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# Incidental or Intentional? Achieving Consumer Empowerment in Electronic Healthcare Information Exchange

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## **ABSTRACT**

The emergence of technology which allows for electronic Healthcare Information Exchange (HIE) has created a need for change in the healthcare industry. Because sensitive health information can be shared electronically between many entities, it is important to re-examine how information should be shared. Recent initiatives have examined HIE technology, with the intention to involve the consumer/patient as a key stakeholder. Such initiatives seek to empower patients, and often claim that new technology can do so. This study investigates the dimensions of consumer empowerment in HIE and how consumer empowerment in HIE could be achieved. The analysis revealed that achieving consumer empowerment is a process of either intentional or incidental change, and is a multi-faceted concept. The process of consumer empowerment is presented from the grounded theory analysis of three levels of data sources. The implications are critical to generate appropriate policy, law, and technology.

## **Keywords**

Patient, consumer, empowerment, healthcare, healthcare information exchange, grounded theory

## **INTRODUCTION**

Health Information Exchange (HIE) is the electronic exchange of medical information. With the potential of new technology such as Electronic Health Records (EHRs), Personal Health Records (PHRs) and the Nationwide Health Information Network (NHIN), there is increased capability to share medical records between healthcare stakeholders to improve the quality of healthcare. However, since sensitive medical information can be shared electronically, there is also a risk that the information may be disclosed in an unauthorized manner. "The public is saying, 'Wait! My information is floating out there, and it's forcing people to take it seriously'" says Fahim-Koster, a privacy officer with Gwinnett Health Systems (AHIMA, 2009). There are initiatives such as the AHIC (American Health Information Community) and the National HISPC (Health Information Security and Privacy Collaboration) which seek to examine in what ways the new technology will affect how, when, and to what extent that health information can be shared. There has been an increased awareness of how consumers will be affected and how their perspectives can be included in such efforts so that appropriate policy and technology will be generated. This interest in the consumer view has led to a call for consumer empowerment in HIE. However, it is not clear what leaders of these efforts consider consumer empowerment to be, much less, how consumer empowerment may be achieved in HIE. This study examines two research questions. The first research question is "What are the dimensions of consumer empowerment in HIE? The second research question is "How can consumer empowerment in HIE be achieved?"

## **EMPOWERMENT**

There are numerous definitions of empowerment. Most research implies that empowerment entails more than just the concepts of self-esteem, self-efficacy, competency, or locus of control (Perkins & Zimmerman, 1995). A literature review was performed to examine the conceptions of empowerment from sociology, marketing, management and IS (Information Systems), and healthcare.

The focus of empowerment in sociology has been on disparities in power, class, and control through surveillance. 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. For example, one way that the government and organizations can enact social control is through the control of information (White, 2002). The obstacle to empowerment is the inherent difference in power due to institutional structures and power relations. Empowerment in the marketing literature focuses on the concept that consumers can enforce power through marketplace economics (Shaw, Newholm, & Dickson, 2006). 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). However, this premise presumes two things: that everyone has a similar capacity and similar 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). According to Shankar and colleagues (2006), this also assumes that consumers are rational utility maximizers in making choices, which may not be true. Wilkinson (1997) and Sjoberg and Timpka (1998) suggest that from a managerial and IS perspective, the emphasis on empowerment began through the management of organizational culture, an emphasis on teamwork, and employee involvement in innovation efforts through participatory design. Healthcare literature discusses empowerment as access to Internet websites so that consumers educate themselves on treatments, medications, procedures, and quality of healthcare providers (Luo & Najdawi, 2004).

The implication of the consumer empowerment literature from these areas is important. The dimensions of consumer empowerment in HIE are not known. In order to determine how consumers might be empowered, it is critical to understand the dimensions of consumer empowerment in healthcare information exchange.

**METHODOLOGY AND DATA COLLECTION**

Consumer empowerment should be understood within the complex context of HIE. HIE is a relatively new phenomenon in healthcare, and many components of it are not well-understood. “What we want to learn will help shape the research questions posed, and the questions posed will depend on the stage of knowledge accrual about the phenomenon” (Rowlands, 2003, p. 4). Because this stream of research entails the examination of a new phenomenon, an interpretive approach is necessary. Interpretive research helps to provide a foundation for understanding an emerging phenomenon within “social constructions such as language, consciousness, and shared meanings” (Rowlands, 2003, p. 3). One type of interpretive research, the grounded theory approach, 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). Therefore, to investigate consumer empowerment in HIE, a grounded theory approach was utilized. The grounded theory approach is a well-established and systematic way to develop theory founded in qualitative data. To seek a better understanding, data for this study was obtained from three data sources, a federal United States group (AHIC), a state group (CACHI), and a group of Everyday Consumers, which are described in Table 1.

Data Source	Purpose	Members	Length of Data Collection (until data saturation)	Type of Data Collection
AHIC Consumer Empowerment Group	Federal viewpoint of consumer empowerment in HIE	From a variety of organizations such as patient advocacy groups, insurance companies, government agencies, and insurance companies	6 months	Meeting transcripts and Meeting audio files
NCHICA Consumer Advisory Council on Health Information (CACHI)	State of North Carolina viewpoint of consumer empowerment in HIE	A variety of members such as a person who represented a public health perspective, a person who represented the senior citizen perspective and others who worked in health IT or health privacy positions	1 1/2 years	Meeting Attendance; transcripts, agendas, presentations, Follow-up interviews
Everyday Consumers	To gain insight into perspectives of consumer empowerment through 'everyday' healthcare consumers in NC	Individual consumers who had no formal IT (information technology) or healthcare work experience; Some of the occupations included retired school teacher, welding supervisor, and administrative assistant.	5 months	Semi-Structured Interviews

**Table 1—Data Collection**

**ANALYSIS**

Systematic methods for constant comparative analysis were utilized according to the grounded theory approach. 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). The constant comparative

methods include open, axial, and selective coding. Open coding is the process of analyzing the data and generating as many codes as possible from the patterns which emerge in the data. After data is saturated and the patterns begin to repeat, axial coding can be performed, which is finding relationships between the open codes (Creswell, 1998, p. 209) by examining their properties and contexts (Glaser & Strauss, 1967). Selective coding is the last step, which means the codes are delimited to generate a parsimonious theory (Glaser, 2004).

To perform the analysis of data for these three groups, a ‘nested grounded theory approach’ was utilized. For the analysis of these three groups, open, axial, and selective coding were performed separately for each group, resulting in three different sets of dimensions of Consumer Empowerment in HIE. The next phase of analysis was to combine these three sets of dimensions from each group into one integrated theoretical model. This integrated theoretical model provided the theory for the first research question “What are the dimensions of consumer empowerment in HIE?” They also formed the foundation for the second research question “How can Consumer Empowerment be Achieved in HIE?”

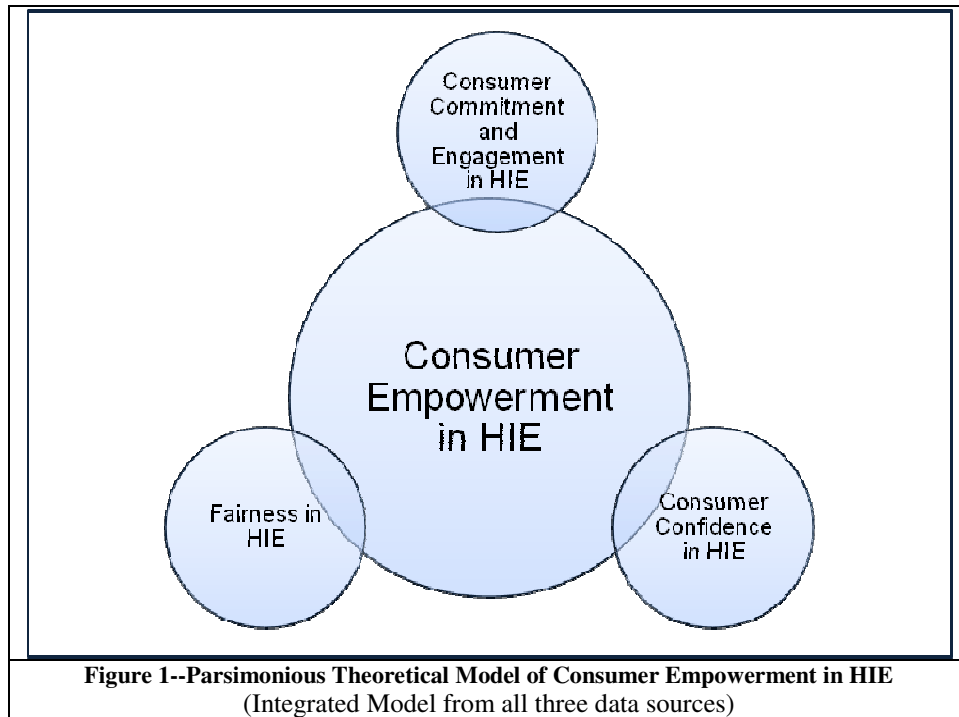
**DIMENSIONS OF CONSUMER EMPOWERMENT IN HIE**

The findings from the first research question are shown in Table 2. From the integrated analysis of these three groups, consumer empowerment in HIE can be formed by three dimensions: Consumer Commitment and Engagement in HIE, a sense of Fairness in HIE, and a level of Consumer Confidence in HIE. What emerged is that consumer empowerment is relative, and each person may have a satisfactory level of being empowered which may be different than another person’s perspective.

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

**Table 2—Integrated Dimensions of Consumer Empowerment in HIE**

These three dimensions of the theoretical model of consumer empowerment in HIE (see Figure 1) , Consumer Confidence in HIE, Consumer Commitment and Engagement in HIE, and Fairness in HIE are the foundation to discuss the process of consumer empowerment in HIE. It should be noted that these dimensions can overlap with one another and can, indeed, be dependent upon one another. For example, a consumer may need to feel confident that HIE technology is important (Technology Mediation) in order to become committed to learn more about it (Education through Sources of Information). These activities are discussed next within the context of how consumer empowerment may be achieved. Because it was a dimension which arose frequently in all three of the data sources, Consumer Commitment and Engagement will be discussed first, at a more detailed level.



**THE PROCESS TO ACHIEVE CONSUMER EMPOWERMENT IN HIE**

“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). To apply the results of the previous theoretical model, ways to achieve consumer empowerment in HIE were also examined. What was revealed from the analysis of the three data sources is that consumer empowerment is a process of activities. We normally think of people as being either empowered or not, with empowerment being a bipolar state. However, it is relative to each person, and can be formed throughout different activities. In which order these activities evolve is also relative to each individual, and a standardized, clear-cut process of steps to take to achieve consumer empowerment in HIE is not evident from this study.

One person cannot hand empowerment to another person. There must be some type of activities which enable a person to become empowered. A doctor may provide a privacy policy for a patient to read, but the patient may choose not to read it. The patient’s choice to read it is a decision which could lead to incidental empowerment. Perhaps through reading the policy, the patient learns something about the disclosure of her information she didn’t know before, and it prompts her to search the internet for more information. Her next step to intentionally search the internet for more information can be considered as a form of intentional empowerment. Therefore, consumer empowerment in HIE can be achieved either intentionally (deliberately and with purpose) or incidentally (by chance or by accident).

Based on the information analyzed from the three data sources, activities which support a foundation for consumer empowerment in HIE are discussed next. These are examined within the context of previous literature and within the three dimensions of consumer empowerment in HIE (Consumer Confidence, Fairness, and Consumer Commitment and Engagement).

**Consumer Commitment and Engagement in HIE**

All three data sources relayed the importance of being able to understand and be active in HIE. **Consumer Understanding** can be achieved through *Awareness, Education, and Literacy* through different *Sources of Information*. **Consumer Action** can be achieved through the *Consumer Voice, Communication, and Participation*. Through an initial level of Awareness, the consumer can learn more about HIE by Communicating and Participating. As the consumer becomes more Educated, she may find 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 to become more Educated.

Awareness, according to the Encarta World English Dictionary<sup>1</sup> can mean “noticing or realizing something: knowing 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 about a disclosure of medical information because a laptop was stolen, she may become Aware such a situation could occur. Therefore, one should be Aware of an issue or concern in HIE before becoming Educated in that area.

According to the Encarta World English Dictionary Educated means “knowledgeable: having the benefit of experience or knowledge” 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.

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. Once they become Aware of an HIE topic (such as privacy issues), consumers may travel through a process to become Educated at a level in which they are comfortable. Thus, a consumer can choose whether to follow-up on their Awareness to act, by, for example, seeking information.

One critical aspect of Education is the role of Functional Literacy and Health Literacy. Functional literacy means a person has an educational level “sufficient to function in a modern society” (National Assessment of Adult Literacy, website). 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). Toni Cordell<sup>2</sup>, a patient advocate in the Everyday Consumer group, stated, “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 level of self-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). “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). “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 they can better manage their own care. 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:

. . . 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 . . .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. . .

What is important to note is this person’s statement that the literature is very weak around the concept of HIT (Health Information Technology) and health literacy. This suggests there may be a new category of HIE literacy which needs to be better understood. HIE Literacy could be incorporated into Adult Basic Education and in the general high school curriculum

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<sup>1</sup> See [www.encyclopedia.com](http://www.encyclopedia.com)

<sup>2</sup> This patient advocate is Toni Cordell who agreed to let me use her name as an Everyday Consumer for this study. 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 her article (“Chasing the Monster” in the North Carolina Medical Journal), which addressed her healthcare experience being a high school graduate with a 5th grade reading level. Due to a very traumatizing healthcare experience, Toni was prompted to become a patient advocate.

in the United States (Diehl, 2007). The faith community in North Carolina, as suggested by CACHI (Consumer Advisory Council on Health Information), has also been engaged in health literacy and communication efforts because the church is an important social structure which provides support and community leadership (Plescia & Newton-Ward, 2007). Public-campaigns can be utilized, however, “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). Therefore, efforts should be made to increase awareness of the population.

Having a variety of Sources of Information upon which to build a stock of knowledge can be important. From both literature and from the three data sources in this study, consumers trust their providers over any other stakeholder to be a Source of Information about HIE. It was found by Roth (1994) that more complicated information should be communicated by physicians. Therefore, there will be a need to ensure providers are appropriately informed about HIE and have educational materials available. The consent process should be clear, with appropriate readability for policies and forms.

Using a variety of sources of information is important. Consumers often discuss different decisions with family members and friends, and it is anticipated that they will also discuss HIE issues with people close to them, to help structure their perceptions of HIE. Groups such as CACHI provide ways for consumers to learn from presenters, the Internet<sup>3</sup>, and collaboration with other groups such as HISPC (Health Information Security and Privacy Collaboration). Collaborative efforts such as CACHI and AHIC 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). Therefore, the process of being Aware and Educated is iterative. As a consumer becomes aware of a new HIE issue, she may choose to become more educated in that area.

It is difficult to achieve Consumer Understanding without some level of **Consumer Action**. The consumer may decide to act at the macro or micro level. She may decide to ask the doctor more questions, or to search for information on the internet, or to use a PHR. These are micro-level activities which affect her directly. Or she may decide to participate in HIE efforts such as CACHI, which would be a macro-level effort.

The 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 voices are sometimes “small voices with limited access to the public legitimation” (Rappaport, 1995, p. 799). “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). For the members of CACHI, this was important. One member felt the discussions 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. Consumer Voice should be more than token, and, as one of the speakers to the CACHI group stated, “should be on equal footing” as others involved in HIE initiatives, such as vendors and insurance companies. The CACHI group was involved in the NC Governance Council and the NCHICA NHIN Project, Phase II, and provides feedback on these projects. A CACHI member attended the HISPC Privacy and Security Solutions National Conference to present CACHI’s efforts. CACHI also provided input on a Consumer Toolkit for the HISPC project. Their voice allowed them to communicate and participate in other HIE-related initiatives.

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). Communication such as asking questions is important to find answers, which only temporarily stop the process of searching. Often, asking questions prompts additional questions, thus the cyclical nature of becoming educated. 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.

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<sup>3</sup> NCHICA CACHI Resources Web Page. <http://www.nchica.org/CACHI/resources.htm>



While it is ideal for consumer participation in HIE initiatives such as AHIC or CACHI, representatives of those groups may be appropriate. 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. As stated by a CACHI member, “the problem is to reach out and get people involved with time commitment to come” suggests 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. Grassroots groups such as CACHI are those which consist of “interventions that “act” small and locally, even as they “think” more globally, are most effective” (Weick, 1984).

### **Fairness in HIE**

Fairness can be supported through **Legal and Institutional Provisions** (*Law, Policy, and Enforcement*) and considerations of **Social Justice** (*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 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 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. Policymakers should examine state and federal laws to determine which is more stringent while also providing strong enforcement, which was a main concern of the Everyday Consumers. In framing HIE issues for legislators, it should be within 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. 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. The legislator 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<sup>4</sup>).

Because it relies 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). The Digital Divide will need to be addressed. How will consumers be provided with HIE technology? Providers could provide kiosks in their offices for patient access.

AHIC examined the ways that needs of different populations of people (for example, people with stigmatizing health conditions such as mental health issues) 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 substance abuse patients can disclose only the information they feel is needed to specific providers. What is critical to understand is that with increased consumer control over their own health records there is also an associated Responsibility to understand and to use HIE in an informed manner. These social justice problems will not be solved any time soon in society, but inequities should be considered when creating HIE technology and policy.

### **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 and to enable efficient electronic consent management. 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 Information Integrity exists. It is not clear that HIE technology will provide clarity to the

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<sup>4</sup> NCHICA website: [www.nchica.org](http://www.nchica.org)



notion of Information Ownership. 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 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 they think is necessary to specific providers. Therefore, clear granular-level Consent Management options should be offered so patients can Control the Access to their medical records as they feel appropriate.

Consumer Assurance entails how comfortable a consumer is with HIE technology and processes. There is a level of Distrust which emerged from the data. The Everyday Consumers especially seemed to speak of their assurance level in negative terms of Distrust, rather than trust. Therefore I preserved the context of their beliefs by using the term Level of Distrust. They particularly didn't have much faith in the government or employees of doctors to keep their information safe, and they wanted them to be accountable for their health information privacy. One of the issues expressed by AHIC and CACHI, and somewhat by the Everyday Consumer group was that of information integrity. If health records which were inaccurate and incomplete were transferred to a physician, an incorrect medical diagnosis could be made. Therefore, it relates back to the Responsibility of both physicians and, to an extent, patients, to verify the information in their records.

Conventions in HIE such as 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 they prefer, and be confident certain security features are included. The capability for consumers to use portable and interoperable PHRs which are based on standard protocols can support Consumer Confidence in HIE.

## **DISCUSSION**

The analysis revealed that achieving consumer empowerment can be supported by a foundation of Consumer Confidence, Consumer Commitment and Engagement, and a sense of Fairness in HIE. Empowerment was revealed to be a process instead of a bipolar state (either empowered or not). It is a multi-dimensional issue because empowerment is relative to each person and even to different situations. It was also discovered that consumer empowerment can be achieved through either intentional or incidental efforts. Different activities were suggested which could build a foundation for the achievement of consumer empowerment in HIE. It is expected that not all consumers will be equally motivated to become intentionally empowered, and that they may experience incidental empowerment at the least, for example, through access to informational brochures about HIE. If consumers and physicians do not adopt HIE technology because of lack of understanding, lack of resources, fear of privacy invasion, or other reasons, the potential for improved healthcare may not be realized. A larger group of Everyday Consumers, from different populations (such as those with stigmatizing conditions, representatives of foster children, different regional/state groups, etc) should also be examined in future research for a more comprehensive view of their perspectives on HIE. It would also be of value to compare these findings internationally to understand how global HIE may be affected. Further empirical testing of these results could be performed through various in-depth qualitative analyses or through surveys. The findings from this study will be important as a foundation for future research to further define consumer empowerment and its multi-faceted nature, as well as for practitioners, vendors, and policymakers who need to consider consumers in HIE initiatives, technology, policy, and law.

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