

MCHB/ DSCSHN May 18, 2005 Webcast

MCHB/ DSCSHN Ready or Not:

The Role of Public Health Information Organizations

ELLEN WILD: Welcome, everyone, to this webcast titled, Ready or Not: Public Health's Role. I'm Ellen Wild, the director of programs and I'll be moderating today's webcast. We're excited about the opportunity to discuss this important national initiative and how our work, integrating child information systems fits in. I want to thank the Maternal and Child Health Bureau for sponsoring this webcasts. It's the first of two webcasts that we'll host for HRSA. The second webcast will take place August 10 from 2:30 to 4:00 and an overview of a tool that the connections community of practice developed the integrated systems program managers in addressing duplicate records.

In today's webcast, RHIO's will include an overview. Followed by presentations from two states and their experiences with working the RHIO, Dr. Roland Gamache from Indiana and Amy Zimmerman from Rhode Island. I want to cover operational issues. Slides will appear in the central window and advance automatically so you don't need to do anything to advance the slides. If you feel you need to adjust the timing of the slide changes to more closely match your audio, you can use the slide delay control at the top of the messaging window. We will be taking questions after all the presentations are completed. However, you can ask the presenters questions during their presentations. Simply type your question in the white message window on the right side of the screen, select question

for speaker from the dropdown menu and hit send. Once the presentations are finished I'll read the questions aloud and direct them to the appropriate speaker.

On the left side of your screen is the audio control. You can adjust the volume of the audio using the volume control slider which you can access by clicking on the loudspeaker icon. Those of you who selected the accessibility features when you registered, will see text captioning underneath the audio control window. At the end of the broadcast the interface will close automatically and you'll be given the opportunity to fill out an online evaluation. Please do so. Your responses will help us plan future broadcasts. Our first speaker today is Dr. Dave Ross, director of the public health informatics institute. He became the director of a program founded by the Robert Wood Johnson Foundation in 2000. They formed the public health informatics institute to advance -- to apply and manage health information systems. Dave's experience spans the private and public healthcare sectors before starting the institute he was an executive with the private health information systems firms. And an executive in a private health system. Dave.

DR. DAVE ROSS: Thank you, Ellen. First I'll apologize to the listening audience for my cough and hacking and wheezing. I managed to pick up a nice cold. So please ignore the coughing, I'll do my best. I would like to start with the title exchanging health information. As Ellen said this webcast focuses on developments that are happening now throughout the nation that are related to the exchange of personal health information. Beginning with the 1999 national committee on vital and health statistics report entitled information for health, a strategy for building the national health information infrastructure or NHII,

momentum has continued to build around the notion that accurate information placed in the hands of the provider at the point of service will reduce errors, should improve search knowledge, quality of care and make care safer. For public health services and from the Maternal and Child Health Bureau program point of view we would certainly hope and I hope that this broadcast helps you agree that we should insist that it improve care coordination and linkage with medical home.

In the 2000 to 2004 period of time, the Department of Health and Human Services focused on articulating what an NHI would do to improve individual health and population health status. As well as identify the major areas of needs. So, for example, they focused on needs for data, vocabulary and communication standards. They focused on identifying concepts that were central to governance for the exchange of patient information across healthcare organizations. And they focused on issues that relate to privacy and security. Last spring, the president named Dr. David Brailer as the head of the coordinator for information technology and named the first I.T. healthcare czar that our nation has ever had. But made the statement that is an important issue and it was one that this administration was going to promote. So his appointment gave the healthcare interconnectivity and interoperability dialogue pretty significant visibility and associated with that came grants and contract awards that were made for the agency last year to promote the growth of regional healthcare exchanges or RHIO's. For those who track this dialogue you're familiar with the eHealth initiative which is a non-profit advocacy group that sponsors frequent conferences that bring all sectors of healthcare together to discuss how to move this agenda forward. They also sponsored the connecting communities for

better health or CCBH grants that are funded under support from HRSA. I would like now to examine exactly what do we mean by regional health information organization.

Moving to the next slide, what is a RHIO. Inherently, this is a concept about something that is either local or regional because it focuses around where care is delivered, or it is, in effect, the notion of connecting a network of people with a like purpose. For example, connecting Children's Hospitals and research efforts together. So a RHIO is an organization that links providers for the purpose of exchanging person-centric information that should be relevant to an individual's health. So that these things, if they're going to emerge, probably will be built around existing care and referral relationships. They're probably going to be built on existing trust relationships. And at a minimum they're going to have to find a way to establish mutual benefit.

So moving to the next slide, I asked the question, is public health chicken soup for RHIO's? I steal a line from two doctors. They made a comment about, is I.T. chicken soup for healthcare? It struck me that maybe a similar parallel exists in thinking about the regional exchange of health information or the exchange of health information within a region that public health may well be chicken soup for RHIOs. It seems there is a strong case that public health must be central to RHIOs. I think asking the question is public health chicken soup for RHIOs is one way to think about it. I don't want to overstate our importance. I think it does make sense, though, to examine who public health is and carefully consider the need for public health involvement in the formation of and in the

operation of any RHIO. As I point out on the slide, public health is mandated to protect and improve the health of all the people within a legal jurisdiction.

We do this through surveillance of health trends, through regulatory actions, through health promotion, through disease prevention, through screening programs, a number of activities. And we also know that public health is very information dependent and very information intensive business. And many of its functions are performed in partnership with healthcare providers and with provider organizations. And I think one other aspect of public health is important to think of here. That is, that it's neutral and charged with representing the interests of all the public. So we see this as a strong argument for the centrality of public health in a RHIO formation and its operation.

Moving to the next slide, public health has been active for a long time in gathering information through systems that link with the healthcare provider community. We've done it through registries like immunization registries or cancer or birth defects registries through surveillance and case management systems. There is a historical legacy of public health involvement in this kind of endeavor. Over the past decade or longer, both HRSA and CDC have funded public health agencies to develop more integrated and linked systems that promote more efficient data capture. That improve coordination of services, that strengthen surveillance of community health problems and that warn of new health threats. So these grants have led to systems integration initiatives in child health, sponsored significantly through grants from the Maternal and Child Health Bureau at HRSA, and the EDDIE grants that have come from HRSA and CDC. There has been very

significant attention to infectious disease surveillance through CDC grants and all the effort on terrorism response and the public health information network grants from CDC.

So I think on the community health front HRSA has partnered with eHealth initiative through connecting communities to help an exchange. I want to point out that public health is in the business of health information exchange and has been for a long time. Public health has significant capability and understanding of the multitude of issues that confront the healthcare industry as it approaches this idea of local information exchange.

So let's examine the next slide, the current State of RHIOs. National surveys show that information exchanges are developing in a number of places. Several, such as the Indiana health information exchange that's based in Indianapolis, and the inland northwest health services network based in Spokane, Washington. Are in operation and have a number of years of successful growth to their credit. A few projects such as the project in Santa Barbara, California and the Utah clinical information network, which is an expansion of the Utah health information network, are in early deployment and a few are rapidly moving through planning stages into deployment. These include the AHRQ funded projects like the Rhode Island quality institute project that Jemy Zimmerman will talk about and the Colorado health information exchange and the Tennessee projects. All of these are projects that have been funded by AHRQ and are moving through planning and implementation efforts right now and all involved state-based or regional sharing and an interoperability services of interconnecting healthcare entities. Our other speakers today will speak more directly to Indiana and Rhode Island projects.

Moving to the next slide, RHIO, what is it? RHIO became a term, really, last summer. I'm going through this in a way to make clear that -- to let you know in my opinion this is a very dynamic area and terms are developing as we go. And some of these terms will disappear later. But the term of the day has been RHIO. And it became a term last summer when Dr. Brailer introduced it as a way to supplant local information infrastructure. Does it adequately address the notion of healthcare entities including public health, establishing networks to support patient care through exchange of data? Is there another entity needed to encompass the concept of local trading area? I don't know.

What name will be given to entities that form a community of interest such as a network of Children's Hospitals and clinics that span a broad geography to expand research by exchanging patient-specific data? In truth, I think the answers to these questions and others are being raised daily and it will take some time to resolve. But what we do know is that the concept of a RHIO must have a few things. It must have some governance, which means it has to have a formal charter and a legal standing. It must have processes for managing stakeholder involvement. And addressing their needs and it must have processes for negotiating changes to this charter over time. It obviously needs a technology architecture and a way to create an assurance or conformance with standards. It's got to have data use agreements. And, of course, at the base of it all it has to have a basic financial and business model that is going to keep it viable. So there are a number of issues to be resolved.

This is the next slide. This new world order of exchanging person-centric data is changing the status quo. I think we have a number of questions. Several are really fundamental to shaping the future role, the purpose and goals that these exchange entities will play. For example, is a RHIO supposed to support improvements in community health status? Is it going to have the interest of the patient and the patient's control over their health and their healthcare core to its mission? Or is it going to be principally a means of supporting the business to business level transactions of healthcare providers? Another question, what is a sustainable business model for an exchange? How can information be valued as an asset, for example? And related to this is given that electronic information that has been costly to create, for example, hospitals that have paid a lot of money to create electronic medical records system and information that has strategic advantage to these healthcare institutions, I think some of these have to answer why should they share it? I think there are answers to these questions but I think it's also important that we put them out there clearly for everybody to examine.

Another question would be who within a community represents the necessary set of core stakeholders? In the effect. Who sits on the board of the health information exchange? We know that physicians continue to say that free is not cheap enough when it comes to automating an outpatient practice. It's a really tough nut to crack, frankly, and I think the technology world has a lot of progress yet to make to do this. But right now the incentives are wrong and it is difficult to convince a physician practice that they should adopt costly technologies to allow us to connect and share data with them. Finally, who serves as the trusted neutral party to convene and manage trust over time? I think that's an important

concept about trust over time within a community. Such that we will all trust that our private health information is used appropriately and used for our benefit.

So let's move to the next slide. Talk a little bit about public health benefits. I think public health can benefit by participating in RHIOs. It's part of the purpose of this broadcast, to give you more background on why we believe that's so. I think that RHIOs will benefit through public health participation. Public health benefits because it's going to receive more timely and complete receipt of disease reports. That's important for public health practice everywhere. Public health is going to benefit through faster transmission of better information to public health case managers. For example, newborn screening follow-up or communicable disease control. Public health will benefit through easier identification and gaps in preventive health services. So, in fact, public health might just be getting chicken soup itself for being part of a RHIO.

Moving to the next slide about some of the challenges. We all know the old saying that to play, you have to pay. I think public health needs to be prepared to offer stable leadership and vision and to push aside partisan politics and needs to accept it will bear a financial burden. We cannot just take, we must also contribute. The contribution may be quality data, it may be improved information that helps at the point of care, for example, immunization reminders. If that's kind of information presented directly to a provider at the time of service, the right, most correct service will be given and public health can help make that happen. The contribution may be financial support to help specific activities within annual formed RHIO take place.

I think we have to acknowledge and be mindful of the potential regulatory conflicts. But most of all, we need to be aware of the consequences of failed participation and failed leadership. I think public health must be at the table and it should want to play a leading role in the formation of future health information exchanges. And play a significant role in their ongoing vitality and viability. That is the end of my remarks and I want to in a second turn it back to Ellen but to say to the audience that I've tried to just provide a very high level overview, for those of you who haven't been involved in this dialogue, to let you know there is this very robust, vigorous dialogue going on nationally throughout the healthcare industry and increasingly involving the public health industry and I urge you in your own location to become involved in these dialogues.

ELLEN WILD: Our second speaker is Dr. Roland Gamache from the Indiana Department of Health. He's the director of the health center at the Indiana Department of Health. His 12 years of public health positions include positions as a statistician, quality improvement planner, director of data analysis and two years as the director of public health preparedness and emergency response. He's an active participant in the public health informatics and policy committees at the association of state and territorial health officials. Roland.

DR. ROLAND GAMACHE: Thank you, Ellen. Good afternoon. And I think good morning still to people a little further west. I would like to thank the public health informatics institute for the opportunity to discuss the Indiana regional health information organizations. As the

title of my presentation suggests, I'll be discussing the role of public health and the partnerships with regional health information organizations in our community. In particular, I would like to highlight some of the areas in our work with the Indiana health information exchange or IHIE. One area in particular I would like to emphasize is the role of public health in knowledge management based systems as we partner with these health information exchange organizations. Dr. Ross's opening remarks he listed four areas to consider in the public health partnership with these organizations. Once again these four areas are the governance of the organization, technical architecture needed for the organizations to share information, the need for data use agreements among the various partner organizations and the financial and business models to support the ongoing viability of the regional health information organizations. I'll try to note these areas in my presentation as I move forward.

On the second slide I've listed the topics for discussion. For this presentation. The areas I have listed are the points that seem to be of significance towards forwarding our relationship with the regional health information organizations in our state. These same points are a recurring theme in my conversations with other public health jurisdictions answer they establish their relationships with RHIOs in their communities. First the development of RHIOs in a community will be driven by the business of the health delivery system. I feel it's really important to recognize this issue early in the process. For public health to be a good partner with these organization you must assume its share of the cost of the system and must be ready to accept the data provided by the RHIOs, to assess the quality of this data, and provide knowledge back to the program areas, to the providers,

and to the community. So these last two points are part of the real value that public health brings to the table in its partnership with RHIOs.

On the slide three titled what drives RHIOs, I've listed there three talking points. The largest initial push for the formation of a RHIO will be the reduced costs from the electronic transmission of health information. As an example the RHIO in central Indiana estimates a \$500,000 per year savings in cost by electronically sharing laboratory results. Isn't it sharing any other information, just the result of sharing laboratory results through the electronic information exchange. In addition, the potential for more timely and complete information in the clinical setting is also a motivation for these systems. In a recent paper in JAMA found from a survey 13.6% of clinical encounters were missing health information needed at the time of the visit. So once again if this information is available it can save a lot of time and money at the time of the clinical encounter. Finally, these RHIOs are business units and need to function as such to be sustainable. Hospitals and laboratories are ready partners for these organizations. I think physicians, as Dr. Ross mentioned as well, are a little more difficult. However, if the RHIO can begin to show physicians a time savings of only half hour or 45 minutes per day, enough time for that physician to make their child's baseball game, I think we have something that we can use for them to become more interested. And just as a warning I'm coaching one of my children's baseball teams this year so I have a few baseball comparisons in my presentation.

As I thought about this presentation a little further, I thought what is different now as compared to five years ago when RHIOs in a different form were becoming seriously discussed? I think there have been two things that have drastically changed to help move this initiative forward. The first is the interaction of public health for emergency preparedness or BT functions. This funding and attention has helped to develop the infrastructure needed for both the community and for public health to seriously undertake these initiatives. This includes both the technical infrastructure as well as the underlying infrastructure and connections in the community to share information. The concern of the health communities with SARS and the communication that had already begun regarding emergency response planning brought to light the need for information to be shared among facilities and to be shared quickly. The second major change is more recent and is with a rapid growth and spending of healthcare delays that is threatening the economic viability of many communities. I think this refocused attention to RHIOs as a way to ease the spending of health dollars.

On the fourth slide I have listed potential areas of public health added value. The first is reduce costs to electronic reporting of public health events. This first bullet is a major contributor for the continued viability of the organization and is related to the financial and business models needed for the organization. Public health data systems need to be organized to accept the data from these data streams. The second point is that more enhanced information can be obtained for vulnerable populations. The best example would be the availability of the complete immunization record of a child even if that child received shots at multiple locations and from multiple providers. I think for the vulnerable

populations they seem to move around more and this information is even more important for these groups of people. We also could include disease reports or other time sensitive information, public health events in this category. Points three and four relate to enhanced savings that public health can provide through knowledge-enhanced community-based interventions. By clinic call messaging designed to improve the overall resilience of the health community. I think these two events are part of what public health can provide in feedback to the RHIOs and is a really critical point in partnership with these organizations.

Slide 5 I asked the question, what does public health need in place to interface and partner with RHIOs? I think the first step in our partnership is a self-assessment of the organization. To determine what it really brings to the table. And what needs to change in order to pursue an effective partnership with the regional health information organizations. I've listed several areas of value that I think public health brings to the table. Dr. Ross has already mentioned a few of these but I think they're worth talking about again. First, public health is a trustworthy data steward. It's true that people in general do not trust government. However, the same surveys that show this lack of trust in government also show that public health has a high level of trust with the public. I think we need to use this good will that we have with the public as we relate with the RHIOs.

Public health also has many of the community-based data stores that can enhance the information and clinical data from the regional health information organizations. Public health is also a good choice for the management of the data use agreements particularly since these agreements will then be a public record for the community to have access to.

Data storage in community focus I think I'll address together as well here. The data storage structure for public health needs to be designed in a way to enable the sharing of data and information with the regional health information organizations while still supporting a community focus. I think this is the area that public health can really enhance its ability to interact with the RHIO and provide even more savings to these organizations. I can -- I'll have another baseball analogy here. A good batter is somebody who hits the ball quite a bit. These players have a high batting average. We could consider the batters the health delivery partners in the RHIOs. In term of money batter. Hits the ball when runners are on the base. They're the batters who get the runs to score and I think in our partnership with RHIOs. Public health needs to be that money batter. When I put this presentation together, I got very vigorous and thought I could cover a lot more material in the time than I had allotted.

I think I want to skip ahead to slide 12 titled the PMI case comparison. On this -- as we put together our organization or our data store in order to accept information from the RHIOs, one of the first decisions we had to discussion was how to organize the public health data to provide value added information to program areas to the executive staff at our organization and to our constituents. Our decision was to use the standards around a person-centered model.

In this slide I compare the person-centric model compared to a case-centric model and it seems to be the point where these operational data stores seem to spread. Most people are headed towards a person-centric model at this time. It not only provides location and

time of the event but enables links to more data sources through the individual than the case-centric model and provides the demographic data that can be aggregated to a population-based model. This population-based model and the information from the population-based models are think are part of what goes back to the community focus and the knowledge management piece we can bring to the RHIO.

On slide 13 I describe the data structure. I have a master person index. Also termed an MPI provides a one-to-one link to events. A particular birth event, death event linked to that individual occurring at one event. Other events that happen can be thought of to enhance the data record as we have additional events that occur we can enhance the data record of that information. In Indiana the majority of our population is born in our state. Births not only are an event that occur but they also are the primary source for the creation of an individual or the person reference in our data store. As I said before, additional events that occur are enhancements to this initial record or record that actually starts that individual. This may not be true for all states. If a state has a high amount of people coming into the state, it may -- the birth record then doesn't provide that source. But for our state this used to be the case. Case-centric events can have a one-to-one or one to many match in the data store. For example, some environmental may be linked to one person or many more. It can be used to produce population-based information. And this happens when we can link that case event then back to an individual to some type of case management or other way to link that event to a person in our database.

I would like to skip ahead again to slide 20. To talk about some of the traditional areas of public health value. I've listed several areas where public health is already providing, I think, valuable community-based information and I would like to add some comments about what Indiana is currently doing or what we've talked about doing in our partnership with the Indiana health information exchange. First, if you can go back a little bit our operational data store started as a \$50,000 pilot project to link births, deaths and hospital discharge records. To develop a child health profile and to establish a more sound birth defects registry system. It's from this initial pilot that we started the foundation for the data structure for the agency which now includes information from nearly every department in our agency.

All the data reported currently in the system, except for deaths, are reported electronically. It's been interesting as we've talked to some other individuals and with the National Center for Health Statistics that work in this area has suggested the need to develop additional HL7 codes to support vital records reporting. I think my boss has stated this quite well that in the future public health reporting will be satisfied by maintaining a timely and accurate electronic health record for an individual. From that electronic health record public health will be able to extract from it the information it needs to do its job well. Some of the other indicators that have helped with this project has allowed enhanced activity for quality indicators. With our work with Medicaid agencies. Enhanced our case identification in birth defects and in the cancer registry. And several other case identification areas.

Overall data quality is starting to improve as we link different data sources and streams together and find ways to improve the data quality. We have a more complete immunization history for children. I have to qualify this. Our immunization registry is a voluntary system but seems to capture the children that we're most interested in making sure that they have their immunizations up to date. Now, the one area -- the last point here that I would like to spend more time on is the reporting of lead data. And most of the other systems I've talked about we have up and running already. This, the area with lead is one we've been discussing recently but I think it provides a couple more steps as far as what might be possible in our partnerships with the RHIOs. The information we have is currently provided for most of our labs in our state. It's HL7 coded, electronically reported to the Department of Health. And when we have a high lead level, generally the program area that needs additional information is after that lead level gets reported. The first thing people look for are the name and address of the individual that has the high lead level.

Part of what we're able to do, then, is this information is not in the initial lab message you have to go look for it if it's not there initially. We're able to then look for some of this information in our data system and provide at least some leads on who this individual might be from other links in the lab reporting. Also many times the primary care provider is not listed in the lab request. The submitter or the laboratory can be part of the report but it may not be the primary care provider's name may not be on this list anywhere. If we match some of this data with our immunization registry data on that registry we have a link to the primary care provider or a primary care provider for the individual. And with that link, then, we can start to track and begin the follow-up case investigation based on that link to

the primary care provider. Again, this is part of the enhanced data or knowledge management that we have out of the system by collecting data from different program areas and bringing them together in an integrated fashion. We can also then use this information in another way.

Let's say a child were to move in a high-risk area for lead and we had the same person come in and find this out by an immunization record that came in that said I have this new child and this is their address. If we have a list already that says that other children at this location have received high lead levels and we could send a notice to that primary care provider to inform them about this potentially high lead situation or risk for that individual. We can also start a possible prevention education through the public health system, then, for that family at that new location. This one is -- the reason why this particular area is so under discussion is, as the CEO of the IHIE said, the next level of interoperability with public health and RHIOs is an integration of the business processes of the partner organizations. Where our businesses need to change, then, to respond to the new information that we're gathering and have available in a way that enhances our involvement with the community and our ability to respond to public health concerns.

On slide 21 the summary I've listed three points that I would like to talk about, or summarize, actually. Public health brings a population-based analysis of the data to the RHIO partnership. We'll take full advantage of these capabilities public health needs a voice in the governance of the RHIO by having a seat on the board. And in Indiana actually with the IHIE both the state health commissioner and the health officer for the

Marion county or Indianapolis area both have seats on the board. Those seats are by title. So if that individual -- if another individual assumes that role in the community, then they automatically have a seat on the RHIO board. For public health also needs to be a world class customer with the RHIO and to do so it must bear its share of the costs of the RHIO. Become a good data steward and help with the management of the data user agreements.

Finally, data integration and knowledge management need to be a part of the developing RHIO. I feel that the data knowledge management piece of this, if we just look at the reporting part we'll save a lot of money. If we take public health and start using its information and knowledge management that it has and its population-based focus, I think we can actually really add considerable value to the RHIO and to the community. These three areas I think are key to provide added value to the RHIO partnership and my last baseball analogy. It's hard to hit the ball if you don't bring a bat. Thank you very much for your time and I look forward to your questions after the presentations.

>> Great. Thanks, Roland. I like your baseball analogies. Our third and final speaker today is Ms. Amy Zimmerman from road island. She serves as both the program manager for the new AHRQ contract to create a master/patient index as part of the state's health information technology effort and as the chief for the Office of children's preventive services at the Division of family health at the Rhode Island Department of Health. She has been responsible for the development, implementation and operations of KIDSNET, Rhode Island's integrated child information system, as well as the state's newborn

screening programs, childhood lead poisoning program, the childhood immunization program and the state's home visiting program. Amy.

AMY ZIMMERMAN: Thank you, Ellen. What I hope to cover in the next few minutes is really to sort of talk about public health's role in our health information exchange and once I get talking I want to focus more on what as a health department our role is and our efforts here but I'll give you a little background about the state and the project that we've engaged in.

So if you turn to slide two, just to give you a little bit of background about Rhode Island.

This slide talks about the healthcare landscape in Rhode Island. It is small enough that it can compare to a county or local region in some other areas. We have two major agencies with healthcare responsibilities, health and human services. A small number of hospitals, some small number of very large group practices, one quality improvement organization, one medical school in the state with a public health program.

Turning to slide three, I want to highlight that actually a few years ago and there was really the development of an organization called the Rhode Island quality institute. Their mission really was a collaboration among hospitals, healthcare providers, insurers, business, insures, government to improve the quality safety and value in Rhode Island. They have a lot of healthcare leadership on the board and at their table and they got formed three to four years ago. They're in a very good position to be evolving as a RHIO for our state.

Turning to slide four, page four, it's important to note they have several guiding principles. Collaboration first and foremost. Laura Adams says it's important to make sure these entities leave the competition at the door when they come in and they're there on a collaborative effort. They want to take on projects where real improvement is needed and required. That it needs to be a win for everybody. The system improvements or efforts they take on are something that no individual organization or entity can do but it needs to be achieved with many together. And that senior participation -- senior leader participation is important here.

With those guiding principles you can see on the next slide page five a little bit about their strategic agenda. Over time they've evolved into really looking at two major areas, statewide coordination and collaboration of health information technology, as well as being the organization that helps pilot the implementation of statewide electronic prescribing. I just would like to thank Laura Adams for the use of those slides. On page six you can see really how the quality institute and the Department of Health have become strong partners. The director of health from the Department of Health has been on the board of the quality institute for its inception and certainly there was a lot of relationships there.

The ones I'll talk about a little bit on this slide are ones more where I've been involved with them and can speak to a little more specifically. In the spring of 2003, the quality institute came together and met with KIDSNET which is our state's integrated child health information system that integrates data from nine different children's health programs and

it was a get to know each other to understand what each other was doing and look and see down the road if there were opportunities to collaborate and become familiar with each other. During that meeting we really could already have some awareness that is national health information infrastructure effort was beginning and through conversations made sure that was shared with the quality institute so they could become aware, which they might have already been on their own but try to link efforts around that.

They then went ahead and were the pilot for SureScripts for electronic prescribing in our state in 2003. They sponsored in the spring of 2004, last year, at that time we were, as Dave Ross indicated, referring to local health information initiatives. They sort of sponsored a forum bringing together lots of healthcare providers and players within the state to really begin to think about statewide perspectives. As the agency for quality healthcare and research put out grants in variety of different categories they applied for a planning grant in the spring. Though we didn't get that, we were successful in getting a state regional and demonstration project. It's important to note here that really at that point the quality institute, along with other community members, really came to the health department and felt that the health department was in the best position to be the applicant and apply for this contract. In our instance the health department in Rhode Island is the contractor to the agency for healthcare quality. We maintain the contract and I'll be talking about this a little bit as we go ahead.

Slide seven talks about the core functions of what our project is. And really our goal -- I'll highlight this because I'll be referring back to it. The goal is to create a master patient

index which identify where the patient has information and then really allow at the point of care for providers to be able to see -- get access to data from various sources in an integrated and uniform manner. I won't talk about how we propose it because we're still working on that with a number of different models. Some of the core functions are to allow the sources to be available and integrated to the extent appropriate into electronic health records and also our electronic health records to be shared with others. It is important to note that in our project we really see consumers as key to this and the ability to control the access to their healthcare information and hope and plan to provide decision support behind this technology that we put in place to allow information to be integrated and then available at the point of care. And also very importantly, we want to be able to have the ability to utilize data for public health purposes including evaluation, surveillance, research and all the other areas that the previous speakers have talked about.

Slide eight I want to now start to focus more about what do we really see as the current role of the health department in this project? There are a couple of points here and I'll go through each one of these. But we're serving as a facilitator helping to define the role of community partners making sure consumers are at the table and to make sure that as a state we leverage organizations' expertise in areas there are already skills as opposed to redefining those. We provide the project management and administrative support. We're working to create a governance structure for this project that evolve into the governance for the RHIO. I think it has some broader issues and so we hope to have put in a governance structure that can be modified as the RHIO evolves. The health department is serving as a data sharing partner and there is some legislative strategies I'll talk about.

On slide nine talking about defining community roles, we've broken this project by actually subcontracting most of the money out to different organizations in the community, some vendors which we'll need to actually identify and procure a contract with but the technical assistance and coordination to make sure the efforts of this project are in line with the rest of the healthcare information technology efforts going on in the state and trying to bring all those together is an appropriate role to give to the Rhode Island quality institute. There is a big area that needs to deal with provider engagement to insure providers have input into the design of this and understanding how they want to use the data. Information work flow issues training and participation and the quality partners will be under contract shortly with us to manage that component of the project. We also want to have some consumer outreach, education and engagement to make sure we understand consumer issues around this and determine and identify how best to create the control and access issues and so we've got a request for proposals out right now and in the process of reviewing those proposals. Obviously technical design and development is very important to this project and at the appropriate time when we have more defined requirements we'll be seeking a subcontractor for the technical design. Importantly there is a defined and rigorous evaluation that Brown University, which has our medical school and public health program, is contracted for.

Slide 10 you can see, as I said before, the health department is the contractor and although we're subcontracting out a lot of the work we're still the lead agency responsible for carrying out this activity and what that means is we're providing the course staff

through a project director, myself the manager, our chief of public health informatics is heavily involved in this and consultants that we've brought in to help support and staff this. We provide some access to other critical resources including our state information office centralized division. And legal counsel and some others. Lastly we're providing the administrative and procurement and subcontracting processes. This provides in some instances a lot of safeguards for how and where we're going to get services, but there also are some challenges here in this because, as many of you well know if you are know state or federal governments, the ability to move money quickly and promptly to get some of this work done in the time frames that we need to can be quite challenging.

Turning to slide 11, we've also been focusing and had a large role in establishing the governance structure. And we felt it was very important, although the contract resides at the Department of Health, this really needed to be community governed. From the start, we envisioned that the health department would help build and deploy the interoperability and connect activity and a master patient index but not continue to maintain, run and operate it. We saw it as something that needed to go back to the community. We thought it was important to create a governance structure that would allow us to build off that and have it be well adopted by the community by having them in the driver's seat of decision making. So we have the quality institute board of directors at the top. At the most strategic level of decision making. We formed a steering committee which is administered by the quality institute and really that is the operational decision making body that meets monthly to really make the decisions technically and policy-wise and bring everyone to consensus. The chief consensus on how we plan to operate there. We have a management

committee which includes the health staff that are on this project as well as the major leads from our subcontractors to make sure we're keeping all of our different subcontracting efforts and components brought together and in line with each other and moving ahead in a cohesive way. We're communication, education, outreach and a data sharing partners group and evaluation. Some of these groups specifically align and are the responsibility under some of the contracts. Other of them are independent groups that we're forming and charging to come up with recommendations to then bring to the steering committee. Again with the concept this needs to be a community collaborative effort. Although the health department is in the management role. Lastly, we as part of the governance structure will be working and have worked with the quality institute e for a consumer advisory committee. They've wanted to have a consumer advisory committee and felt it was a good time to do it and put it at the quality institute level so they can focus on a number of efforts but they'll be a critical resource to this project.

On slide 12 it is a schematic of what I've just described. On the right hand side you can see the different work groups where a lot of the work will be getting done and hashed out. Recommendations then going forward and on the left-hand side you can see the actual governance and subcontractors working up to the management committee which staffs the steering committee and so forth.

On slide 13, we're now talking about the Department of Health's role as a data sharing partner and you can see from the first two bullets that we actually will be contributing data as one of the first data sources into this community health exchange. Both our KIDSNET,

integrated child health information system which has immunization, lead poisoning, newborn hearing screening and blood stat screening data is a data sharing partner as is the clinical laboratory system. Further down you can see the other initial data sharing partners, life span, electronic health system. Sure scripts, our electronic prescribing. The health center association which has a data warehouse through all the health centers, east side clinical laboratory, a private laboratory in the state but has a large market share and Medicaid will also be contributing data primarily for evaluation purposes.

On slide 14, you can see the proposed data elements that we're talking about initially sharing. Importantly you can see the child health data is in there as a proposed data elements to share through this effort. And again I think that our work around KIDSNET positioned the Department of Health to really be able to help provide leadership not just from a data sharing perspective as well as having had the experience of trying to integrate data, work with providers and do some quality improvement and make that information available. Because in our KIDSNET system that information is available to the primary care community. Actually, the pediatric and family practice community at large. Then you can see the rest of the information that we're proposing to incorporate in this healthcare exchange. The core data elements are the first set and some future data enhancements with the goal of having more information available.

On slide 15 I want to talk a little bit about another role that the health department can play and that is providing legislative strategies. In our case for pooling funds. Last year we had a healthcare information technology and infrastructure government fund created through

some legislation. And this basically allows the health department to administer this fund and basically states that funds are to be used for efforts to develop, maintain, expand and improve health information technology infrastructure and help adopt health information technology. It requires a community advisory committee and states the fund can accept grants, requests, donations, gifts, services in kind, bonds, appropriations both from insurers or states and then the funds can be expended through contracts, grants or loans. Now, it's important to state we haven't fully operationalized this yet.

There are some real advantages to this kind of legislation. It does allow one to sort of pool money strategically and then really disperse in a strategic manner. There are some challenges with this and that is that again, once the money comes into this fund it is considered state funds. Therefore, it is subject to all of the state procurement processes and policies which then again could potentially slow down moving the money out and also potentially, depending on the way states operate, limit who could be involved in deciding who gets the money. Because at least in our state for our processes it is primarily state employees that are making that decision. So again, you know, I put it out there as a model and an example as the role a state health department can have. We're working through a number of issues and haven't operationalized it fully yet but I think there are real opportunities to consider this kind of effort at a statewide Department of Health level.

So on slide 16 what I really want to do there is again emphasize that the -- that the Department of Health has an important role but it is also important to recognize the roles of other community partners.

This slide is really just to sort of highlight three major organizations and entities and how we're working together on a statewide effort. The health department is focusing on developing the statewide infrastructure. The Rhode Island quality institute is working on providing the governance, fostering collaboration, promoting electronic prescribing and also worked to begin to think about how to reduce barriers to electronic health record adoption through thinking about some group purchasing methods and really very importantly to think about and to help orchestrate a business model and a sustainability model. We've heard that, that it's critical to be able to come up with that and they're really - - there real -- there really aren't a lot sustainability.

Really trying to build off their expertise working with providers and provider offices. They're taking the role in two areas, directly with providers. One around the EHR adoption. They sponsored a large vendor fair and they have, through their contract are Medicaid, the requirement to work on a docket project which again, through CMS, is really trying to help promote the adoption of EHR's and offices and help offices identify the appropriate electronic record for them and getting them to use it as a quality improvement tool. We want to capitalize on that and asked them to take the leading role for the provider engagement on our MPI project. They'll be creating a professional users group and helping to incorporate the ability to get information from disparate sources and use it within the office and practice setting.

On slide 17 I won't go through all the bullets but what I wanted to do is highlight as the previous speakers have what public health and integrated child health information systems can offer to RHIOs and vice versa. In my public health has a lot of expertise and experience in a whole range of areas from registry developments in a host of areas to the child health integration systems. Expertise and experience in the design and development of health information working through some of the issues in doing duplication and engagement. The whole issue of security privacy state laws and data sharing policies. The concept of really trying to think through and work through consumer engagement and consenting processes. Data quality controls and data standards. And as you can see a number here.

Moving on to slide 18, I think equally there are opportunities that working with a RHIO where they can offer and help public health. I think that by partnering with RHIOs there is the ability to increase and collect and store aggregate and individual level data to help populate the demographic information and other public health data for integrated child health information systems and other public health systems to promote a uniform way to share data and really push the standards. I think that can come from both public health and RHIOs to each other to work something else. I think that they are positioned well to promote the use of electronic health records and its connectivity to public health reporting systems. That might be a huge gain to public health and save time and money. The ability to help get the provision of a single method for sharing data with users and share data between registries and between entities. And really to help if we can accomplish all this to help look at a person's health data in combination with other healthcare data.

Importantly, also helping to bridge new partnerships and bring resources and some cost sharing to the table.

So on slide 19 I just want to talk a little bit about what is it the right time to get public health to get involved? I profess the time is now. Even if the payoff and benefits appear to be down the road. I say this because I think that there are foundations that need to be built and I think that they will be clinically driven. And I think that's OK. But I think the public health being involved now with the foresight of how these efforts can move to meet both traditional clinical and public health needs is important. I think we need to consider now issues around the current and future use of data, privacy, policies, misuse, data ownership issues and importantly the business case and realignment of summary streams. I think as our previous speakers have that public health has a lot to gain. There is an opportunity for partnerships and seek out what things are going on in their community and see how they can become a partner. I'll turn it back to Ellen.

ELLEN WILD: Great. Thanks a lot, Amy, thanks to all of our speakers for giving us such a wonderful overview. We have time for questions. So I will read out the questions. And direct them to the speakers. The first question is how does this emerging health information infrastructure that links public health and healthcare help support newborn screening follow-up and care coordination? I'm throwing that out to any of the speakers who would like to answer that.

AMY ZIMMERMAN: Well, I can start with that a little bit. You know, in our integrated child health information system, we do have newborn screening information available. And that is made available to providers now. So that to some extent they do have some way of accessing that information. But we don't necessarily have a lot of ongoing information about final diagnosis or about ongoing status of the patient or care coordination information. And I think if we had a more interoperable connected healthcare system, we would be able to be better positioned from a public health perspective to get final diagnostic information and to be able to follow that patient over long term to assure that they're continuing to get the care that they need. And I think in many instances where newborn screening information may not be electronically available to providers, that that would -- this would provide an opportunity to do that.

DAVID ROSS: This is Dave. I think that's a great answer, Amy. I think essentially the notion of strengthening care coordination and linking with the medical home will reinforce and built an understanding of the medical home, reinforce the concept as well as make it much more of a reality. So I think public health participation in RHIOs, that newborn screening and newborn screening the follow-up and care coordination for kids who are identified with a disorder really stand to benefit by public health being an integral part of RHIOs.

ELLEN WILD: Great. As a second part to that actually is how do these health information infrastructure, how will it help the regional collaboratives?

AMY ZIMMERMAN: I can address that only a little bit because actually focusing on the work of trying to get this project up I have not been too involved in the regional genetics efforts group. My preliminary understanding there is some of what is trying to be achieved is looking at where care is available and provided and where the cases are. And so, you know, again, without speaking with a limited knowledge in this area, I think again if we can envision a connected healthcare information system that had individual cases and also then be able to sort of look at that against were there specialty resources available? It might help gather that information to try to make better connection for care coordination.

ELLEN WILD: Roland, do you want to try?

ROLAND GAMACHE: This actually follows up on a lot of what Amy presented in her talk itself is I think if we look at the regional genetic collaboratives looking encompassing about standards that might be needed to help support this movement, the type of information that really needs to be collected, some of the privacy and confidentiality laws that might need to be addressed in order to allow the sharing of this information a little bit easier, I think they get a perspective that an individual state may not be able to get.

ELLEN WILD: All right. Our next question is, how can or will RHIOs improve access to data for public health systems research? I'm opening that up to anyone.

AMY ZIMMERMAN: I can try to take a crack at that. Again, as I was sort of talking about in my talk, I think the foundation -- a lot of the real work is sort of really being discussed in

terms of making individual patient data available comprehensive individual patient data available from multiple medical sources available at the point of care when and where it's needed for the purpose of the clinician and providing care to the patient but I think that a number of folks and places where this is happening has the vision and the desire to say that at some point once the interoperability is there it's important to be able to get this information, if needed, in a way for privacy and confidentiality in a aggregated, linked manner. I think if there was a D identified database with all the information linked, it would allow a whole host of uses for that data from a research perspective as well as from a surveillance and evaluation perspective. I hope that gets to the question.

>> I think so. Dave, did you want to chime in on that?

DAVID ROSS: I don't have a lot to add beyond what Amy said. I do think that this is an area where it's obvious there is potential. When people are now looking at the concept of RHIOs, it's almost a piling on phenomenon. Everyone starts to see something in it for them and that's good. It's also going to be a challenge and this is where I think the governance and the structure of governance becomes so critical. As Amy pointed out, how they're thinking about getting consumer representation, this -- these entities will represent a public good, in effect, a utility that serves -- that should serve the benefit of everybody in a community. And so they're going to have to have guidelines and decision processes that make clear decisions about the use of the data for research. I would argue that this movement towards electronic healthcare is, of course, going to lead us to making discrete data elements, captured and stored in databases in a standardized way. One of

the up sides for that is going to be that we'll actually -- we should be able to get comparable data and it certainly opens a number of doors for research efforts both in clinical research and also in health services research. But it's not right around the corner. We have so much foundational infrastructure building to do. We have process choices to make about interoperability standards. There is a lot of that kind of work that has to go on before we can get to using the data for research. But this is another area where I think public health has a tremendous amount to offer because health departments, particularly state health departments, have been analyzing data, linking data to produce different kinds of analyses for a long time and so they have experience to bear on this.

ELLEN WILD: The next question, can you address data stewardship issue a bit more? What is the public health role in this? This was geared towards Roland.

ROLAND GAMACHE: Yeah. That's a term that we've used in our agency to talk about how we will establish a lot of different issues related to the data. First of all, we need people who understand and program area people, basically, who understand the particular data that they are collecting. The data stream we're taking a look at. We start talking about RHIOs, we're talking about clinical data. So the data steward is not just -- it's not just a person, it's generally a group of people but probably organized by the health department about issues related to the data and how to address those different issues. Part of -- probably the major one that comes up a lot is when you have conflicting information coming in from different sources. You have one piece of information that comes in with one diagnosis and another piece of information that comes in with a

different diagnosis. And you need people with both public health experience and clinical experience to decide whether or not once this information is correct or incorrect or if the two are both correct and suggest a different diagnosis by the combination of the two. So it's that type of dealing with the issues of the data, the data quality issues and how to address those. It also addresses are we getting the information in and the format we want? Are the standards correct for how we're sharing the information? Are we getting enough detail we need in order to do future work? So it's a whole -- it's addressing that whole gambit of issues related to multiple data sources, multiple sources of information, and how to address the overall issue of data quality in the organization.

ELLEN WILD: OK.

AMY ZIMMERMAN: If I can pipe in for a second. Again, I put this out more as a question and food for thought and will share my own thought. It's interesting how much we sort of distinguish between clinical and public health data. The more I've start had to work in the area. I'm not sure they're different. I think how we use them in different. Some sources of information we just in public health that we would like clinicians to use more and think they could incorporate and vice versa but I put out there to some extent I'm not sure is there is a clean cut barrier between the type of data and see it more in the use of data.

Stewardship in a different context could refer to, although this isn't how Roland spoke about it, with regard to data ownership. Those are issues that I think we'll have to think through and contend with in the sense of, you know, once we -- it gets back to the research question about if you have a pool of data, and it does become, you know, it is

aggregated in a particular way and sitting in an entity or agency, you know, is it -- sustainability models, is that aggregate data for sale and it gets into a host of complexities with that. Again, there are some issues there that I just put out for people to think about as they move more into this area.

ELLEN WILD: Thanks, Amy. Next question, will states be able to exchange information with each other or is the focus interstate? Dave, you want to start?

DAVID ROSS: Read me the question again.

ELLEN WILD: The question is, will states be able to exchange information with each other or is the focus interstate?

DAVID ROSS: I think the big national vision that was initiated with the NCVHS report in 1999 portrays a vision of a national health information infrastructure which would, I would assume, allow the exchange of information across states by state health departments. I think the current view is that -- at least with the notion of a RHIO or some kind of a sub network organization and sort of the national network being the conceptualization of the ability to move data -- personal health data around, because there are uniform set of standards that create interoperability in place, but that, in fact, most of these are being envisioned in a locale because they're associated with a medical training area. Is there a possibility to exchange data nationally? Yes, from public health point of view, it's a major goal. Certainly if you look at public health laboratories, they have as a vision being able to

Internet work all public health laboratories so they cannot only exchange data but exchange knowledge and help one another in times of emergency and handle surge capacity. So there are a lot of reasons why this needs to be able to happen nationally and from state to state. I think we'll watch it emerge more on a regional basis. I would certainly be interested in what Roland or Amy has to think about that.

AMY ZIMMERMAN: Well, from the national efforts that I've been involved with meetings I've been to, my sense is that there is a sense that, you know, healthcare is provided within a particular sub network or regional area and it makes sense to build these RHIOs or health community exchanges at a community level. And then but to do them in somewhat of -- as much as possible a standard way. There are some folks promoting this so from RHIO to RHIO there is the ability to communicate. So it's sort of a bottom up and then cutting across way of sharing information.

ROLAND GAMACHE: I would like to add, I agree with everything that's been said but also there are some RHIOs being formed or are formed that actually do cross state lines and share information.

DAVID ROSS: Right.

DAVID ROSS: There are a lot of cities that major metropolitan areas that sit on a state border and almost by definition the RHIO will have to be a multi-state effort.

ELLEN WILD: Next question. In all these efforts how are consumers being engaged and how are the security and privacy issues being dealt with?

AMY ZIMMERMAN: Why don't I try to take a crack at that. I can tell you what we're planning to do. We aren't quite there yet. We really view that it is critical to allow consumers to be able to have the access to -- to control the access of who can see their data. And so in our project we've built in the ability to have a vendor come in and do some focus groups and intercept interviews and understand from the consumer point of view how they want to do this, you know, at what point do they want to consent or have some sort of pin or access number they could give to a provider along with provider authentication to allow them to get into the data and allow the data to be shared with the provider. So we're trying to involve consumers at several levels both from that point of view of getting direct input from individual consumers and from healthcare settings as well as, again, having a consumer advisory committee which will likely be representative of consumer organizations advising us. We see a lot of our technical solution is -- needs to critically be influenced by what we learn from the consumers. We're just not quite there yet for me to share with you what we've learned from the consumers.

DAVID ROSS: I would also say just for those in the audience that are new to this dialogue, Amy referred to the Markle foundation. That foundation has partnered with Robert Wood Johnson foundation and Markle has taken the lead in connecting for health. They have a policy subcommittee that Amy and I sit on that is working to develop a common framework, if you will, of how to approach the technical and security standards, policies

and procedures, that would become a starting point, I think, for everybody. So there is an awful lot of attention and thought by many people, including many lawyers, to how to put a framework together that assures personal privacy and confidentiality and security of the data. I also want to offer an opinion in that I think consumer representation is essential. I'm really pleased to hear what the Rhode Island project the doing and how they're approaching that and the same with Indiana. In my view, the citizens have to want to support these things if the RHIOs if they're going to be sustainable and know they're working in their best interest. In areas of children with special healthcare needs, there is already a very vigorous parent advocacy movement and capability and those parents can be very helpful in assuring that the end product, the real goals that the RHIO seeks to attain, are actually met.

AMY ZIMMERMAN: Those parents are some of the largest healthcare users. The ability for them to have to transport their children's health his trees and information along with them would be a huge plus for them. But they certainly have certainly the awareness and lots of concerns around privacy and confidentiality.

ELLEN WILD: Roland, did you want to comment to that?

ROLAND GAMACHE: I would like to emphasize, too, I think the consumer control of the health record is really a critical component of this long term. I wish we were as far along as Rhode Island was on the issue but we're using our established consumer groups to get input to these -- as we develop the -- further development the electronic health record and

sharing of information. Public health by its nature I think allows this information to be provided to the RHIO, particularly on the governance board at all because we have to report back to the legislators who are elected by the community as well. So part of what we need to do is to have these focus groups with the community and then be able to address the issues. Both at the community level and the people who represent the community. So it is a good and big issue.

ELLEN WILD: Great. Well, thank you. I think that's all we have time for right now. I just want to thank again all of our speakers and if you did send us questions and we weren't able to get to them, rest assured we'll email you and answer your questions. I want to also give another plug for our next webcast which will be August 10 at 2:30 and again we'll focus on matching duplicate records. We hope to see you in August.