

Consumer Opinions of Health Information Exchange, e-Prescribing, and Personal Health Records

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Abstract

Background—Consumer satisfaction is a crucial component of health information technology (HIT) utilization, as high satisfaction is expected to increase HIT utilization among providers and to allow consumers to become full participants in their own healthcare management.

Objective—The primary objective of this pilot study was to identify consumer perspectives on health information technologies including health information exchange (HIE), e-prescribing (e-Rx), and personal health records (PHRs).

Methods—Eight focus groups were conducted in seven towns and cities across Nebraska in 2013. Each group consisted of 10–12 participants. Discussions were organized topically in the following categories: HIE, e-Rx, and PHR. The qualitative analysis consisted of immersion and crystallization to develop a coding scheme that included both preconceived and emergent themes. Common themes across focus groups were identified and compiled for each discussion category.

Results—The study had 67 participants, of which 18 (27 percent) were male. Focus group findings revealed both perceived barriers and benefits to the adoption of HIT. Common HIT concerns expressed across focus groups included privacy and security of medical information, decreases in quality of care, inconsistent provider participation, and the potential cost of implementation. Positive expectations regarding HIT included better accuracy and completeness of information, and improved communication and coordination between healthcare providers. Improvements in patient care were expected as a result of easy physician access to consolidated information across providers as well as the speed of sharing and availability of information in an emergency. In addition, participants were optimistic about patient empowerment and convenient access to and control of personal health data.

Conclusion—Consumer concerns focused on privacy and security of the health information, as well as the cost of implementing the technologies and the possibility of an unintended negative impact on the quality of care. While negative perceptions present barriers for potential patient acceptance, benefits such as speed and convenience, patient oversight of health data, and safety improvements may counterbalance these concerns.

Key Words: health information technology; health information exchange; e-prescribing; personal health records

Background and Significance

The goal of the Health Information Technology for Economic and Clinical Health Act (HITECH), signed into law in 2009, is to increase the use of health information technology.^{1,2} One component of the act that has received significant attention and funding is the development of health information exchanges (HIEs), particularly statewide exchanges. A HIE connects healthcare providers, allows the electronic sharing of health information, aids in the management of data exchange, and strives to reduce duplication of services and operational costs.³ A planned national network of such exchanges has the potential to improve the nation's overall health.⁴

Three dominant types of HIEs exist. A directed exchange is generally used to support coordinated care and allows health information to be securely transmitted between providers. Query-based exchanges allow a provider to search for health information from a large network of participating healthcare organizations and providers. Consumer-mediated exchanges allow patients to share their aggregated personal health information with the providers of their choice.⁵

The Nebraska Health Information Initiative (NeHII), part of the planned national network, is a statewide, Internet-based HIE sponsored by Nebraska healthcare providers and health insurers who share and use information for both treatment and payment purposes.⁶ NeHII, a query-based HIE, allows participating providers to access more complete electronic health records (EHRs) and thus serve patients more efficiently by acting as a transfer source for medical records.⁷ A statewide network of providers is able to query information from other participating providers in near real time and securely transfer patient information among the network as necessary. Additionally, NeHII can connect pharmacy, laboratory, and insurer data to a physician's EHR, allowing prescribers to view patient laboratory results, medication histories, and formulary information from multiple sources.

Electronic prescribing, or e-prescribing (e-Rx), is a technology that allows a physician's EHR to transfer prescriptions securely to a pharmacy. Either the pharmacy software or the physician's EHR may screen prescriptions for interactions or perform other safety-related checks, depending on the level of clinical decision support available in the software. Electronic prescribing also reduces legibility problems associated with handwritten prescriptions.⁸

A personal health record (PHR) is "a private, secure application through which an individual may access, manage, and share his or her health information. The PHR can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers."⁹ PHRs have the potential to improve self-management, enhance communication between the provider and patient, and reduce redundant tests. Numerous studies discussing the potential value of PHRs have been published, including several randomized controlled trials.^{10,11}

Consumer satisfaction is crucial to HIE utilization because high satisfaction is expected to increase HIE awareness and participation among healthcare providers. The underlying technology of the HIE has the potential to affect consumers positively, enabling them to become full participants in their own healthcare management through the development and use of PHRs.¹² Including consumers as key players in their own healthcare management and streamlining the information exchange process are part of both HIE utilization and improving patient care.¹³⁻¹⁷

The primary objective of this pilot study was to identify consumer perspectives on health information technologies including HIE, e-Rx, and PHRs.

Methods

Eight focus groups were conducted in April–June 2013 in seven towns and cities across Nebraska. Participants were recruited through local health departments, clinics, and public organizations. Directors or administrators recruited 10–12 participants from their board of directors, employees, and networks of consumers. Recruitment for the Omaha focus groups was conducted by researchers at the local food bank while clients waited in line.

We utilized questions to start the focus group discussions and organize the flow of conversation. Discussions were organized topically in the following categories: HIE, NeHII, e-Rx, PHRs, and the desired format of HIE education. Participants were asked about familiarity and experience with each category as well as their perceived advantages and disadvantages. Focus group audio files were transcribed and imported into NVivo qualitative data analysis software (version 10) for analysis.¹⁸ The qualitative analysis consisted of immersion (i.e., reading and exploring the data as a whole and in pieces) and crystallization (i.e., reflecting and identifying relevant substance, themes, and patterns from the immersion process). We engaged in this iterative and nonlinear process to develop a coding scheme that included both preconceived and emergent themes. Common themes across focus groups were identified and compiled for each discussion category.

This project was a component of a broader evaluation of the Nebraska Health Information Initiative. The University of Nebraska Medical Center Institutional Review Board approved the study.

Results

The focus groups had a total of 67 participants, of whom 18 (27 percent) were male. Focus groups ranged in size from 2 to 11 individuals (see Table 1). Consistent with the recruitment strategy, the majority of participants were employed in the healthcare industry or at a health department.

Consumers generally had low awareness of various electronic medical information services. Few people (on average two to three individuals per focus group) were familiar with or had heard of electronic medical record sharing via HIE, or NeHII in particular. Just a few consumers were specifically aware of having used NeHII, and they expressed overall satisfaction based on the availability of medical information to multiple providers. One participant commented: *“Everything I had heard was very positive and I remember hearing Nebraska was one of the few states to have a statewide HIE already, and our area was one of the first to use it for immunizations.”*

Regardless of the topic discussed, common themes emerged in all focus groups. Almost all participants expressed at least some level of concern about the use of Internet-enabled sharing of electronic medical records and data. These concerns were common in discussion of each of the specific services: HIE, e-Rx, and PHRs (see Table 2).

Privacy and security were common concerns across all of the focus groups. A large proportion of individuals across all groups were worried about high accessibility of private medical information. In addition, many contemplated inappropriate, broad access and deliberate misuse of this information. Some concerns included potential information spread and damage by hackers or perpetrators of fraud. Many of the participants' statements on this topic appeared to have a fearful, emotional quality. Other perceived disadvantages of Internet-based electronic medical records were more specific, such as prescription fraud, potential insurance company misuse of information to deny claims, and Social Security number theft. Comments included *“I share the . . . concerns about confidentiality. I would not want people to see my diagnosis. So confidentiality is really important to me, and if you spread it out over the statewide web-based program, there is a chance to lose that confidentiality,”* and *“I think that there are some really smart people out there who could ruin your life with the knowledge [they could access]. I don't like my Social Security number being out there.”*

Many participants pointed to electronic infrastructure as a potential problem. Concerns in this area included Internet reliability, especially in rural locations, potential problems with connections between providers, the impact of power outages, the potential for data loss, and the impact of future changes in technology. In addition, participants felt that technology could be a possible hindrance to patient interaction for a healthcare provider. A few participants expressed a general lack of trust for technology, and noted that older individuals in particular may not be comfortable with computers and technology. One participant commented: *“My physician uses this system. I've gotten missed a few times, probably electronically something happens and it doesn't get there. It's another phone call, and call the doctor that the pharmacist didn't get it. But my MD always hits send when I'm there so I know.”*

Participants commented about responsibility for data accuracy and errors in electronic data that could have negative and even devastating consequences. Many participants suggested that documentation of

access to online medical records—by whom and when—is a necessary safeguard to protect privacy. Several participants across groups expressed concern about the impact of possible mistaken identity and mix-ups of individuals with the same or similar names due to use of electronic medical records. For example, one commented: *“The biggest thing I see is same names and birth dates, if you’re on a nationwide system if the MD doesn’t pay close enough attention they could pull up someone else’s record.”*

Although a few participants expressed appreciation for electronic medical records’ use of technology, these points of view were in contrast to the general consensus across the groups. The major positive feedback regarding Internet-enabled services using electronic medical records was consolidation of diverse medical data across providers: *“One advantage would be, once the information is there you have it all in one place. My doctor was going through my information with me before my surgery and I forgot about a knee surgery I had and I couldn’t remember the year and so—those things, you give it to them once, it’s there for yourself and any doctor or provider.”*

Health Information Exchange

The negative feedback specifically related to HIE centered on possible decreases in the quality of care, inconsistent provider participation, and potential cost. A small number of participants expressed concern about physician bias based on previous diagnoses. Several participants independently expressed concern about reduced interaction between physicians and patients with HIE due to increased physician focus on the computer during visits; for example, *“I think the personal relationship with the doctor suffers with [the doctor’s focus on] the computer instead of visiting, and you aren’t getting more comfortable with the doctor.”*

Several people were concerned that not all physicians would participate, potentially leading to incomplete medical records. In addition, the cost to providers was discussed as a potential limitation. Some worried that providers with smaller practices would be at an unfair disadvantage. Additionally, several people from different groups expressed concern about delays and accuracy in data entry that could negatively affect patient care.

Positive feedback regarding HIE focused on potential improvements in the quality of care. A large number of participants noted that an advantage of HIE is improved communication, coordination, and access to information between healthcare providers. A few noted avoidance of duplicate procedures and services as other advantages; for example, *“For me [a benefit] would be coordination among specialists, because when you’re dealing with multiple health issues and each one requires a specialist, matching up the care and ensuring there’s no conflicts in treatment plans, is probably going to be our biggest priority.”*

Many participants noted that quick access to medical information, especially in an emergency situation, is a benefit of HIE. Additional advantages included accuracy and completeness of information without having to rely on the memory of the patient or caregiver. Some commented that HIE could reduce medication errors and could help identify medication abuse: *“[I]f there were any medications that couldn’t go with each other because of health risks or harm, they would know right away. Or abusers of prescription medicine, the doctors would know so they can avoid contributing unknowingly.”* In addition, a couple of participants noted the possible benefit of using HIE data for public health research.

E-prescribing

Negative feedback specifically related to e-Rx was based on possible limitations in choice of pharmacy, cost impact, and lack of resolution for some existing problems. Some participants noted the limitation of the system not crossing state lines. In addition, one participant was concerned that some drugs may be excluded from the system. Several participants worried that they might not get to choose their preferred pharmacy or that it would be challenging to change pharmacies once one is selected. One commented: *“[O]ne bad thing would be a convenience thing, . . . if you changed your mind about the pharmacy you wanted to go to, you’d still need to go to the pharmacy you told the doctor.”*

A few participants expressed concerns about cost of the e-Rx system. They wondered about costs being passed on to consumers, and about the potential negative impact on smaller pharmacies. Some also noted that e-Rx does not necessarily solve existing problems, such as human error, insurance issues, and lack of notification if a pharmacy does not stock a particular medication.

Positive feedback specifically related to e-Rx centered on improvements in safety, reduction of fraud and abuse, and speed and convenience. Several participants across groups remarked that e-Rx might improve prescription accuracy and reduce errors. The online format allows physicians to avoid drug interactions and over-prescribing, while also avoiding problems with handwriting legibility. One participant commented: *“As someone who calls in prescriptions rather frequently, having it in an electronic form it would save my time. And if I have a transcription problem and I give the wrong prescription from the pad, someone could be in jeopardy of being given something they weren’t prescribed. It cuts down on medication errors.”*

A few individuals also remarked that e-Rx could reduce fraud and prescription abuse, and several people mentioned the convenience of paperless prescriptions. More than a third of participants verbally noted that speed or convenience would make e-Rx more advantageous than a paper/call/fax-based system. Several specifically talked about appreciating the speed of prescription transmittal, and not having to wait at the pharmacy; for example, *“I don’t live in the same town as my doctor so being able to save that time wise without having to drive down there and wait however long it’s going to take, just to have it right away would be really nice.”*

Personal Health Records

Just a few participants had heard of PHRs, and only one individual indicated having actual experience using a PHR. Negative feedback specific to PHRs was primarily based on concerns about some consumers’ lacking sufficient computer access or knowledge to take advantage of the service, and about the difficulty of interpreting medical information for some consumers; for example, *“I think a negative would be access, there are a lot of people who don’t have Internet and computers and wouldn’t be able to obtain those records.”* Positive feedback specific to PHRs focused on patient awareness of health data, and the convenience of a consolidated information source. Participants noted the advantage of being more aware of or having access to one’s own health data, as well as potentially having access to monitor a family member’s (e.g., child’s or aging parent’s) health. Several commented that PHRs allow patients to be more proactive about their health, and provides the convenience of access anytime from anywhere. A few individuals specifically said that they would like to see details such as lab results, x-rays, and provider notes.

Participants noted the advantage of patient access to the consolidated information from multiple doctors in one place. They said that having an electronic file would be easier than keeping track of many papers. In addition, several commented on the benefit of not having to remember the details of their health history; for example, *“I would say that in our particular situation we have such an extensive medical history that it just would not be very practical to maintain hard copies of it. I mean it would fill filing cabinets. So, to have that electronically would be a lot easier for us. Also, having it at your fingertips right when you needed it.”*

Several participants said that they would like to be notified about who accesses their health data. Also, patients’ access to their own electronic health records could facilitate identification and correction of errors.

Input on HIE Education Delivery

Participants provided feedback as to the methods and media they believed would be effective in educating consumers about the state’s query-based HIE (NeHII). A majority of focus group participants specifically expressed a preference to be informed about NeHII in an in-person setting. Some said supplemental written material would also be helpful. Many participants indicated that a physician should educate patients about NeHII. Others added that nurses, other healthcare providers, and office workers could also participate in education. One participant commented: *“I think it needs to start with your doctor*

and then they can expose you to it and have something in writing so when you do leave you can go back and look at what they said.”

A few participants said that a local health department could be involved in education, and others suggested in-person workshops. Multiple types of media outlets were also discussed as education options, but participants had differing preferences for types of media to support education. Generally, participants agreed that coordination of several types of media would be necessary to reach a range of consumers effectively. Some recommended brochures and/or posters in medical offices (and possibly elsewhere), and others thought letters via postal mail would be effective.

Participants commented that education efforts should be tailored to different age groups. Some noted that older individuals are less likely to be comfortable with computers and need to be approached differently than young people who are more familiar with technology. The need to address non-English speakers was also noted. When participants were prompted, reactions to whether the government should be involved in HIE education ranged widely from strong resistance to suggested involvement.

Discussion

Focus group findings revealed both perceived barriers and benefits to consumer adoption of HIT including HIE, e-Rx, and PHRs. In general, participants were very positive about the potential benefits of these technologies. Improvements in patient care were expected as a result of physician access to consolidated information across providers as well as speed of sharing and availability of information in an emergency. In addition, participants were optimistic about patient empowerment in the form of convenient access to and control of personal health data. Participants were generally open to seeing HIE and related services as beneficial tools to reduce concern and effort in the tasks of organizing and monitoring medical information for oneself and one's family members.

A major barrier was the perceived risks of sharing confidential medical information via the Internet. Focus group participants' concerns centered on general fear of technology, accidental inappropriate sharing of information, and crimes such as fraud and identity theft. Many participant statements conveyed fear and apprehension either directly or indirectly. Indeed, Internet crime, such as fraud and identity theft, is a reality and a justifiable consumer concern.¹⁹

Although consumer feedback on the sharing of health information is relatively new in the medical setting, businesses have been working to address consumers' fears of online fraud and general apprehension about online information sharing for the past two decades to assess and improve online purchasing behavior.^{20, 21} Higher education levels and behavioral factors such as use of online communication have been associated with lower levels of apprehension and greater frequencies of online purchasing behavior.^{22, 23}

The overall patient population has become more informed about health and treatment options with the increased availability of health information online.²⁴ Consistent with other studies focusing on Internet use, our study found feedback and comments about HIE to be similar among men and women.²⁵

Individuals may show some differences, by age and socioeconomic status, in use of the Internet as a source of health information; previous research has observed that younger individuals and those with higher socioeconomic status are more likely to use the Internet for this purpose.²⁶ Compared to a younger population, older adults are less knowledgeable about computers and Internet security, in general, and are at greater risk when using the Internet.²⁷

In this study, older participants generally expressed more apprehension about HIT than their younger counterparts. Our results suggest that public health efforts to encourage consumer HIT adoption should be attentive to potential age and socioeconomic differences in readiness to adopt. In addressing the barrier of perceived risks, efforts could be made to limit potential inequities by focusing on increasing perceived self-efficacy among these groups.

A majority of focus group participants expressed interest in in-person education about NeHII, Nebraska's query-based HIE. Additionally, many expressed a preference for at least an initial explanation

of NeHIE from their physician. Most agreed that multiple touch points and media would be most effective in communicating information about NeHIE to a wide-ranging audience. As several participants suggested, targeting educational efforts on the basis of demographics such as age will be helpful in achieving broad adoption.

This study had several limitations. First, with the exception of two focus groups, we relied on local public health department directors to recruit participants. This method resulted in some participants' having healthcare experience as nurses or health educators. Given the variety of geographic locations, ages, and socioeconomic statuses, however, we believe our participants were representative of the Nebraska population. Second, we audio recorded the conversations for record-keeping purposes. We emphasized confidentiality and allowed participants to use pseudonyms. While it is unlikely, a few participants may have altered their opinions to appear in a more positive light in the group setting.

Study strengths included a fairly large sample size of 67 participants and a geographically representative sample. Also, participants ranged in ages and occupations from high school students to retirees. Participants' experience with healthcare and HIE varied widely from no familiarity at all to being a nurse educator. Participants were eager to learn about HIE and planned to share this information with their family and friends. Finally, the majority of participants reported the focus group to be an enjoyable experience and were excited to utilize HIE when it is available in their areas.

Given that HIE is still relatively new in Nebraska, the overall focus group participant awareness was low. The feedback among the few participants who had utilized HIE was overwhelmingly positive. Some feedback was based on speculation, however, rather than on actual experience. As HIT becomes more widely adopted, larger segments of the population will be able to provide actual user experience testimonials.

Conclusion

Consumer concerns expressed during focus groups surrounding HIE and related services revolved mostly around the privacy and security of health information. Additional concerns regarding the cost of implementation and the possibility of an unintended negative impact on quality of care were raised. While these negative perceptions present barriers for potential patient acceptance and use of HIE in Nebraska, perceived benefits such as speed and convenience, patient control of health data, and safety improvements may provide a counterbalance. Our findings also point to the importance of appreciating generational, behavioral, and demographic differences among patient users to both increase understanding of HIT and assess expectations among consumers.

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Table 1

Focus Group Participant Demographics, Nebraska, 2013

Variable	N (%)
Gender	
Female	49 (73.1)
Male	18 (26.9)
Location	
Broken Bow, NE	11 (16.4)
Lincoln, NE	11 (16.4)
McCook, NE	10 (14.9)
O'Neill, NE	10 (14.9)
Hemingford, NE	9 (13.4)
Omaha, NE	9 (13.4)
Chadron, NE	5 (7.5)
Omaha, NE	2 (3.0)
Occupation	
Employed, healthcare or health department	25 (37.3)
Unknown	12 (17.9)
Employed, office work	11 (16.4)
Employed, other	9 (13.4)
Retired	5 (7.5)
Homemaker	3 (4.5)
College student	2 (3.0)

Table 2

Emerging Themes from Focus Group Discussions

Familiarity with and use of health information exchange (HIE) and related services
Feedback about use of electronic medical records in HIE, e-Rx, and PHRs

- Security issues, risks to privacy and confidentiality
- Suggested privacy safeguards
- Dependence on Internet and electronic infrastructure
- Lack of comfort with technology among some consumers
- Potential consequences of data errors and mistaken identity
- Consolidation of medical information in one place

Specific feedback on health information

- Potential decrease in quality of care due to HIE
- Provider participation in HIE
- Cost of HIE
- Potential improvements in quality of care

Specific feedback on e-prescribing (e-Rx)

- Pharmacy limitations
- Cost of e-Rx
- Safety improvements
- Speed and convenience

Specific feedback on personal health records

- Concerns about user computer knowledge and access
- Difficulty of interpreting medical information
- Patient access to and awareness of health data
- Convenience of patient access to consolidated information
- Patient control of health data

Input on HIE education delivery

- In person, face to face
 - Media
 - Targeting based on demographics
 - Role of government in HIE education
-