



Central Florida RHIO

Focus Group Reports

Perceptions among Key Stakeholders

June 2006

Prepared for the
Central Florida Regional
Health Information Organization

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Introduction

In April and May of 2006, at the request of the Central Florida Regional Health Information Organization (RHIO), the Health Council of East Central Florida (HCECF) conducted eight focus groups with key stakeholders from the region in order to probe the issues surrounding electronic sharing of health information through the RHIO.

The focus groups were organized into eight constituency groups, representing healthcare consumers, providers and payers, as follows:

- *Consumers* -
 - Healthcare consumers, age-banded into three separate groups – age 20-39, age 40-59, age 60 and over
 - Attorneys and consumer/patient rights advocates
- *Providers* -
 - Physicians
 - Ancillary service providers, representing pharmacy, clinical lab and diagnostic radiology
 - Healthcare managers and administrators, representing healthcare administration, information technology (IT) departments and community clinics
- *Payers* -
 - Insurance carriers and other healthcare organizations

The objectives of the focus group discussions were:

- To obtain honest opinions based on practical experience and industry knowledge
- To help define system requirements
- To help determine obstacles to implementation
- To build community consensus for participation in the RHIO

The purpose of this report is to present a qualitative analysis of the focus group discussions in order to identify and to gain insight into the major issues and commonly held perceptions among the community about electronic sharing of health information.

Methodology

In order to be aware of the issues and potential problems involved in the formation of RHIOs nationwide, the HCECF conducted an extensive literature review before developing the questions to be probed in these focus groups.

Focus group discussions lasting approximately ninety minutes were facilitated by a representative from the HCECF and took place, as a convenience factor, either during the business day over lunch or during the evening over dinner.

Before each discussion, the CFRHIO project director presented a brief overview of the RHIO in order to inform group participants of the anticipated structure of the system and to respond to questions about how the system will work.

All participants were guaranteed that their comments would remain anonymous and confidential. The facilitator read a "Consent to Participate" statement and asked for agreement from the participants before soliciting any responses from the group.

The facilitator then asked a series of open-ended questions. Conversations were allowed to flow naturally in each group according to the degree of importance assigned to each issue by that group.

The following topics were discussed in every focus group:

- **Conditions for participation in the RHIO** – What would have to be in place in order for a stakeholder to consider participating in the system? What kinds of issues would present obstacles to participation?
- **Access** – Who should be able to access medical information in the system? How much access should providers have to that information? How much access should patients have to their own medical records?
- **Identification of patients and their medical records in the system** – How will we find someone in the system? How will we make sure that they are connected to their own records and not the records of someone else?
- **System sustainability** – How should we pay for the system?

There were also some questions that were specific to some groups but not to others:

- Physicians and healthcare administrators were asked to identify the types of information required for informed medical decision making. Physicians were also asked to suggest ways to incentivize small physician practices to participate in the RHIO.
- Healthcare consumers were asked about their knowledge, use or likelihood of using their own personal electronic health records.

Focus Group Findings – Common Themes

Following is a listing of common themes that were discussed in the focus groups. It is not possible to quantify the themes, because the groups were not “equal” in their composition or in their levels of interest or expertise in the health care field. In order to attach some sense of weight to each of the themes, the number of groups discussing each issue has been listed.

The fact that an issue was not discussed in every focus group does not imply that the issue was not important to that group, only that the issue did not surface in the course of the discussion.

Conditions for participation

- The RHIO must ensure that confidential medical information is protected at all times. (8)
- System security is essential, including good backup systems, virus protection and an audit trail. (5)
- Ongoing community education is critical to participation in and correct use of the system. (3)
- The sole purpose of the RHIO should be for improved medical treatment. (2)
- Objective medical information should be separated from provider opinions, which may be erroneous or prejudiced. (2)
- Information in the RHIO must be accurate, verifiable and if inaccurate, easy to correct. (2)
- There should be an ethical oversight component of the RHIO. (2)

Access

- Access to information in the system should be allowed only to medical providers who are actually treating the patient. (7)
- Insurance carriers should not be allowed to access any identified patient data in the system for any purpose. (6)
- Healthcare consumers should control who is or is not allowed to access medical information in the RHIO. (4)
- Consumers should have access to their own medical records. (4)

Unique patient identifiers

The following identifiers were discussed in the focus groups as potential ways to uniquely identify patients and their health information in the RHIO:

- Medical ID card
- Finger or thumb print
- Retinal scan
- User ID and password or PIN
- Medical ID number
- Combination of [name/ date of birth/ gender] or [name/ date of birth/ mother's maiden name]
- Driver's license
- Microchip
- Barcode
- "Smart card" technology: patient health records maintained on a swipe card

System Sustainability

- With the exception of healthcare consumers over age 60, participants are generally unwilling to directly pay to use the system. (7)
- The government should be the largest sustaining contributor to the RHIO. (4)
- Consumers favor a transaction-based fee structure of from \$2 - \$35 per access. (3)
- Healthcare organizations favor a monthly or quarterly fee structure. (2)
- Providers should pay for the RHIO but pass on costs to consumers. (2)
- Carriers could offer incentives to providers to maintain electronic health information systems and to participate in the RHIO. (2)
- Some insurance carriers and healthcare organizations are willing to partner in the development of the RHIO on a short-term basis, but the RHIO must demonstrate overall cost savings before they will make long-term investment in the system. (2)

Medical Decision Making

Two of the groups, the physicians and the healthcare administrators, discussed the minimum information that providers need in order to make informed medical decisions. The groups agreed on the following:

- Allergies
- Current medications
- Most recent test results

- Current patient profile
- Hospital discharge summaries

Electronic Health Records

Consumers were asked whether they maintain their own electronic health records (EHR). None of the participants maintain their own EHR, but most agreed that access to their EHR would be one of the greatest benefits of the RHIO.

Conclusion

In general, the focus groups were enthusiastic and optimistic about the expected benefits of the RHIO. Focus group participants believe that most healthcare consumers and providers will participate in the RHIO as long as security and confidentiality are assured, health information is never accessed without patient consent, and the RHIO would not increase the overall cost of medical care. Ongoing community education is needed to allay fears and to educate consumers and providers on the correct use of the system, and an ethical oversight committee should be considered to protect the system from misuse.

Central Florida RHIO
Consumers Age 20-39 Focus Group
May 23, 2006

Group Composition

Eleven consumers participated in this focus group, five men and six women. A confidential 90-minute session was held at the MD Anderson Cancer Center in Orlando.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Conditions for Participation in the RHIO

- Participants would like to see a guarantee that information would not be sold or used outside of medical treatment purposes before they would participate in the RHIO.
- The RHIO must have redundant backup systems in case of hurricane or other disasters.
- Information in the system should be objective:
 - “I also don’t want them making diagnoses relying so heavily on the reports of other physicians. You also run the risk of staff relying on someone else’s opinion, whether it is accurate or not.”
- Information should be verifiable and correctable, similar to credit bureau information.
- Information must be secure.
 - “It is not safe to assume your information is secure and no one else can access it. No matter how many safeguards exist, someone can always get through them. If anything, we should start small with limited information and access and in the years to come, expand it as technology improves to advance security.”
 - “For every one person providing security of this, 500 people are out there trying to break in. If someone didn’t like you and they broke in they could change your medical record to say you weren’t allergic to penicillin, when in fact you were.”
 - “I think this should start out first as an intranet so you have more control, rather than external access via the Internet. Then you could record, time-stamp and identify who is accessing the records and when and also who is entering it, to keep a history. And maybe a flag to let someone know that there has been unusual activity in someone’s records.”

Access

Consumer control of access to the system was the single most important issue for this group. All other issues kept coming back to this one.

- Most of the participants would like to tightly control all levels of access to their medical information.
 - “I would like to sign a consent form each time another hospital joins.”
 - “The releases have to be really specific. From specific providers and no one else, from this date to this date -- a definite ending date so it doesn’t go on and on.”
 - “It would make it more efficient because you are just giving [providers] what they want instead of them wading through reams of extraneous stuff.”
- Some participants would allow greater access to their medical records.
 - “I would want my doctor to know everything about me so that they have a more exact and better diagnosis in a faster amount of time, rather than them having to go back and forth..”
 - “I would want them to have my family history, too. Because when my grandparents die, there goes a lot of family medical history. I would like it to be linked so that it could be retained. A lot of things can be prevented, just by knowing genetically what came before you.”
 - “On the consent form there could be a place you sign off that you give permission to access the family history or not.”
- Some participants would like to be able to opt in or out of the RHIO on a per-visit basis.
- Some participants would like to allow the schools to access their children’s immunization records through the RHIO.
- Most of the participants agreed that access to the identified data should be limited to treating medical providers only.
- De-identified data could be available for research, but only for improved medical care. Most participants did not want any medical information used for marketing or other non medical purposes.
- The group agreed that insurance carriers should not be allowed access to the RHIO.
 - “Insurance companies are out to cut costs and if they had access to the system, it would deny people who really need it. I have a nurse friend who went to work per diem so he needed to get his own insurance. The company requested some documents which he stupidly gave them permission to have and they denied his coverage, and because they share the information, no one else will cover him, so he can’t get insurance.”
- Unauthorized access to financial information is not as large an issue as unauthorized access to medical information:

- "If someone stole \$5000 from my [bank] account, I would be reimbursed. If someone stole my medical records then they know my medical history. It's more of an invasion of privacy."
 - "My concern is that we live in a political climate that is almost at odds with the concerns of private citizens... Since 911, [the government's] approach to things [like privacy] has been very rushed, very much in the guise of national security."
- Some participants expressed fears that the government would access confidential medical information in the RHIO without their consent.

Personal Electronic Health Records (EHR)

- No one in the group currently maintains an EHR.
- Most participants agreed that they would like to be able to access their own medical records and the records of their children.
- Opinions varied about whether consumers should have access to their test results before they talk to their doctor.
 - "I think your doctor needs to tell you what the test results are. Some people would freak out or may not understand the results. "
 - "It seems almost irresponsible to have them find out test results online without a medical professional available."
 - "I think it is your information and if you choose to access it and interpret it yourself, you are responsible for your own actions. It's the same as reading a medical book and assuming you have the diseases that are in it."
 - "I wouldn't want to do it because I wouldn't understand it."

Unique Patient Identifiers

Ideas suggested by the group to uniquely identify individuals in the system were:

- Barcode on a medical ID card or on the back of drivers licenses.
- User ID and password.
 - "Maybe there needs to be a set of things, a user ID and password, or a social security number and a PIN number.
- Biometrics.
 - "Thumbprint."
 - "People are still a little freaked out about that. Or retinal scans. But if you go out of the country, you put your fingerprint out there."
- Unique ID number.

System Sustainability

- Cost is a concern for some of the group. Participants expressed concern that system costs being passed on to providers and consumers would increase the cost of medical care overall.

- Not all participants were willing to pay for access to their medical records. Those who were willing to pay were only interested in infrequent access to their records.
- One suggestion was that fees for accessing patient records should be bundled into the charges for the service. If consumers choose to access their records online, it should be free for x days after a visit or hospitalization, and thereafter on a per-access basis. Suggested charges ranged from \$2 - \$15.

Other Issues

- Some participants expressed concern over whether the RHIO will have liability insurance to cover lawsuits if a patient's records are accessed without his or her consent.
 - "It opens up a huge can of worms as far as liability. Think about something large-scale happening like what did with the VA. That was a matter of somebody taking a CD home."
 - "And then an insurance carrier doesn't want to pick you up because they saw you were a high risk and you can't get health care coverage because of that. Then there's a law suit alleging the leaking of the information."

Central Florida RHIO
Consumers Age 40-59 Focus Group
May 2, 2006

Group Composition

Eleven consumers participated in this focus group, four men and seven women. A confidential 90-minute session was held at the MD Anderson Cancer Center in Orlando.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Conditions for Participation in the RHIO

- Participants felt that the information in the RHIO must be accurate and easily correctable when errors are found.
 - “There’d have to be some sort of easy system of correction, as well. So when you do find a mistake it’s not some sort of bureaucratic nightmare to fix it.”
- There was some discussion as to how erroneous information would be corrected, and the consensus was that it would need to be corrected at the source (i.e., originating physician’s office, hospital, lab, etc.). In order for that to occur, there must be an audit trail which includes the name of the originating source (‘author’) of the information.
 - “Like a time and date stamp.”
 - “It wouldn’t be any different than when they transcribe it at the hospital or doctors office. They put the doctors name and the transcriptionist and attach a date to it.”
- The RHIO must have good redundant backup systems.
- The group agreed that there should be a defined set of ethical standards governing the use and preventing the abuse of the RHIO.
- In addition to security, there should be a considerable educational component informing the public about exactly how secure the system is.
- The RHIO must be transparent to the public. There should be an ongoing educational effort to avoid suspicion (‘Who is behind this?’ ‘What is their purpose?’).
 - “The more transparent it is, the easier it’s going to be for people to trust...”
 - “I think there’s a lot for the public to know, because we are going this way whether we want to or not.”

Access

- The group agreed that the RHIO should be restricted to medical access only. Employers, insurance companies, landlords or other individuals or organizations who are not connected with medical care should not be allowed to access the system.
 - “You would have to be sure that the records can only be accessed by a medical provider that you are going to. You don’t want all kinds of people accessing your records.”
 - “This shouldn’t be there for the insurance companies to save money. It is there for the consumer and their personal welfare.”
 - “There has to be a real safeguard or insurance companies will use it against you.”
- Except in emergency situations where the patient is unconscious, participants felt that access to a consumer’s medical records should be limited to his/her own healthcare provider and only other providers that have been authorized by the patient.
 - “If I get referred to another physician, I can go home to my computer and turn that physician on to my record, or that hospital, or lab.”
 - “For example, I am a nurse and if I am taking care of you, I want your cardiologist and your primary care physician. I don’t need your dermatologist or your dentist. The patient would give consent for the cardiologist and the PCP in that case.”
- If the patient is conscious and able to give his/her consent, participants agreed that no one should be allowed to access medical information in the RHIO without permission from the consumer.
- Some participants added a condition that the RHIO allow an option to share only diagnostic information and not the physicians’ opinions, which may be erroneous or damaging to the patient’s reputation.
 - “You would need to separate lab results from doctor’s opinions. If you are going for a second opinion, there’s a chance the original doctor could be wrong and you should have a chance when you go someplace else to say you cannot access Doctor A. I have looked at my medical record and there are some remarks on there that made me wonder if he was talking about me or did he have me confused with somebody else.”
 - “I would want the doctor to know that I did break my collar bone, but not the first doctor’s opinion that maybe the injury was done by a beating. You may not want anyone to see that.”

Personal Electronic Health Records (EHR)

- Participants did not know what an EHR is, and none of the participants maintain their own EHR.
 - “It’s something you wouldn’t really think about doing, until you hear it mentioned. Like for hurricane evacuations. With Hurricane Katrina all that stuff got lost... I was thinking what a nightmare.”

- "I love it when a patient comes in with one, but I don't have one personally."

Unique Patient Identifiers

- One participant suggested that a national medical ID standard be created. Other participants objected to this idea:
 - "But you wouldn't want it to be a known formula, because the way society is, with identity thefts, you wouldn't want the number or the ID to be comprised of things that could be from somebody's garbage like date of birth."
 - "The government already has more information [about me] than they need to have."
- Also discussed were a unique number and PIN on an ID card along with a photo of the consumer.
 - "Like with credit cards and ATMs, you need a PIN that says you are the person who is supposed to be using that card."
 - "I know it's an exaggerated point, but you get a hair cut or color change and the emergency room refuses to help you because you don't look like the photo. Do you really want your care to depend on a picture?"
 - "I was just thinking that the majority of people have an insurance card or a Medicaid card or something, so maybe it should be a card for the majority of people... It won't work for the homeless population, but the vast majority could use a card with the metal strip and a PIN that you swipe."
- Implanted microchips, fingerprinting and retinal scans were also discussed briefly.
- Participants agreed that the patient's name and birth date are the minimum information needed to identify medical records. Parents' names and birth dates would provide another level of unique identification.

System Sustainability

- Participants would like to be able to access their personal medical records from home, but none of the participants is willing to pay for access to their medical records.
 - "When they first came out with electronic banking they wanted to charge you to pay your bills and I thought that was crazy, so I didn't do it. Now it's free, so I do. The principle of me going to my doctor and paying him to keep my records, whether he writes them on a piece of paper or he puts it in the computer, he's keeping my records. Then I have to go home and pay him to see what he wrote about me? I already paid him to write it -- I'm not going to pay him to look at my own personal record. Just like with my bank. I don't pay to go on-line to look at my account."
- Several of the participants are willing to pay for their physicians to access the RHIO by way of added fees for provider services.
 - "I would not want to pay to access my own medical records, but I would be willing to pay \$3-\$5 per office visit for the information to be input. It would be

worth it to me, health-wise, to have my information out there so that many doctors could access it.”

- “Think of it like cable TV. You pay for what you want to use.”

- “But the reason doctor visits are so expensive now is because we are paying for those who can’t pay. It may need to be one of those things where you don’t get denied access because you can’t pay for it.”

- One participant said that he would have no part in the RHIO if it is government-sponsored.

Other Issues

- Some participants thought that the RHIO should add a central repository for medical records when a doctor’s office closes due to retirement, death, etc.
 - “What happens when a doctor who is in the system goes out of the system and your records are gone? If they are locally stored, he isn’t going to keep a server running in his office when he retires or leaves the state.”

Central Florida RHIO
Consumers Age 60+ Focus Group
April 24, 2006

Group Composition

Nine consumers participated in this focus group, three men and six women. A confidential 90-minute session was held at the MD Anderson Cancer Center in Orlando.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Conditions for Participation in the RHIO

- The following benefits of the RHIO were discussed by the group:
 - “I can see where this would be a big improvement, because a lot of times you go to the doctor and you’ve already had all these tests, but they may have a problem getting the information from the other doctors. It may expedite things for you because they get the information quicker.”
 - “I can see it reducing some medical costs. Because if a patient has had current tests and then they go to a specialist, and then they start all over again and that is very costly.”
 - “I think that there is ultimately one great positive in this if researchers use it well, I mean, what an incredible data base to start to figure out, ‘Gee, does this treatment for diabetics really work, or how does this compare to something new?’ And certain folks in the government research could do an incredible job on variation analysis.”
- All participants agreed that security is essential:
 - “Security of the system is the key [to participation].”
 - “Yes, I would see that as absolutely fundamental and essential”
- The RHIO must have a good backup system and virus protection.
- Consumers will not participate if sensitive medical histories are not properly protected.
 - “I can picture parents being very concerned about access to some of their children’s records. Say if a child has a drug problem or an abortion.”

Access

- All participants agreed that every physician should be able to access their patients' medical records via the Internet, even if they are not able to share their own records in the RHIO.
- The group added that physicians should not be allowed to access everyone's medical records just because they are physicians -- only records for which they have permission (i.e., current patients).
- Consumers should have the ability to change authorizations / permissions at any time, perhaps by entering a username and password or by carrying a card with an authorization code and entering a PIN.
- Participants acknowledged that there could be problems with consumers accessing their own medical records.
 - "I think there are a lot of people that would not know what to pick out of there."
 - "Yes, I have seen test results before and it was like Greek to me."
- The group agreed that the RHIO should be restricted to medical access only. Access should not be allowed to employers, insurance companies or unauthorized family members.
 - "This system should be there for medical reasons, to benefit the patient."
 - "To get the best possible care for each individual person. But not for people like family members or prospective employers to go meddling into the system."
 - "This [system] should be restricted to the health and well-being of the individual."
 - "I have an idea they [insurance companies] will find a way to access it."
 - "I agree, but in the beginning, don't voluntarily give it up."
- The group agreed that no one should be able to access a consumer's medical records without permission from the consumer, unless the patient is unconscious.
 - "I think that, considering our culture, I think you could say that any time a person is unable to make decisions, responses that a certified emergency room physician or whatever is the case, has the ability to access this information one time only. Other than that, I would be a person who would want to say you have to make an affirmation to the system".

Personal Electronic Health Records (EHR)

- Most participants did not know what an EHR is, and none of the participants maintain their own EHR. One participant maintains his/her own personal health record on paper.
- All participants agreed that the ability to log into the system and to access their own health information would be a great benefit.

- Participants would like a comprehensive history to be available to medical decision makers.
 - “If you had a child that had diabetes and he was 55 now, you would certainly want to know that the patient had had diabetes since he was a child.”

Unique Patient Identifiers

- The group agreed that, at a minimum, there should be a unique user ID and password combination.
- Participants also discussed that some banks use several levels of authentication, such as a picture or color, a word, and a set of numbers.

System Sustainability

- All participants agreed that they would be willing to pay for access to their medical information on an as-needed basis. However, they were not willing to pay for unlimited access on a subscription basis.
 - “It could be [as high as] a \$35.00 access fee – it would be worth it to go in that one time and look. You shouldn’t have to go back every week looking at the same thing. That fee would be reasonable.”
- The group agreed that physicians should not be charged to access information in the system
 - “It would not create a hassle factor for them, especially in the beginning as I’m sure a lot of this will be voluntary.”
 - “Most private physicians have seen a ratcheting-down of their income over the past couple of years. I think the first thing you are going to hear is ‘Who’s going to pay for my office becoming electronic and enter all these records.’ “
- Potential sources for system sustainability are researchers and the government (state, federal and local).
 - “The federal government has the hugest stake, dollar-wise, in the implementation of this and I feel very comfortable in saying they should pay.”
 - “I think both the state and federal government should have a line item in their budget. Medicaid is state, Medicare federal.”
 - “Ultimately, we are going to give researchers an incredible data base that we will all benefit from, so to me, the federal government is the appropriate source for that.”

Other Issues

- One challenge identified by this group was how to ensure that providers will update their medical records in a timely manner. Medical information will not be available through the RHIO until it has been entered by the providers at the source.
- Some participants would like to see as a future enhancement of the RHIO an archiving capability to house medical records for retired physicians and physicians who have moved out of state.
 - "A lot of times people have trouble getting their records when a doctor does die or retire."

Central Florida RHIO
Legal Rights Focus Group
May 11, 2006

Group Composition

Seven people participated in this focus group, representing attorneys and health advocates. A confidential 90-minute session was held at the Winter Park Health Foundation.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Conditions for Participation in the RHIO

- Participants agreed that the RHIO should eliminate or cut down on redundancy and create certain efficiencies. Patients should not have to fill out the same information for every provider. They should be able to review their information as it appears in the system and approve or make corrections.
- Another redundancy that participants felt could be reduced by the RHIO would be fewer duplicate tests being run.
- Participants stated that pertinent information must be easy to find.
 - "I think you would have to have categorized information so that the provider can find a specific record that they are wanting to consult, if it exists in the records. As opposed to making them read someone's record that has been in an intensive care unit for 30 days and in an ALF for 8 months and then maybe some sort of a neurological facility for two years after that."
- Participants agreed that information in the RHIO must be protected via an audit trail.
 - "If I have someone who has no business in the record, say the desk clerk at the general practitioners office, looking at my psychiatric records, what business do they have?"
 - "It's not any different than now, where under HIPAA, a patient has the right to get a list of everyone to whom their record is disclosed. But are you going to be able to find out everyone who pulled information from this RHIO? Does the RHIO have the same kind of accountability?"
 - "I think it will protect consumers as to who and when their records are reviewed to protect them against fraudulent fetch-and-view."
 - "With the credit report analogy, a lot of requests for your credit report will drop your credit score. I'm wondering about ways this may be misused with this trail."

Like an insurance company seeing how often your records are accessed and labeling you a higher risk, because you have a lot of providers accessing your records, you must have a lot of patient visits. As attorneys, we get a lot of information that is innocuous, and that leads me to ask questions in a totally different area.”

- One participant said that it is important that RHIO software must have good interfaces.
 - “It comes down a lot to the interfacing. There is a Regional Connectivity project in North Carolina where they are connecting 16 hospitals and they have all different methods. So they brought in a team, IBM and AccessPoint, and these guys did the software. And one of the things they spent a lot of time on and did well was writing those interfaces.”
- The group agreed that there should be a large educational component of the RHIO. This will be needed to get consumers past the fear and to emphasize the benefits.
- Participants expressed concerns that consumers unwittingly waive their privacy rights by not reading what they are signing or by accessing confidential information over the Internet using their employer’s computers.
 - “When you say there is going to be an opt-in, do you think people are going to read what’s involved in what that opt-in says? It’s just like HIPAA... [Currently,] you are signing something that says anybody who enters into agreement with the doctor will have access, so you don’t even know who the people are on the trail.”
- Another area where consumers give up privacy rights is by using computers at work to access personal information.
 - “Imagine people sitting around at work using their employer’s computer -- Hmmmm, let’s see if this doctor has my test results back. Again they are on their employer’s computer. At that point the employee has waived their right to confidentiality by using their employer’s computer. That employer will have access to all of the employee’s health records ...”
 - “One of the first things we do when we have to fire somebody is grab the hard drive, get the records from the server.”
- After a lengthy discussion of all the perils, most of the participants agreed that there are more advantages than disadvantages to the RHIO.
 - “The benefits of this, so far, outweigh the negatives... If I were going to the ER, I would want them to have quick and complete access to anything they would need to know.”

Access

- Some participants felt that one of the greatest benefits of the RHIO would be to give consumers access to their own medical records.
 - “Can it be built into the system so that the consumer has access to all his records electronically and he can carry them on a smart card to eliminate that potential? You can have your own centralized records that way, but not within the

RHIO. I personally would like to see the RHIO records de-centralized so the government can't get in there and look at them."

- "In theory this is an excellent idea, having a complete record available all the time."

- Participants agreed that the consumer must strictly control both access to medical information through the RHIO and the purpose for the access.
 - "I think there has to be some opportunity for the consumer to say you can't release the information -- which is how it is with HIPAA now."
- The group also agreed that employers should not be allowed access to the RHIO, including the HR departments of the hospitals.
- Participants discussed the pros and cons of whether insurance carriers should be allowed access to the RHIO.
 - "They already get their billing information so I can only think their reasons would be insidious."
 - "Having insurance companies involved for legitimate reasons is one of the reasons I suppose the RHIO was set up. To reduce fraud, to reduce cost, to have access to accurate records. For reduction of multiple services, absent a carrier making an inappropriate decision about insuring a person, I think it's a good thing."
 - "You have some carriers that will deny claims the first go around, and you have to keep at it. So if the carrier can see through the RHIO that it has been done... It may cut down on some of the wait-time."
- One participant suggested there could be different levels of access, for example, general health information vs. confidential information such as psychiatric records.
 - "What if there are multiple levels of access where someone could have access to general information and then access to a separate holding area for confidential information -- psych records, HIV stuff, gynecological records... What if a doctor in the ER could access Patient A's records, but only the general stuff, and the confidential stuff would be a separate screen that they wouldn't go to unless the patient added additional consents. Something that said it is available if needed, in case of a life-threatening moment. And if there was a circumstance like that, it would be available instantaneously."
- Most participants agreed that there will need to be national standards as well as legislation to protect those standards.

Unique Patient Identifiers

- The group agreed that the best way to uniquely identify patients in the RHIO would be to use fingerprints or iris scans.
- The group also discussed using a microchip in a medical identification card.
- Participants also discussed and rejected using a number as a unique identifier, unless that number is on a swipe card and is never entered manually.

- “A record or provider might have Patient A and Patient B in the RHIO, but they are really the same [patient] with two numbers; and the worry would be that when you access the records you aren’t going to get them all, because a provider or staff might have made an entry under the other [identity].”
- Participants also discussed using a smart card to access to the system. Patients would present the card to the providers, and their medical information would be downloaded or printed out for the provider.
- One participant added that e-prescribing groups use a unique number composed of 5 different identifiers.

System Sustainability

- The group agreed that the long-term funder of the RHIOs should be the government, because this is an economic development activity similar to building the national highway infrastructure.
 - “It’s like a toll road. The government builds it and you pay to use it. You don’t have to use it. There will be economic benefit in this system. And if anyone is in the position to exploit that it is the insurance carrier. I’m looking to use the system to cut down on my wait times and get better care with a more informed decision for my doctor. But the insurance company will be more than that. And they need to pay for that access, because they are going to be using it for something other than patient care.”
 - “This is a Bush Administration proposal, they should pay for it, end of story.”
 - “It should be the government paying. There’s so many mutually-exclusive interests clashing.”
 - “I think it should be a government mandate to use the system. We have healthcare costs that are spiraling in this country and the quality of care is decreasing. If it is for the greater economic good of the country as a whole why shouldn’t they fund the system? And mandate it be used.”
- Participants felt that insurance carriers could facilitate provider participation in the RHIO by providing incentives for them to move to electronic record systems.
 - “If the carriers want to be a part of the system and are willing to pay for it, what if participation by a carrier in the RHIO was in agreement or in exchange for assistance to the providers? Some sort of extra activity by the carrier to help the provider so that they would want to scan?”

Central Florida RHIO
Healthcare Administrators Focus Group
May 16, 2006

Group Composition

Nine people participated in this focus group, representing hospitals, nursing homes, health departments and community healthcare centers. A confidential 90-minute session was held at the Winter Park Health Foundation.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Conditions for Participation in the RHIO

- The group maintained that the RHIO must result in better patient care.
- Participants also agreed that the information in the system must be valuable and timely.
- The group also agreed that a successful RHIO must insure confidentiality and accuracy of information.
 - "Encryption is wonderful but is that enough? And the answer currently is 'no'."
- Education and communication are the keys to the success of the RHIO. Participants felt that the education effort, done correctly, would be extremely time consuming but would be necessary for the public to trust in the security of their records.
 - "I see this as one of the biggest challenges, getting the information to the grassroots communication level where they will have read about it and are knowledgeable about it and can see the benefit to themselves."
 - "You would almost have to have a central body for people to refer to when they have concerns or issues -- whether they couldn't access the website, or they need a lab interpretation -- Some central entity to help administer the process."
- The group felt that there should be a standard definition of what constitutes a record set.
 - "There would have to be a common nomenclature. What I might define as one data point, you might define as something totally different in that interpretation."
- Too much information was a major concern for the group. How will doctors have time to review all of the available information? Will they then be liable for forming or not forming their medical decisions based on all of the available patient records?

- “What if a patient had a reaction to a contrast procedure five years ago and the hospital has access to that information but it is buried under multiple volumes. They redo the test, patient has a reaction. Are they liable then?”
- “The hospitals used to make a copy of your ER record if you came in and sent it to your primary care physician. They stopped because the doctors asked us to, saying that they’d ask for it if they wanted it. They are just too busy. The past five years things have escalated. It’s gone back to “I’ll just ask the patient when I see them and I will believe what they tell me. So, the liability must be addressed. What if a client has a CT scan and it shows a mass, here they are in your office and you don’t say anything about it, six months down the road they have brain cancer and suddenly this is all your fault!”
- “I think the liability is going to be a huge issue. You could be given the information at one point, but at each point of entry there is a caregiver that is responsible for that information. As in the Emergency Room, the ER physician is responsible for it. Not only would it be the physician, if something did happen with a lawsuit, how are you going to figure out the percentage of liability for each caregiver?”
- Participants affirmed that the RHIO’s value for hospitals and community medical centers will be enormous.
 - “The only way to get a handle on healthcare costs is something like this where you can say, ‘You already got a prescription for this yesterday.’ And it isn’t just the drug-seeking. It’s all kinds of things. Sometimes it’s people who are just really confused. It’s not just people trying to beat the system. Sometimes it’s people who don’t access it very well. Maybe they forgot for one reason or another. Even in the same hospital we have repetitive studies because physicians don’t talk to each other.”
 - “There is a huge cost factor involved in going paperless. But the benefits outweigh this. Our doctors are not currently computerized. They are writing in charts. Some new equipment will need to be obtained.”
- Most participants believe that the RHIO will not put an end to duplicate testing.
 - “I think for practicality if not for liability they [physicians] are going to do those diagnostics regardless.”
- Participants also felt that the amount of unnecessary duplicate tests is not as high as has been represented.

Access

- Accessibility was discussed at great length. The group agreed that there should be different levels of access for different groups, depending on their need to know and the level of understanding required to interpret the information.
 - “Right now, patients do not access their health records within the hospital system. There’s a lot of issues to be looked at - whether they should be allowed to access the records. Who can access and how secure is it?”
 - “Maybe there can be certain things that everybody has access to, and the physician has a higher level of access, having a higher level of understanding

and need to know. The physician or nurse trying to find something for the patient might need access to their whole medical history.”

- Most of the participants were not comfortable with the idea of giving healthcare consumers total access to their own medical record.
 - “Realistically, how many physicians are going to be comfortable with that level of accessing anyway? I don’t know many who would be.”
 - “You wouldn’t want [patients] to misinterpret what they are reading. And also, if the physician is concerned about who will have access to [the medical record], it might get even more difficult for them to write anything down.”
 - “Psychiatric records -- I have worked in agencies where the doctor checks off at the end of the encounter whether the patient can get copies of it and if he says no, they don’t get it. To me, the website would need to act the same way.”
- Participants agreed that the RHIO, at least in the early years, must be for medical purposes only and should be accessible only to healthcare organizations and providers.
- The group also agreed that access to the RHIO should not be allowed to insurance companies.

Minimum Information Required for Medical Decision Making

The group discussed the information that is needed by physicians for medical decision making. The following items were listed:

- Allergies
- Medications
- Recent tests
- Recent encounters for specified diagnoses
- Hospital discharge summaries

Unique Patient Identifiers

- Social Security number was debated and then ruled out as a patient identifier.
- Other possible identifiers discussed were:
 - Combination of Date of Birth, Name, Mother’s Maiden Name
 - Photo ID
 - Fingerprints or retinal scans
- Participants were curious about what identifiers other RHIOs are using.

System Sustainability

- Responses were mixed as to whether participants would be willing to pay for access to the RHIO. The general consensus was that hospitals and other healthcare organizations would probably pay for access, if they could justify the cost.
- Those who were willing to pay for access said that, most likely, a monthly or quarterly fee structure would work best for healthcare organizations.
- Participants also discussed the possibility that Medicare or Medicaid might reimburse providers at a higher rate if they maintain an electronic health records system.

Central Florida RHIO
Physicians' Focus Group
April 18, 2006

Group Composition

Seven physicians participated in this focus group, representing private practice, public health and not-for-profit organizations. A confidential 90-minute session was held at the MD Anderson Cancer Center, Orlando.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Conditions for Participation in the RHIO

- All participants agreed that physicians' access to electronic medical records must be cost-neutral.
 - "It is difficult to make ends meet right now, and if it's a fairly costly system for the software or hardware, we probably couldn't do that."
 - "A lot of people resist the idea because they see it eventually going as another unfunded government mandate. It's very difficult with all the mandates we have now. And it will put people out of business."
 - "Just creating the intra-hospital interfaces has cost hundreds of thousands of dollars for hospitals. Will there be enough grant money to implement this electronic record system for all of our different computer interfaces?"
 - "A shared cost would be helpful, as would the organization of a rolling implementation for interfaces."
- System interfaces are very costly. Participants felt that the RHIO should have a roll-out plan for interfaces in order to spread the expense over time.
- Participants expressed fears that participation in the RHIO will be required at some point as another unfunded government mandate.
 - "Follow what has happened with the insurance companies and electronic submissions. You had paper forms and you sent them in. Twenty years ago it wasn't even our responsibility -- the patients took care of it. My billing staff was one person then. Now you have to hire three people just to handle the insurance submissions, just to get paid. Then you add the electronic stuff, you have to buy the computer system and hire five people to manage the system. So should we anticipate this increase in staff to manage the medical records?"
- The group agreed that audit trails are necessary for system security.

“What’s going to let the system know that I have the authority to look at this stuff if I am not treating this patient, just snooping?”

- Participants were particularly enthusiastic about the RHIO’s potential for providing a lookup for hospital records 24 hours a day and 7 days a week.
 - “If [patients] came to us from another hospital the day before and it takes two to three days to get [their] records, the patient can already be discharged from my care before the records arrive. I would find it helpful for that reason -- even if it is only hospital-to-hospital.”

Access

- Some participants expressed their concern over patients controlling the access to their medical records:
 - “If they [the patients] can selectively rule out various types of information, then you render the system useless.”
 - “Well, like on the current HIPAA forms, there’s a long list of things that they can check off that cannot be shared, and you cannot share regardless. And if this system is set up the same way, it would be very easy for patients to manipulate the system to prevent information being passed around.”

Unique Patient Identifiers

The group discussed several options for identifying a patient’s medical records...

- Every patient should have his/her own password. Most financial identifiers such as mother’s maiden name are not private enough.
 - “A lot of times you get family members who want to know about information. And all the usual questions like mother’s maiden name, where were you born, social security number...they know all that.”
- Patient Name is not a good identifier for medical records.
 - “You’d have to stay away from names, because people develop so many aliases. Say a hospital has a record for Baby Jones, who is renamed George Jones, who is renamed George Michaels and three years later is now known as George Lopez -- all the same patient. Say Jones was the mother’s maiden name. Then Mom remarries and it changes again. That change happens every day.”
- Date of Birth is a good identifier.
 - “People go back and forth about social security numbers, but certainly the date of birth and some unique number.”
- Driver’s License Number is a good identifier.
 - “Drivers licenses are good for adults and they are harder numbers to get than social security numbers. And you might use the drivers license of the parent if it is a child under 18.”

- The best patient identifier would be some form of biometrics, such as retinal scans or digital fingerprints.
 - “They do it [retinal scan] when you come into the country now -- they put it on your passport. You’d do it on every patient, regardless of who they say they are, whether they are conscious or not. They’ve got the machines in Miami sitting right there. It’s not that expensive. Or digital fingerprints. To go to Disney World you have to do it.”
- Participants also discussed maintaining patient identification and medical records on a smart card that could be carried by the patient to each provider.

Minimum Transmitted Information for Medical Decision Making

The group discussed the information that is needed by physicians for medical decision making. The following items were listed:

- Current medications
 - Allergies
 - Current patient profile
 - Most recent diagnosis
 - Present history: most recent lab/radiology results
 - Problem list: all diagnoses
 - Past history
 - Past surgeries
 - Hospitalizations
 - Audit trail
- Participants said that not every part of a patient’s medical record is pertinent to treatment of the current condition:
 - “There are static, past and current elements [in the medical record]. So, some of the static elements are: my gender. Then there are past conditions. Knowing that a patient had an asthma attack ten years ago actually is pertinent today. Then there is the active stuff, like the medications they are on today. That someone took Lipitor a couple years ago and stopped taking it, I don’t care about that.”
 - “If I am in the ER and I put in a name to scan and say, they have been to the Center For Drug-Free Living and have been treated for substance abuse, and the problem here is that they cut their leg, they may not want everybody knowing that. It’s not necessary information and should be kept confidential. What about an HIV patient that doesn’t want everybody to know that. How do you keep people out of that?”
 - “A patient profile, where you know that 10 years ago the patient was diagnosed with diabetes, but you don’t want to wade through 20 histories and profiles to get that information -- a basic sheet that has this static information.”
 - “A problem list could be developed that shows the patient had a MI 10 years ago, but you don’t have to wade through the follow up visit reports that are irrelevant to my care of the patient, but administratively necessary.”

- Other discussion centered on who is the owner of the patient's record – the patient or the facility?
 - "If I am the patient, I would like to be able to see my records and authorize what elements can be seen by other people. That [the doctor] thinks I'm schizophrenic, I don't want that to get out. So I would want to exclude all of [that doctor's] data."
 - "And what do we do about an active TB patient? Are we going to allow them to exclude it from our knowing? I don't think so. Or is it our record? And if it is our record, then maybe the patient doesn't get to see anything, except what we may let them see, like how they paid their bills, and maybe the immunization record."

System Sustainability

- Participants unanimously agreed that physicians will not participate in the RHIO if they have to pay for access, unless they could pass that cost on to the patients.
 - "Maybe the RHIO hub should be paying us for accessing our information."
 - "Maybe the people to look at are the patients themselves. Ask them if they want to have their records available to their doctor on the internet, and they would pay, just in case they need to have the information accessed. Like insurance. They may not need it, but it's nice to have it there just in case."
- The group recommended that the cost of sustaining the RHIO should be a line item in the government budget.
 - "The bigger system would have a larger stake in [the RHIO] and that would be the federal government. I saw where something like 60% of all health costs are paid for by government at some level or subsidized by tax breaks for employers health plans. And if the system costs 2 trillion, I propose 0.1% of Mr. Bush's plan to have this activated in 10 years. It would lay it out and pay for it."

Small Practice Incentives

- Two big hurdles to overcome for physician buy-in are cost and time. Participants agreed that cost must be minimal or free, and training time must not be lengthy.
 - "Physicians feel like they will have to shut their offices down to get the staff trained and running with the system."
- Participants said that training should involve the office manager or the medical records personnel, rather than the doctor.
 - "I'd be willing to pay for them to go to the training."
- One participant stated that creation of electronic health records is time consuming and not yet efficient.
 - "If it were a matter of having VRS (Voice Recognition System), then 90% of the offices would not be able to participate."
- Several participants said that they would not be able to participate in the RHIO if electronic capability is a requirement.

- Participants suggested that the best way to incentivize small or medium size physician practices to participate in a RHIO would be to provide software installation and training at no cost and little inconvenience, similar to what some labs have done.
 - “I can go on the Internet and get my results the next day.”
 - “It was very convenient. And it would be great to have something like that with Florida Hospital or ORMC, to get the patient’s discharges and information, but I don’t have it because nobody has come to my office and told me about it. I don’t have the time.”

Central Florida RHIO
Ancillary Service Providers Focus Group
May 9, 2006

Group Composition

Six people participated in this focus group, representing pharmacy, clinical lab, diagnostic services and counseling services. A confidential 90-minute session was held at the Crosby Wellness Center YMCA in Winter Park.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Conditions for Participation in the RHIO

- The group agreed that providers must be assured that system security and the integrity of the information will be maintained.
- The group felt that ethical oversight will be critical to the success of the RHIO. There should be an ethics review panel to ensure that the system is used ethically.
 - “That’s what this system all boils down to -- ethics.”
- Participants stated that the RHIO needs to be sensitive to current legislation, which prohibits posting HIV test results on the Internet.
- Participants also felt that most people will opt into the system. The RHIO should move ahead with those who opt in, rather than try to convince everyone to join.
 - “I think the RHIO... shouldn’t obsess about getting 100% of the people to agree to it because we won’t ever do that.”
- The group agreed that sharing healthcare information is a good thing.
 - “There are a lot of studies out there which report that 20-40% of the tests we perform are redundant. So one of the biggest things we hope the RHIO can achieve is to cut the redundancies. Say your cholesterol is high by a test your primary physician ordered and they send you to a cardiologist. The cardiologist doesn’t have the information immediately, so he orders another test. If he had access to a RHIO, the treatment could begin that day, but you end up waiting another week for a redundant test to be performed.”

Access

- Participants stated that small clinics do not have the infrastructure to provide data to the RHIO. They access their own data using remote third-party servers. They would not be able to participate in the RHIO unless the third party agrees to participate.
 - “The RHIO is going to be different, sort of live, 24/7 web-based activity. And that’s a real problem for us, as we are part of an alliance of community health centers throughout the state. The alliance has come together to house all of our client information for security purposes. This larger group doesn’t permit access into the group. So while I may be comfortable with what is needed for the RHIO, there are going to be real roadblocks to accessing the data.”
 - “I don’t think there are many people who are going to be willing to open up their systems and all people to be constantly in and out of it. I don’t think it is feasible. Each of us would have to recreate a central data base for RHIO to get into. Access into our operating systems is not going to happen.”
- Labs will typically be data contributors to the RHIO, but there are circumstances where labs would also need to be data receivers:
 - “As a laboratory testing facility, they don’t but as a provider of pathology they do. As soon as someone’s lab test hits the laboratory, the medical director becomes the official referral physician of that patient. So there are times that we want to look at what has happened. We only have a sample and we would like to have the whole picture. A lot of time we want additional information which would really help us to diagnose and perform certain tests. Maybe the patient is on medications that affect the test. A drug can affect the test result. Rather than tracking everything down, it would be good to have available.”
 - “But there are some things in medical records that would not be necessary for people at Quest to see. So my problem with this is who is going to designate what can be seen?”
- Most participants agreed that consent for access to medical records should reside at the treating provider’s office.
 - “As a clinician, the more information I have access to, the better. If the patient is hiding something, from a care perspective it can be a very serious issue. I am not for opening the patient’s record without consent, but I would probably push toward you wanting me to treat you, then give me all the information, not bits and pieces where in my mind I cannot tell.”
 - “I’d say it’s a yes or no deal. If you are going to give me information access, then give me all of it. Rather than limiting me, if I go to the computer and see there’s some sort of filter there, that I am only seeing part of what is there, I cannot tell if this is the whole picture, and from the patients benefit standpoint, I would be worried. When I render my judgment it is dangerous.”
 - “When you provide your consent to treatment, you agree to sharing your information. The HIPAA form just says you agree you have been informed. It’s not a consent form at all, just an acknowledgement that your physician has told you what HIPAA was. In our lab, a violation of HIPAA would be that we accidentally faxed someone’s lab to anyone other than the physician who requested the test. But we do not have to ask permission if the requesting doctor has written orders to have the results sent to another physician. The sharing of information is allowed without the consumer’s direct consent, they have already to consented to treatment, which includes consultation.”

- The group agreed that access to clinically identified information in the RHIO should only be for purposes of medical treatment and that access to de-identified data should be allowed to public health entities like the CDC and health departments.
- Participants agreed that insurance carriers should not be allowed to access clinical data in the RHIO but could be allowed to access the de-identified data for research purposes and to establish evidence-based practices in patient and provider education efforts.
 - “Based on their history, I think there’s a pretty great chance they will abuse the data for their own good. They are a for-profit industry.”
 - “I would just hope that the RHIO wouldn’t make it easier for people to get hold of information they shouldn’t have.”
- Participants also agreed that employers should never have access to the RHIO.
- The group agreed that only treating physicians should be allowed access to the RHIO; all other providers should be denied access.
 - “I don’t have a problem with a physician looking at my record, but I don’t think the person drawing my blood at Quest needs to know.”

Unique Patient Identifiers

- Participants discussed using a combination of Name, Date of Birth and Gender as a unique patient identifier or of assigning a unique number, like the Master Patient Index number.
- One participant objected to using a number:
 - “What we don’t want to do is duplicate or create just another number. You deliver that to the providers and they don’t know how to use it. It’s just one extra field in their record to add.”
- Participants also discussed the possibility of using smart card technology, where consumers carry their health information with them on a swipe card.

System Sustainability

- Some participants felt that providers should pay to use the RHIO, but should pass costs on to their patients.
 - “Most medical providers are used to paying for access to information. Every time we scan an insurance card, we pay a fee for accessing that. I don’t think they will be uncomfortable, generally speaking.”
 - “I have no problem with them paying, but they should reflect that on their reimbursements as well.”
- All providers felt that insurance carriers have the potential to abuse the system. Therefore, they shouldn’t be allowed to pay for the RHIO.

- Participants agreed that, as the federal government is the biggest third-party payer, it has the most interest in subsidizing cost saving systems like the RHIO.
- One participant expressed fears that changes in the government could lead to inconsistent funding patterns.
- The federally-funded Veterans Administration system was discussed as a model.
 - "I've seen the value of the system from the VA side, and it sure can be valuable."
 - "The VA is a centralized data base. But the purpose is the same. They actually donated their software as a centralized data base for anybody to use. In Indiana's RHIO it currently takes 190 people to run it."
 - "With VA those folks don't have a choice. The government is paying the bill so you have to do what they say."

Other Issues

- One participant suggested that registry data might be a more efficient source of data for the RHIO:
 - "[For] each person who comes in to a provider we collect the data and send it to a registry. Along with that registry, there might be a group of data, like a continuity of care record, for a minimal data set -- so that there will be critical data that we decide might be good for the repository. That way it is faster to get the information out."

Central Florida RHIO
Payers' Focus Group
May 9, 2006

Group Composition

Five people participated in this focus group, representing major insurance carriers and a county health department. A confidential 90-minute session was held at the Central Florida Health Care Coalition offices in Orlando.

Results

Following is a report of the discussions that took place. Quotation marks indicate the actual words used by participants in the group.

Participation in the RHIO

- Participants did not feel that insurance carriers have much of a role in the RHIO at this time. The group defined the payers' role as a supportive one.
 - "I don't know whether we would know what the role would be. It's very difficult to make a commitment right now as to what they [payers] would do. It has never existed before, so it would be pretty speculative."
 - "The reason that there is a thought that the payers should pay for the system is they think medical costs will go down. This is the first conversation I have been involved with that we were even asked. It has been thought until now that insurance companies will benefit, therefore you will pay."
- Participants stated that many payers already enjoy the benefits that the RHIO will provide to consumers and providers.
 - "There may be some argument for [obtaining] accurate data [through the RHIO], but we have accurate data now."
 - "Some of the payers are starting to offer programs now to encourage patients to use personal health records and encourage providers to develop portable information. Maybe once there is a totally seamless RHIO system in place throughout the world, then it would become redundant. But now there is an impetus to have an electronic health record that patients can keep on a flash memory device or centralized."
- Participants felt that the most helpful data available through the RHIO for all stakeholders will be pharmacy data and lab and imaging results.
 - "[Currently,] aggregate data from pharmacies is questionable -- so many of them sub out their pharmacy to another provider health plan. It is very fragmented data."

- “The fact that someone went to a cardiologist is of very little use. The fact that he had a cath done is of great use. The fact of seeing the doctor, not so important. The results of the physical, that’s big.”
- The group agreed that the direct cost benefits of the RHIO will initially be for consumers and providers, rather than for payers. One benefit to providers, from a payer standpoint, might be in increased speed of claims reimbursement and less time spent making copies if payers could immediately access additional patient information.
 - “If we could see a hospital’s billing system, it would save them a whole lot of copying and stapling and reviewing time -- If we could see what happened to a person in the hospital before a claim got paid.”

Access

- Participants acknowledged that payers already have access to more patient medical information than consumers realize.
 - “I don’t think that most people understand the level of access [to patient information] that there really is already.”
 - “When you go to the doctor’s office you sign a form that says you can release what is needed to get a claim paid. And if you don’t sign that, they won’t see you. So you have already signed away your right before you ever went back in the room. I think the lay person has no idea what their rights are under HIPAA.”
 - “The consent issue is really only if it is not your claim. If it is our claim we have access to it already.”
- Participants agreed that anticipated payer access to the RHIO should be very limited.
 - “There are two very distinct areas. One is claim payment and the other is medical management. On the medical management side, the answer is that there are instances where unlimited access will be helpful. On the claim payment side, it is none of our business.”
 - “The access we would have to ask for is ‘Can we go and look at everything that ever got done to you, regardless of whether it was with me or not?’ And I don’t think there are a lot of people that are going to want to give that away.”
- Participants agreed that payers should not be allowed to access the RHIO for purposes of denying medical claims.
 - “We really have to allow access in such a manner that it couldn’t be used by insurance companies against claim payment, but rather to facilitate patient care.”
 - “I wouldn’t want 26,000 [insurance company] employees to be able to go out and access patients medical records whenever they wanted.”
- Participants also commented that RHIO access standards must be an extension of the current HIPAA processes, i.e., patient records may be accessed only with patient consent.

Unique Patient Identifiers

- Participants discussed the problems of using a numbering system as a unique patient identifier in the RHIO.
 - Cannot use Social Security number
 - Many people are undocumented
 - People can give wrong numbers
 - Office staff can make typos during entry
 - Forms and computer systems must be redesigned
- Participants also pointed out that any numbering system that is developed regionally will likely change with the implementation of the NHIN.
 - “If it joins the changes with the ones that are already implemented, it needs to be something flexible. So you come up with something and suddenly they are taking a different best practice that doesn’t fit with what you already spent money to develop.”

System Sustainability

- Participants said that some insurance companies are interested in partnering in the development of information sharing systems like the RHIO.
 - “There is an acceptance or support of cost-sharing between payers and employers. It ultimately is helping our members, which is what we are all about.”
 - “Philosophically they are pretty supportive of partnering in the development of electronic information systems.”
- Some participants felt that payers might be interested in paying to use the clinical data.
 - “If we are going to take the aggregated data and do what we want with it, we should pay.”
- Participants felt that there would be a lot of resistance on the part of payers to ‘paying for the system’ in any way other than reducing premiums -- at least initially.
 - “There is support in other ways besides paying for access.”
- Participants agreed that long-term insurance industry commitments to the RHIO will only come after long- term savings can be demonstrated.
 - “Ultimately, it is going to be the consumer who pays [for the RHIO], one way or another.”

Other Issues

- The group shared their opinions that the expectation of overall cost savings due to the reduction of redundant tests has been overrated, because providers cannot be prevented from running duplicate tests.

- "I have walked in to doctors offices with [copies of] x-rays before, and they have redone them, anyway."
- "If I go to the ER with a broken foot and get x-rayed, I go to the ortho with my x-rays and he says they are no good, he is taking his own -- the insurance pays. We cannot deny payment."
- "Many times the report of the test, if you are a specialist, is not the actual test itself. You want to interpret the test yourself. You are only seeing the radiologist's report of an image or study. There may be some cost savings if you know the report is adequate. But the amount of redundancy taken out will be minimal."
- "There is the issue of quality, the issue of [the provider] needing to see the original and the financial incentives for the provider, which we are never going to be able to get out the system."