverables were provided with the patient's interest in mind. One member stated that he did "*want the thought to be when we get done with this and when we're all ready to endorse it and say, "This is what we're handing over to the Community," we can say with all sincerity, "This has 'consumer empowerment' written all over it*" (Transcript, April 25, 2006) to which another member replied that "*the comment about taking a step back and looking at the consumer empowerment notion and reviewing the perspective from that look may lead us to want to take a stronger role at defining the consumer's requirements. If you look at it from a -- call it a system engineering perspective, we really don't have a good sense of the consumers' requirements for the system*" (Transcript, April 25, 2006). This reveals the need to further understand what patients want and need to feel empowered.

Discussion

It is anticipated that consumer empowerment will likely remain a multi-dimensional construct, as revealed through this initial study. Further review of the literature in security, privacy policy, conflict theory, sociology, management, management information systems, information politics and healthcare information systems will be carried out to better develop theoretical underpinnings of consumer empowerment in e-Healthcare apart from the concepts and constructs identified through the analyses of the data. The purpose here is to develop a rich theory of consumer empowerment in e-Healthcare so that with better understanding and insight we are able to develop better interventions that are practical and better research designs that are more informative. In the context of consumer empowerment in e-Healthcare and the struggle to determine power issues over patient information, literature on intellectual property/copyright and e-commerce opt in and out could be beneficial to examine in the context of e-Healthcare.

As the AHIC documents are analyzed further, along with focus groups providing additional rich descriptions of a variety of perspectives, integration with previous literature will enable the generation of parsimonious constructs for understanding consumer empowerment in e-Healthcare. One AHIC member states this very succinctly, what is needed is to: "*. . . . [take] all the stakeholders and, from the patient's point of view, make some recommendations about what should be done or what should be researched that will really enhance and bring value to all the work that I don't think anyone else is doing*" (Transcript, March 20, 2006). Further examination of these issues will be important to the efforts for building consumer empowerment in e-Healthcare through in-depth investigation of the specific stages of consumer empowerment and detailed interrelationships between the stakeholders.

The initial theoretical model presented in this research is the first step towards developing a conceptual model of consumer empowerment in e-Healthcare. In this study, the initial findings about consumer empowerment are presented. It was found that the role of different stakeholders and their perspectives are critical to move ahead with a practical roadmap for consumer empowerment. The implication of this is that the technological innovations and corresponding e-Healthcare policies will be generated and implemented properly while also appropriately including consumer empowerment concerns and safeguards.

Future Research

From this preliminary analysis, there is a foundation to further study the dimensions of consumer empowerment in e-Healthcare. The next phases of this study will be to utilize the grounded theory approach to further generate concepts and categories through coding of the documentation from at least the following data sources: AHIC Consumer Empowerment Group (CEG) meetings, NCHICA Consumer Advisory Council on Healthcare Information (CACHI) meetings, individual interviews with NCHICA Consumer Advisory Council on Healthcare Information Members, and Consumer Focus Groups and Provider Roundtables. The manner in which these data sources will be used to generate grounded theory for consumer empowerment in e-Healthcare is discussed next. These data sources will help in the development of a comprehensive theory of consumer empowerment in e-Healthcare.

Conclusions and Implications

It is my hope that my contribution to the field of consumer empowerment in e-Healthcare will enable a better understanding of why patients and providers feel the way they do about these issues. It should provide the basis for education of all parties involved, if appropriate, and should support the foundation for a trusting relationship to form between these parties. The implications are to provide knowledge for future academic research in the area of e-Healthcare consumer empowerment. This study could serve as a foundation to stimulate more research in this important area to make the U.S. healthcare system more efficient and effective.

Abbreviated References

[1] American Medical Association (AMA). *E-7.02 Records of Physicians Information and Patients*. Accessed January 2006 at http://www.ama-assn.org/ama/pub/category/8378.html

[2] American Medical Informatics Association (AMIA). (September 14, 2006). *Toward a National Framework for the Secondary Use of Health Data*. Accessed September 2006 at www.amia.org.

[3] Anderson, Joan. (1996) *Empowering Patients: Issues and Strategies*. Social Sciences Medicine. 43:5, 697-705.

[4] Berger, Peter, & Luckman. (1966) *The Social Construction of Reality*. Anchor Books, NY, NY.

[5] Bogdan, Robert C., & Biklen, Sari Knopp (2003) Qualitative *Research for Education: An Introduction to Theories and Methods*. 4th Edition. Allyn and Bacon, Boston.

[6] Botkin, Jeffrey. (Jan. 10, 2001) *Protecting the Privacy of Family Members in Survey and Pedigree Research.* Journal of the American Medical Association. 285:2, 207-211.

[7] Broder, C. (January 18, 2006) Survey: Consumers concerned about control, access to medical info. *Healthcare IT News*. Accessed at http://www.healthcareitnews.com/prinStory.cms?id=4335 on January 28, 2006.

[8] Clemons, Eric K. and Hitt, Lorin. (Fall 2004) *Poaching and the Misappropriation of Information: Transaction Risks of Information Exchange*. Journal of Management Information Systems. 21:2, 87-107.

[9] Congress. House Committee on Commerce, Subcommittee on Health and Environment. *Medical Records Confidentiality in the Modern Delivery of Health Care*. Congress, 1st Session, May 27, 1999.

[10] Enrado, Patty. (Dec. 18, 2006) *Washington State Unveils Health Data Exchange Map.* Healthcare IT News. Accessed Feb. 2007 at http://www.healthcareitnews.com/story.cms?id=6068.

[11] Fernandez, Walter, and Lehmann, Hans. (2005) *Achieving Rigor and Relevance in Information Systems Studies: Using Grounded Theory to Investigate Organizational Cases*. The Grounded Theory Review. 5:1, 79-107.

[12] Ferris, Nancy (Feb. 13, 2006) *Hidden Keys to Health.* Government Health IT. Accessed March 2006 at http://www.govhealthit.com/article92279-02-13-06-Print

[13] Ferris, Nancy (April 2007) *Finding Foreman.* Government Health IT. Pg. 16-21.

[14] Geller, Jeffrey, Brown, Jule-Marie, Fisher, William, Grudzinskas, Albert, Manning, Thomas. (April, 1998) *A National Survey of Consumer Empowerment at the State Level. Psychiatric Services*. 49, 498-503.

[15] Glaser, Barney, Strauss, Anselm. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine Publishing Company: Chicago, IL.

[16] Glaser, Barney. (November 2004) *Remodeling Grounded Theory.* The Grounded Theory Review: An International Journal. 4:1, 1-24.

[17] Goldman, Janlori. (1999) *Privacy and Individual Empowerment in the Interactive Age*. Visions of Privacy: Policy Choice for the Digital Age. University of Toronto Press. 97-115.

[18] Gregor, Shirley. (Sept. 2006) *The Nature of Theory in Information Systems*. MIS Quarterly. 30:3, 611-642.

[19] Gue, D'Arcy Guerin and Upham, Randa. (Sept. 2004) *The HIPAA Prescription for Healthcare—Why Isn't It Working?* Health Management Technology. 34-37.

[20] Hayes, Heather (Feb. 2007) *Advantage: Dems*. Government Health IT. 32-33.

[21] HIMSS (Healthcare Information Management System Society) (2007) *Health Information Technology: Cutting Costs, Saving Lives*. Accessed May 2007 at http://www.himss.org/advocacy/news_editorials.asp#14.

[22] Kamenka, Eugene, editor (1983) *The Portable Karl Marx.* London: England, Penguin Books.

[23] Lake Research Partners. (November 2006) *Survey Finds Americans Want Electronic Personal Health Information to Improve Own Care*. www.lakeresearch.com

[24] Luo, Wenhong and Najdawi, Mohammad. (Jan. 2004) *Trust-Building Measures: A Review of Consumer Health Portals.* Communications of the ACM. 47:1, 109-113.

[25] Mercuri, Rebecca. (July 2004) *The HIPAA-potamus in Health Care Data Security*. Communications of the ACM. July 2004. 47:7., 25-28.

[26] NC HISPC (Healthcare Information Security and Privacy Council). (2007) *Privacy and Security Solutions for Interoperable Health Information Exchange: Final State Implementation Report.* NCHICA (North Carolina Healthcare Information and Communications Alliance). Accessed May 2007 at http://www.nchica.org/NCHISPC/NC%20HISPC%20Final%20Implementation%20Plan%20Published.pdf .

[27] NCHICA (North Carolina Healthcare Information and Communications Alliance). www.nchica.org

[28] Perkins, Douglas, and Zimmerman, Marc. (1995*) Empowerment Theory, Research, and Application*. American Journal of Community Psychology. 23:5, 569-579.

[29] Rindfleisch, Thomas. (August 1997*) Privacy, Information Technology, and Health Care*. Communications of the ACM. 40:8, 93-100.

[30] Rose, Nikolas (1999) *Governing the Soul: The Shaping of the Private Self.* Free Association Books. London.

[31] Shankar, Avi, Cherrier, Helene, Canniford, Robin. (2006) Consumer Empowerment: A Foucaultian Interpretation. European Journal of Marketing. 40:9/10, 1013-1030.

[32] Shaw, Deirdre, Newholm, Terry, and Dickinson, Roger. (2006) Consumption as Voting: An Exploration of Consumer Empowerment. European Journal of Marketing. 40:9/10, 1049-1067.

[33] Slone, Sean. (May 2007) *health-e Connections: States Make Plans for Health IT to Improve Quality, Lower Costs*. State News. The Council of State Governments. 50:5, 9-13.

[34] Tang, Paul, Lansky, David. (Sept/Oct 2005) *The Missing Link: Bridging the Patient-Provider Health Information Gap*. Heath Affairs. 1290-1295., Luc, Brenner, Lyle, Carmon, Ziv, Drolet, Aimee, Gourville, Muthukrishnan, AV, Novemsky, Nathan, Ratner, Rebecca, and Wu, George. (2002) *Consumer Control and Empowerment: A Primer*. Marketing Letters. 13:3, 297-305.

[35] White, Kevin. (2002) Foucault and the Sociology of Medical Knowledge. *An Introduction to the Sociology of Health and Illness.* Sage Publications.

[36] Wilkinson, Adrian. (1997) *Empowerment: Theory and Practice*. Personnel Review. 27:1, 40-56.