

# HISPC

Health Information Security and Privacy Committee State of Nebraska

## Security and Privacy Barriers to Health Information Interoperability

### Report 3: Consumer Views about Privacy and Electronic Health Information Exchange



Partial resources support from the Creighton Health Services Research Program (CHRP) and grant no. 1P20 HS015816 Building Research Infrastructure Capacity from the Agency for Healthcare Research and Quality (AHRQ); and the Office of Rural Health, Nebraska Health and Human Services System



## Security and Privacy Barriers to Health Information Interoperability

### Executive Summary

### Report 3: Consumer Views about Privacy and Electronic Health Information Exchange

This is the third report in a series developed by the Lieutenant Governor's State of Nebraska Health Information Security and Privacy Committee (HISPC), formed in 2006. The vision driving the HISPC is to create the flexibility to electronically exchange patient authorized health care information, confidentially and securely between the patient/client and all appropriate persons involved in the health care process. In 2004, the President of the United States issued Executive Order 13335 to promote health information technology nationwide, to improve efficiency, reduce medical errors, improve quality of care, and provide better information exchange for patients and physicians. The key goal this order is intended to support is for most Americans to have electronic health records by the year 2014. This order also supports the more aggressive goal to have all prescriptions generated and transmitted electronically that are provided to Medicare beneficiaries by the year 2009, as identified in the Medicare Prescription Drug, Improvement, and Modernization Act (Public Law No. 108-173, 117 Stat. 2066, also called "MMA legislation") that was enacted in 2003. A major challenge to meeting these goals is the provision of safeguards to protect the privacy of personal health information. Other challenges include assuring the accurate identity of a patient when records are exchanged, and understanding what laws, rules and regulations presently exist that may be a challenge to overcome in order to exchange health information between patients, providers and organizations while diligently protecting the patient's privacy.

The HISPC Steering Committee works with stakeholders to identify major health information privacy and security issues and to create an action plan to resolve issues for patients/clients and all appropriate persons involved in the health care process. The Committee has identified 3 stakeholder groups for which little information is known: 1) the Health Licensure, Certification, and Facilities Oversight Board managers for the State of Nebraska Health and Human Services division, 2) the professional associations that are involved in health care delivery and services in the state, and 3) patients/clients/consumers of health care. Each group is being studied to determine their present level of awareness about health record interoperability, security and privacy considerations, and their impressions about the general state of knowledge of others in the stakeholder group they represent.

*Report 3: Consumer Views about Privacy and Electronic Health Information Exchange* summarizes the finding of the examination of these issues with consumers in the state. The purpose of this report is to improve our understanding of consumer's views of how their personal health information should be managed. There is a paradigm shift to the use of electronic systems that is observed in the younger generations of our citizens. This suggests to us that use of electronic health records and personal health records will likely increase with the consumer be involved explicitly in this aspect of their care. Little is known about consumer viewpoints, especially as they may differ for individuals who experience care through their own socioeconomic, cultural and past experiences. There are

three major parts to the report. First, a small pilot in-depth interview study was conducted with consumers who represent varying socioeconomic, healthcare experience, and cultural backgrounds. Six health care consumers agreed to speak with an interviewer about their views of the management of health information. Interviews lasted 20-30 minutes and were conducted at a time and place of convenience to the participant. Interviews were voice-recorded and transcribed verbatim.

The case analysis describes each persons “story” with a cross case analysis leading to some overarching findings. Second, a group of consumers who are engaged in health quality related work in the state responded to a written survey about their knowledge, viewpoints, experiences and concerns. The findings from our 2 previous reports, this current report, and the deliberations and expertise of the HISPC Committee members provide the background for recommendations from the HISPC Committee for consideration.

## **Research Findings Summary**

The combination of data received through surveys and interviews expresses a here-to-fore missing voice in the discussion of security and privacy barriers to health information interoperability. The voices of consumers are critical as we move to the electronic management and exchange of health information. Consumers’ have unique perspectives on security and privacy. There is plurality in their identified concerns and needs. To achieve full engagement, multiple approaches to addressing their perceived needs will be necessary. However, overall, consumers are focused on the belief that personal health care information should be shared to improve their care. As promoters, developers and planners, we must be able to answer their questions and concerns.

Preliminary data indicates a lack of consumer knowledge and misperceptions about the current management of health care information as well as future electronic management and exchange. Most consumers are unaware of all the ways health information is used once access has been granted to a provider or third party payer. Without complete and accurate information, consumers may make decisions that are not in their best interest.

We know a little about consumer viewpoints now, but we need to know more. The six individuals interviewed represent the major ethnic, age, socioeconomic and severity of illness characteristics that are typically considered “diverse”. However, we learned through this work that “relevant diversity” is broader. Care continuum, care settings, and other access issues are highly important to learn about in order to understand the consumers’ viewpoints and needs. We need to know more than we know about consumers in our state.

Consumer knowledge is represented at a higher level by this survey of consumers than is likely in the state. This initial sample of consumers who participated in the survey are individuals who are more informed, as a result of their advisory participation to the quality improvement organization in the state. We are likely to have received the “best picture”, not the “average picture”.

## **Recommendations**

The HISPC recognizes that state governments, boards and health care providers need more knowledge about the Nebraska consumer. Consumer viewpoints are critical to this broader understanding of health information exchange and interoperability. A larger and broader representation of consumer viewpoints and needs will greatly improve our understanding of “what” consumers will participate in and “how” they will participate.

Similarly, consumers are in great need of information and education about health information exchange and interoperability. Consumers have concerns that must be addressed through knowledge dissemination. This will facilitate the best decision-making possible for the consumer. A dissemination process for essential and timely information related to progress of this initiative occurring at both the federal and state level to consumers is needed.

**Action:** We would recommend that citizens be incorporated in a variety of ways to assist in the design of the processes of education of all stakeholders and policy formulation as the macro system of sharing health information electronically unfolds over time. We suggest that citizens be invited to participate on community, regional or state workgroups, councils and other entities presently active or formed in the future that are related to the health information sharing initiatives in the state. This is an essential step to facilitating citizens and providers to more easily establish a common understanding and agreed upon set of solutions to health information exchange as security and privacy issues are addressed. A larger and broader representation of consumer viewpoints and needs will greatly improve our understanding of “what” consumers will participate in and “how” they will participate. We cannot put ourselves in the place of consumers.

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- ◆ Senator Pat Bourne (Past Member)
- ◆ Senator Jim Jensen (Past Member)
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**Table of Contents**

<b>Content</b>	<b>Page</b>
<b>Background .....</b>	<b>7</b>
<b>Purpose .....</b>	<b>7-8</b>
<b>Research Findings Summary .....</b>	<b>8</b>
<b>Recommendations.....</b>	<b>8</b>
<b>Consumer Survey Results .....</b>	<b>10-15</b>
<b>Personal Interview Stories .....</b>	<b>17-21</b>
<b>Consumer Interview Results.....</b>	<b>22</b>

## **Background**

This is the third report in a series of explorations conceptualized by the Lieutenant Governor's State of Nebraska Health Information Security and Privacy Committee (HISPC) formed in 2006. The vision driving the HISPC is to create the flexibility to electronically exchange patient authorized health care information, confidentially and securely between the patient/client and all appropriate persons involved in the health care process. In 2004, the President of the United States issued Executive Order 13335 to promote health information technology nationwide, to improve efficiency, reduce medical errors, improve quality of care, and provide better information exchange for patients and physicians. The key goal this order is intended to support is for most Americans to have electronic health records by the year 2014. This order also supports the more aggressive goal to have all prescriptions generated and transmitted electronically that are provided to Medicare beneficiaries by the year 2009, as identified in the Medicare Prescription Drug, Improvement, and Modernization Act (Public Law No. 108-173, 117 Stat. 2066, also called "MMA legislation") that was enacted in 2003. A major challenge to meeting these goals is the provision of safeguards to protect the privacy of personal health information. Other challenges include assuring the accurate identity of a patient when records are exchanged, and understanding what laws, rules and regulations presently exist that may be a challenge to overcome in order to exchange health information between patients, providers and organizations while diligently protecting the patient's privacy.

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## **Purpose**

The HISPC identified key stakeholders which are influential in the movement forward on health information exchange and interoperability. The Committee has identified 3 stakeholder groups for which little information is known: 1) the Health Licensure, Certification, and Facilities Oversight Board managers for the State of Nebraska Health and Human Services division, 2) the professional associations that are involved in health care delivery and services in the state, and 3) patients/clients/consumers of health care. Each group is being studied to determine their present level of awareness about health record interoperability, security and privacy considerations, and their impressions about the general state of knowledge of others in their stakeholder group they represent.

*Report 3: Consumer Views about Privacy and Electronic Health Information Exchange* summarizes the finding of the examination of these issues with consumers in the state. The purpose of this report is to improve our understanding of consumer's views of how their personal health information should be managed. The inevitable availability of electronic health records and personal health records will require that the consumer be involved explicitly in this aspect of their care. Little is known about consumer viewpoints, especially as they may differ for individuals who experience care through their own socioeconomic, cultural and past experiences. There are three major parts to

the report. First, a small in-depth pilot interview study was conducted with consumers who represent varying socioeconomic, healthcare experience, and cultural backgrounds. The case analysis describes each persons “story” with a cross case analysis leading to some overarching findings. Second, a group of consumers who are engaged in assuring quality of health care provision to Medicare recipients in the state responded to a written survey about their knowledge, viewpoints, experiences and concerns. Finally, an analysis of these sources of information provides the background for recommendations from the HIPSC Committee for consideration.

## **Research Findings Summary**

The combination of data received through surveys and interviews expresses a here-to-fore missing voice in the discussion of security and privacy barriers to health information interoperability. The voices of consumers are critical as we move to the electronic management and exchange of health information. Consumers’ have unique perspectives on security and privacy. There is plurality in their identified concerns and needs. To achieve full engagement, multiple approaches to addressing their perceived needs will be necessary. However, overall, consumers are focused on the belief that personal health care information should be shared to improve their care. As promoters, developers and planners, we must be able to answer their questions and concerns.

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## **Recommendations**

The HISPC recognizes that state governments, boards and health care providers need more knowledge about the Nebraska consumer. Consumer viewpoints are critical to this broader understanding of health information exchange and interoperability. A larger and broader representation of consumer viewpoints and needs will greatly improve our understanding of “what” consumers will participate in and “how” they will participate.

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## **CONSUMER SURVEY RESULTS**

An electronic e-mail survey was sent to 24 consumers who reside in the state of Nebraska who provide quality improvement advice to the states Medicare Quality Improvement Organization. The survey consisted of 29 items with a multiple option and open-ended response format. Sixteen (67%) of the 24 who were invited to participate completed the survey.

*Demographic information about respondents.* There were 5 male and 11 females who range in age from 27 to 79 years old. The educational level distribution is: 3 completed some college, 7 completed a baccalaureate degree, 5 completed a masters degree and 1 a doctoral degree. The personal annual income reported ranged from \$25,000 to greater than \$100,000. Of the 80% who identified their ethnicity, all were self-reported Caucasian. The health care needs of these respondents varied. One third reported having chronic medical conditions. Three quarters have medication prescriptions filled on a regular basis.

### **How People Keep Track of Personal Health Information**

*People were asked how they keep track of their personal health for either themselves or family members.*

- Half of the respondents do not keep track of personal health information at all.
- Of those that do, they usually carry a paper list of medications and may also include a list of conditions or diseases they have. One indicated they use a Smartcard and access a web interface to do so. No one in this group maintained a personal health record on a hand-held device such as a PDA (personal digital assistant).

### **Consumer Knowledge About Health Information Exchange**

*Consumers were asked if they were familiar with the entity known as a Regional Health Information Organization (RHIO).*

- Only four individuals responded that they had ever heard of a RHIO.

### **Opinions About Sharing Health Information (Exchange)**

*Consumers believe health information should be shared between their health care providers... with some boundaries and assurances identified.*

- Respondents believe (88%) that the different health care providers who they visit should be able to exchange electronic health records. One respondent stated “to provide a seamless continuum of care.” And another stated, “To the extent that sharing health information may facilitate my recovery, I would want these records to be shared.”
- The respondents commented that “consistency of care is vital between ‘patient’ and all providers”...“otherwise they might not know what happened to me prior to this visit”.

- Another explained, “to the extent that sharing health information may facilitate my recovery, I would want these records to be shared.”
- A few also pointed out boundaries and assurances they desire. Respondents explained sharing should occur, “Only if it is pertinent to my health care” and “there needs to be secure transmission of data”.
- One respondent did not believe records should be sent electronically.

***Consumer selection of health care providers may be influenced by the availability of a shared electronic health record.***

- The availability of a shared electronic health record may influence a consumers selection of health providers. All but one indicated they would prefer a physician who could share records and all but two indicated they would prefer a pharmacist who could share records.
- One person indicated they would prefer providers who did not electronically share records.

***Consumers are comfortable sharing a wide range of Health Information in order to improve the coordination of their health care service delivery.***

**Kinds of information the patient would be comfortable sharing among health professionals**

Respondent	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
name, address, phone, date of birth	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
list of current medications, including vitamins, over the counter medications and herbal supplements	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
allergies	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
past history for health issues (childhood, previous illness or injury)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
payment information (health plan, health savings account, credit card, or other)	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
names of physicians or other health professionals from whom you receive care	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
family history of disease		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
chronic disease conditions (diabetes, lung disease, cancers)		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
preferred choices for pharmacy, lab, diagnostic services, inpatient services		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
employer		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
mental health diagnosis / treatment history		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
sexually-related diagnosis / treatment history		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
infectious disease history (HIV, tuberculosis, hepatitis)		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
social security number				•			•	•	•	•	•					•
Other																

### ***The Consumer Should have the Final Authority Over Granting Permission to Access Health Information***

- All respondents felt that only the patient (themselves) or a person that they designate to have specific authority should have access to their health information records. One specified this designate should only have authority if the patient was not able to make their own health care decisions.
- A small proportion indicated that also a family member or the health provider who gave the care should also have this privilege.
- Only three indicated the payer of health services, such as an insurance company, and one indicated the government.

### ***Consumers Identified Exceptions to Having Final Authority Granting Permission to Access***

- Half of the respondents indicated that there were some situations where health information from the medical records should be accessible to others without expressed permission from the patient. These situations included:
  - Emergencies
  - Life threatening circumstances
  - Person is unconscious and can not respond or incapacitated
  - If the treatment depends on history of the patient...the health care provider should have access to past records

### ***Consumer Opinion Was Evenly Split Between Methods of Granting Permission to Access Health Information***

- There are two common ways for individuals to give permission to others for access to their health information:
  - an "opt in" requires an action or affirmation by an individual for inclusion; the default is exclusion;
  - an "opt out" requires an action or affirmation for exclusion; the default is inclusion.
- There was an even split amongst respondents about whether the "opt in" or "opt out" method to determine permission for others to access their health information should be the preferred method. Plurality of solutions is needed.

### ***Consumers Were Most Likely to Give Permission to Access Their Health Information at the Point of Care or Demand***

- All respondents indicated they would sign a form at doctor's office, hospital, pharmacy, lab, clinic, or other locations as needed. Half indicated they would sign on-line electronically. One indicated they would sign paper forms at locations such as a mall kiosk.

***When Given a Listing, Consumers Said They Would Give Permission to A Wide Variety of Individuals to Access Their Health Information***

**Patient would give permission for the following to view information.**

Respondent	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
to doctors who are responsible for my personal health care services	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
to family members who would make decisions if I am incapacitated	•	•	•	•	•	•	•		•	•	•	•	•	•		•
to my pharmacist	•	•	•	•		•	•		•	•	•	•		•		•
to emergency responders (EMS, ambulance, etc.)	•	•		•		•	•	•	•	•	•	•			•	•
to nurses or other office staff who assist my doctors	•	•		•	•	•	•	•	•	•	•					•
to technicians in laboratories, imaging centers, clinics		•		•		•	•		•	•	•				•	•
to public health officials responsible for tracking bio-terrorism, disease outbreaks, public health trends		•		•			•		•	•		•				•
to home health agencies, caregivers		•		•			•	•	•	•						•
to persons tracking and reporting quality improvement measures		•					•		•	•						•
to those responsible for payment for my health care (employer, health plan)							•		•		•	•				•
to organizations conducting research for clinical purposes (medical treatment procedures, pharmaceutical, medical devices, etc)		•					•		•	•						
to persons tracking and reporting cost-efficiency measures							•		•	•						

***Consumers Expect to Have Access to All of Their Own Health Information in the Records and Also Others Who Have Accessed Their Records***

- Consumers expected that they themselves would have access to all information in their own records.
- Three quarters of respondents would want to have a list of all who had viewed their records, including time and date of access, and a list of information viewed.

***Consumers have concerns about the privacy and security of their health information.***

- Half have concerns about privacy and confidentiality of their health records. Representative comments include: “access should be limited to those who have your authorization” and “it is a loss of privacy”. Another indicated that, “it may become too easy to share with others.”
- More pointed comments included, “I am concerned about electronic piracy”, and “it seems that just about anyone can hack in.”

### ***Consumers Do Perceive Risks from Sharing of Health Information***

- Half of the respondents viewed the primary risk from sharing of electronic health information as the loss of privacy. They further felt that this would increase their risk to having denial or loss of payment for services of health care from third party payers.
- A smaller proportion identified the loss of relationship.
- One identified the risk of sending the wrong records to the wrong places.

### ***Consumers Identify Several Benefits to the Sharing of Health Information***

- All respondents but one indicated that sharing of patient electronic health information records would lead to improved coordination of health care, reduced travel time to providers, and reduced repetition in completing forms and providing information to health providers. One indicated that there may be less time spent by providers collecting health history information and another indicated that there would be increased medication safety as a result.

### ***Consumers Generally Believe that the Quality of Health Care for Themselves and Their Family Members Would be Positively Impacted by Sharing of Health Information***

- Three quarters of respondents indicate that electronic health records would positively impact the quality of their/their family's health care. Comments were made indicating that quality would improve because:
  - providers would have information they need,
  - more accountability and less duplication would occur,
  - providers would make better treatment decisions because of a more thorough understanding of health conditions
  - there would be quicker access to services
  - there would be quicker sharing of information between all health care provider that is necessary information to be used for the patient's treatment.
- One individual insightfully identified the problem of "identity mixup" in records. They comment, "they would need to make sure that the electronic health record is in fact my information and not someone else with a similar name."

### ***Consumers Generally Believe that the Safety of Health Care Will Improve By Sharing Health Information... With Some Reservations***

- A little over half of the respondents believe that patient safety would improve. This comment illustrates the reasoning, "My health care providers would get a better picture of all my health care issues. This would result in avoiding dangerous treatment interactions."
- One quarter believe that safety may be worsened or are unsure of the impact. The concerns expressed are both that of wrong records going to the wrong people, i.e., human error, and a continued concern about confidentiality overriding safety. Reasons for worse safety include the inappropriate access to the health information through incorrect email and facsimile distribution.

### ***Consumers Generally Believe Their Health Care Providers are Responsible for Protecting the Security of Health Information***

- Half of the respondents indicated that their health care providers are responsible for protecting the security of health information.
- Only three indicated that the consumer was responsible.
- The remainder believed that a combination of consumer, health care provider, and government shared the responsibility.

### ***Consumers Believe that There Should Be Penalties for Release of Their Health Information Without Permission***

- Seven people believe that there should be loss of certification, license or credentials for health professional
- Six people indicate civil charges and fines
- Five believe that reprimand and retraining of the employee is most appropriate
- Three suggest firing the employee and two suggest loss of the business license for the organization.

### ***Consumers Indicate Several Preferred Approaches to Communication About Electronic Health Information Exchange.***

- Consumers have identified various combinations of these different ways that they would prefer to be educated about Health Information Exchange systems:
  - written information at the health professional's facility
  - verbal explanation at the health professional's facility
  - direct mail from the health care provider
  - online website information
  - general media information

## **Experiences and Opinions About Electronic Prescribing**

### ***Consumers have a positive experience with electronic prescribing at the doctors office.***

- Ten of the sixteen respondents have experienced prescriptions electronically generated at the doctor's office.
- Consumers felt that the process is usually smooth, easy, quicker...saving everyone time.
- I thought it was good; however, one of the prescriptions was optional, but when I reached the pharmacy, the prescription had already been filled. I believe it takes some choice away from the patient.

I feel it is a benefit when you are traveling or vacationing

It alleviated concerns that a written prescription could be misread or illegible

### ***Consumers have a positive experience with getting prescriptions filled using the electronic prescribing process.***

- Consumers find it faster, easier and more convenient. One commented that "it was nice to have the prescription ready for pick up instead of having to wait for it to be filled.

## **Errors, Harm, and Sharing Health Information**

*Medication or health care errors are commonly experienced by consumers.*

- Six of the sixteen individuals who responded have experienced a medication or health care error. One of these individuals experienced harm as a result.

*Half believe that health information sharing would have had a positive impact.*

- Three of the six cases who reported experiencing a health care error indicate that they believe that having exchangeable health care records would have made a positive difference in their case.

## PERSONAL INTERVIEW STORIES

Six health care consumers agreed to speak with an interviewer about their views of the management of health information. The stories that follow were developed from the interview data.

### *Aleka, a Healthy Middle-Aged Chinese-American Woman*

Aleka is a 53-year-old Chinese-American woman who was born and raised in Hawaii. She and her family live in a middle class suburban community. She is a health care professional with a doctoral degree who is employed as a university faculty member. Her annual family income is over \$100,000.

Aleka's husband is retired following a career in the military. She has had experience keeping her entire medical record (including radiographs) at home and hand-carrying the information to her health care providers prior to the adoption of electronic health records by the military. Now that her family's healthcare occurs in the private sector, she is concerned that records "seem to disappear and reappear" in her family doctor's files and becomes annoyed when asked to provide her medical history each time she visits a new provider. She maintains a Pendafile with hardcopy records of her family's vaccinations and results of testing procedures like mammograms and pap smears.

Aleka believes that access to a patient's health record should be "based on need so you can get the best care." She would like her health information available in case of an emergency when she or a member of her family might not be able to give permission. She admits that she might not always be the "best judge" of who should have access to her health information because she "doesn't know all the ways that this information can go to other people." She was not familiar with the concept of a Regional Health Information Organization. But when it was described to her, she thought it might improve the availability of information and timeliness in delivering health care. She was particularly interested in a system that would be readily accessible to a provider if needed when she was traveling.

Aleka described a medical error that occurred when a family member received the wrong medication in a prescription refill. She noticed the error because the pills looked different. The medication was exchanged and no harm was done. It was not clear to Aleka if e-prescribing and an electronic health record system could have prevented this error.

#### *Aleka's Beliefs and Behaviors*

- Important medical information kept at home in a Pendafile
- Concerned that records "disappear and reappear" in her doctor's files
- Health information should be available in case of emergency
- Considers the advice of others when giving permission for access to her health records
- Did not know what a RHIO is. When informed, she thought it could improve efficiency and availability of health information
- A family member has experienced a medical error

### ***Barbara, a Middle Aged Caucasian Woman with Chronic Medical Conditions***

Barbara is a single, 54-year-old Caucasian woman who lives in a middle class urban neighborhood. She has a baccalaureate degree and teaches children in grades K-8 in a private school. Her personal income is in the \$25, 000-49,999 range.

Barbara has chronic medical conditions, is seen by health care providers on a frequent basis, and has a number of prescriptions filled on a monthly basis. She describes a medical error that occurred when she was hospitalized. She was “very groggy” when a nurse brought her pills to take. Her sister asked what they were and prevented her from taking medication to which she was highly allergic. Although Barbara was wearing a wrist band that identified her allergy, it was not checked until her sister alerted the nurse to the error.

Barbara keeps a list of the medications she takes in her billfold “in case there would be an accident or something.” She relies on her memory for her medical history and other personal health information.

Barbara limits the concept of a health care provider to her primary care physician. She believes her health information should be accessible to her doctor. “In case of an emergency, I think that the hospital should be able to contact the doctor and get (my records)” and “my doctor would provide the information that the pharmacist needs.” She has concerns about the security and privacy of an electronic health record and equates identity theft with stealing health information.

Barbara had no prior knowledge of a Regional Health Information Organization, but thought it was a good idea. In spite of her concerns about security and privacy, she believed it would be convenient if her doctor could receive reports electronically and not have to wait for paper copies. She also believed that shared electronic health records would allow providers to “look at the whole picture of a person.”

#### ***Barbara’s Beliefs and Behaviors***

- Written medication list is kept in purse
- Hospitals should get my medical records from my doctor’s office
- My doctor will give the pharmacist any needed information about me
- my health information may be stolen
- Did not know what a RHIO is. When informed, she thought it would be convenient if her doctor could receive reports electronically
- An electronic health record would allow me to be seen as a “whole person” by provider

### ***Charles, a Healthy, Middle-aged Caucasian Male***

Charles is a married, 61-year-old Caucasian man who lives with his wife in a middle class urban neighborhood. He has a college degree and is retired, although actively engaged in volunteer work. His annual family income is in the \$25,000-49,999 range.

Charles believes his personal health information has been “scattered over time” as he has used different doctors and different medical facilities. He is concerned that he may have “forgotten about a few things” regarding his medical history that could be important and usually relies on his wife’s memory or the accuracy of the records in his current doctor’s office. He carries a card with his current medications but admits that he doesn’t always keep it up to date.

Charles believes his wife and a designated family member should have access to his health information in addition to his primary care doctor. His concerns for privacy and security are outweighed by the need for health care providers to have complete information to make the best decisions about his care. He also thinks that insurance companies should have access to all of his records because “they’re paying.”

Charles did not know what a RHIO is. However, he has a positive view of electronic health records. He believes that sharing health information electronically would improve accuracy and make the health care delivery process “smoother” for both the patient and provider.

***Charles’ Beliefs and Behaviors***

- Relies on his wife’s memory and his doctor’s files for accurate health information. Carries a card with medications listed
- Access to needed information outweighs his concerns for privacy and security
- Positive view of electronic health records
- Quick access and transmissibility of EHR could improve quality of care
- “It’s important to have information...to have a comprehensive review of your situation.”
- Did not know what a RHIO is. When informed, he thought it would improve the quality of care by improving accuracy and making the process “smoother” for the patient and provider.

***Delores, an 80 year old African American Woman with Chronic Medical Conditions***

Delores is an 80-year-old African-American woman who lives with her sister and niece in a middle-class urban neighborhood. She has a Master’s degree and is retired from teaching high school students, first in a private, and then public school. Her personal income is in the \$50, 000-74,999 range.

Delores describes her personal health information as “volumes of papers.” She keeps a list of her medications in her pill box. In addition to her own health information, she also tracks her sister’s health information by keeping all paper copies of health-related information they receive. She has “stacks of papers and bills that high.”

Delores wants her sister or niece to have access to her health records, but is reluctant to allow third-party payer or government access. She has growing concerns about security and privacy, “the more you read and hear on the news about what’s going on...dipping into your financial records. Not too good for everybody to know your business.”

Delores would like her health providers to have access to her health information. “Now that health fails, I think it’s important for them to know and coordinate.” She believes her primary care physician should have the final word about who accesses her information.

Delores is not aware of any medical errors that occurred as she or a family member received health care and said, “If there was, well, they did a pretty good job of hiding it.”

Delores did not know what a RHIO is. She is satisfied with the current system and doesn’t see a need to change it. “I’m not having a problem with the way it is so I see no need to get any more people involved. You don’t want too much information floating out there. I hope it doesn’t go get too much more complicated than it is.”

#### *Delores’ Beliefs and Behaviors*

- Lists medications and keeps **all** paperwork related to health care.
- Health records should be available to my sister and niece.
- My doctor should have access and decide who and when to release the information to other providers, but not third-party payers or the government.
- Views electronic health records and electronic sharing of information as complicated and involving too many people who don’t have a need to know.

#### *Edward, an Older American Indian with Chronic Medical Conditions*

Edward is a married, 65-year-old American Indian who lives on the Macy Indian Reservation with his wife. He was raised in Lincoln, NE and graduated from high school there. He is employed in transportation for a health care facility. He is currently undergoing physical therapy rehabilitation following a total knee replacement. His annual family income is in the \$25,000-\$49,999 range.

Edward perceives that he is in good health, “I never did have any major problems with my health.” He doesn’t keep a record of his personal health information, “I just live my life day to day” and “keep it up here (pointing to his head).” However, he does keep track of being diabetic. “I watch what I eat and I watch my body and I keep on my medication.”

Edward believes that his wife and family physicians should have access to his health information, but not insurance companies or the government. If other providers “want to look at my background, fine, they can contact them. I sign a release for them and they can get the information.” He believes his health care information “is my own personal file and I really keep [it] confidential.” There were no circumstances where he would want his record accessible to others without his permission.

He had no knowledge of a RHIO. When it was described to him, he replied, “I still like going the old way. But if they start going electronic, I’m just going to see how it works out before I can say it’s good or not. I can’t say because I haven’t experienced that yet.”

Edward has concerns about change stating, “Everything is where I know it is and that is where it should be.”

***Edward’s Beliefs and Behaviors***

- My health care information and records belong to me.
- My record should be accessible to others only with my permission.
- A perception that health care records only important when a patient has health problems.
- I want my records kept in a place that is familiar to me and I want to know where that is.
- I don’t know what a RHIO is and I can’t make any judgments about it.

***Fernando, a Middle-aged Mexican-American Male with Chronic Medical Conditions***

Fernando is a 60-year-old Mexican-American man who was born and raised in Scottsbluff. He left high school prior to graduation, but later earned his GED. He lives in an inner-city Omaha neighborhood with his wife and two granddaughters. He is retired due to complications from diabetes, but worked as a car salesman and repo man for many years. His family income is between \$15,000 and \$24, 999 annually.

Fernando’s wife manages his medications because of his vision loss due to complications from diabetes. The medications are kept in a brown paper bag on the kitchen table. Otherwise, he “just goes to the doctor when I supposed to and let them handle it (his personal health information).”

Fernando believes his doctors should determine who has access to his health information, “Whoever docs feels they should, whoever the doctors feel that they need to tell somebody.” In addition, he would like his wife to have access to the information. He believes the government would also have to know because “they’re the ones that pay.”

Although he doesn’t express concerns about privacy and security, he believes “the ones I tell is the ones that should know. If I don’t tell them, they shouldn’t know nothin’.”

Fernando had no knowledge of a RHIO and no difference in opinion about sharing health information electronically vs. current methods. He believes his pharmacist, those providing dialysis three times a week, and his doctors currently have the information they need to care for him.

***Fernando’s Beliefs and Behaviors***

- My doctors handle my personal health information and my wife handles my medication.
- My doctor should determine who has access to my health information.
- The government needs to know my health information because “they’re the ones that pay.”
- Health care providers currently have the information they need to provide care.
- No knowledge of a RHIO. No opinion about how this could affect the sharing of health information.

## CONSUMER INTERVIEW RESULTS

The overarching theme that emerged from the interview data was that **personal health information should be shared to improve patient care**. None of the participants keep a complete personal health record. Although they may “keep papers” related to the healthcare they have received or create a list of medications they take, they rely on the health care provider(s) to keep thorough and accurate records of their personal health information. In one case, where this information “disappeared and reappeared”, the participant kept copies of important reports in a file at home.

The **consumers lacked knowledge about electronic health records and health information exchange**. Beyond making copies and sending/receiving facsimiles, only one participant knew that electronic health records existed. None of the participants had any knowledge about a RHIO. When a RHIO was described, those participants willing to consider a change thought it might be a convenient way to improve timeliness and efficiency.

Participants **expressed strong views about who should have access to their personal health information**. These convictions were based upon personal values and beliefs that were strengthened by personal experiences. Although participants were willing to grant access on a need-to-know basis, there was wide discrepancy among their views about the needs of various providers, third-party payers and the government. In general, the participants lacked understanding of how various health care providers used personal health information to improve the quality and safety of patient care within their scope of practice.

Consumer **concerns about security and privacy were related to information the participants received from the media related to identity theft and misuse of information**. Again, these viewpoints varied considerably depending upon participants’ experiences and knowledge. There was a **high degree of trust placed with the individual’s primary care physician with the expectation that information would be shared in an appropriate manner**.

Consumers **do not understand processes used in health care systems to exchange information if the process does not involve them directly**. Participants were not always certain about how their prescriptions for medication reached the pharmacy if they did not take them to the pharmacy themselves. When prompted, they thought their doctors talked to the pharmacy, FAXed the prescription, or gave it to them to hand-carry.

**Two of the six participants who described a medical error that occurred while they or a family member was receiving healthcare**. Both errors involved medications but did not result in harm because a family member, serving as an advocate, caught the mistake.