Privacy and Security Solutions for Interoperable Health Information Exchange:
Phase II
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Here are some of the highlights from the recently released impact report, which describes the impact that this project has had in the 34 participating states and territories and beyond. To set the stage for the report, here is a brief review of the core goals and objectives of the project so that everyone can better understand the progress we have made toward achieving those goals. Also is a brief introduction of the 2008 work involving the multi-state collaboratives and a more deep description of the planned work for two of those collaboratives, the Consumer Engagement and Education, and the Harmonizing State Law Collaborative work group.

The overarching goal of this project has been to identify and reduce the variation in privacy and security practices, policies and state laws that create a barrier to widespread electronic Health Information Exchange. We need to ensure that adequate protections remain in place or are put in place to protect patients' privacy and an appropriate level of security to protect the data from

unauthorized access. In addition, because they all share concerns related to the privacy and security of health information, we need to ensure that consumers, organizations and state and federal entities all have a role in this process.

The project seeks to incorporate community interests into an open and transparent consensus-building process and we've done that by promoting a process that supports the stakeholders at the local level to identify the sources of variation, develop practical solutions to reduce the variation and to develop strategies to implement those solutions. Finally, we plan to leave behind in states and communities a knowledge base about privacy and security issues related to electronic Health Information Exchange that endures to inform future Health Information Exchange activity.

When the Privacy and Security Solutions Project began back in 2005, the participating states were at very different stages of Health Information Exchange development. The state teams were required to compete and participate in their projects. And we had received 43 proposals from states and territories. And in those proposals, they reported the type and level of activity that was going on at the time. What we found, we were able to cluster those activities really into three broad categories. One was to engage in independent and isolated health IT efforts generated by individual health care organizations. The result of some implementation of one or more local multi-organizational Health Information Exchange efforts. And the third category is really early planning of state-wide electronic Health Information Exchange. And there were a couple of states, a relatively small number of states like Indiana and Massachusetts that had reported a high level of maturity in their local efforts, some the establishment of foundational components of a state-wide exchange and others with fully operating state-wide exchange.

So basically, the information that we had from the states that were looking to participate in the project initially was consistent with the findings of the first and second surveys of local, regional and state Health Information Exchange activities conducted in 2004 and 2005 by the eHealth Initiative and the findings from an independent evaluation that was conducted on the evolution of state HIEs like AHRQ in 2006. But what was clearly missing was an organized effort to address the privacy and security issues, something that all the states who submitted proposals to participate in the project identified as a great need, regardless of where they were in their level of advancement.

The impact of the privacy and security solutions project is difficult to measure because frankly there's so much activity around health IT and Health Information Exchange that it's creating synergies, propelling the work forward that attributing true cause and effect to any one initiative is virtually impossible. However consistent with the approach that the project has taken, a community-based approach, we have drawn some conclusions based on the reports that each state team drafted, describing the impacts of the project on their activity working in their state. And based on those reports, we have observed impacts in five major domains: state legislation, executive orders, leadership and governance, stakeholder education and knowledge, and support for Health Information Exchanges. And it's fair to say that the process of the privacy and security project has played a critical role in state teams advancement towards interoperable Health Information Exchange.

One of the key objectives of this project, to reduce the variation in state law that creates a barrier to widespread HIEs, we have the variations that we're dealing with now because in no point in time did states sit down and develop a comprehensive state privacy law that covers Health Information Exchange, whether electronic or otherwise. The laws evolved really in a piecemeal way, often in reaction to certain events so that we now have a body of law that impacts privacy, that's scattered throughout many codes that's sometimes in conflict, it's sometimes so vague it begs for multiple interpretation.

So the intent of state legislation, as reported by the states participating in the project, is to update and align statutes with the electronic Health Information Exchange environment and address legal barriers to electronic exchange resulting from the existing patchwork. States have worked diligently to mitigate the risks of codifying existing variations related to Health Information Exchange and involving broad groups of stakeholders in the development of their bills. We do have 11 states identified as working on, or having passed, legislation already. Those states are Arizona, Kentucky, Louisiana, Michigan, Minnesota, New Hampshire, New Jersey, New Mexico, Rhode Island, Vermont and West Virginia. And it would be remiss if Nebraska wasn't mentioned, who although not officially a subcontractor to the project initially, they did work in parallel and they did submit a report. And so there's just, to give you a sense of what we're seeing, Rhode Island's draft legislation pertains to the protection of information within the state's planned Health Information Exchange. And the language has been drafted and approved by the Rhode Island Quality Institute's board and they plan to introduce a bill in the next legislative session. Vermont is exploring the possibility of updating statutes related to emergency access to heath data. And they're all expected to consider expanding the role of the state ombudsman to include privacy and security of health information within their domain.

As recently as January 13th of this year, Governor Corzine signed the New Jersey Health Information Technology Act into law, establishing the New Jersey Health Information Technology Commission. And in section 5(c)(7) it specifically mentions the New Jersey HISPC work and calls for the integration of the recommendations, findings and conclusions of the HISPC project into the New Jersey health IT plan. Another example is Minnesota. They've also made some important updates to their privacy and security legislation. Minnesota HF 1078 modifies existing statutes to require the Commissioner of Health to develop a form that enables patients to access their health records. And there are additional components of the legislation aimed at clarifying definitions of multiple terms and specifying the definition of terms for the exchange of information between providers. And anyone interested in the legislation is encouraged to actually read the bills and go to the source. A number of reports have been inaccurate, so everyone is encouraged to go to state teams directly and take a look at actually what's actually being done. The links to the contact information for all the states are on the Archive C30 page. So it's easy enough to access their work and check in with them.

For an organization to represent a state as a subcontractor to this project, the organization or entity needed a letter of support from the governor. State leadership is critical to sustaining the efforts of this work. And through our partner, the National Governor's Association, the project team has had a number of opportunities to brief the health policy advisors to the governors on the work over the course of the project. Some states reported executive orders that pre-date the project, but they cite them as serving as an impetus for applying for the funding to participate in the project. And there are a couple of states who cited an executive order as a direct result of the project. And those states are Kansas, Mississippi, Ohio and Oklahoma. And here are a number of other states who have reported that executive orders are under consideration by their respective governors. The executive orders are important because they offer formal support for the project. And that helps to sustain the efforts going forward.

As state teams move through the process of this project, many identified a need for specific privacy and security leaders to take ownership of the implementation process and oversee future steps. If you recall the goals of the project, it was designed to support sustainable solutions. So the recommendations along the lines of leadership and governance took two main forms. One was an independent privacy and security governing body and the other is a privacy and security subcommittee that is part of a larger governing body. There was a clear message from a number of states, particularly those with a single state Health Information Exchange, but whatever body governs privacy and security policy decisions should be independent from the Health Information Exchange governance that would make business decisions, citing that the two charges would be in conflict with one another.

California is an example of one model. California has created a new independent privacy and security body, the California Privacy and Security Board. It was established to provide a governance structure to facilitate and guide the considerable amount of regional health information organization activities in California. There are more than 30 active HIEs in California right now. The mission of the Board is to establish security standards, develop privacy principles and policies, and in general continue the privacy and security efforts be done under this project. The Board has established four committees: the Privacy Committee, the IT Security Committee, a legal committee and then also an education committee.

Back to our goals and objectives, one of the key goals of the Privacy and Security Solutions Project was for state teams to create a broad base of support among stakeholders in their states to develop consensus solutions and sustainability that would extend beyond the end of the contract period. The stakeholder engagement project was a learning experience for all of us working on the project. One key lesson was that to engage stakeholders in this process, you need to provide some education and remind them of the stake that the hold. This is a challenge across the board but it was a particular challenge with consumers, who everyone speaks for but I don't know that we've been able to actually sit down in many cases with consumers and have a frank discussion about this.

A couple of examples coming out of the project, North Carolina established a very active Consumer Advisory Council, which the team supports by providing many educational opportunities and they travel members to important meetings and really have provided a great deal of support for their Consumer's Council that they developed. The Massachusetts team recently held a conference this past Fall, bringing together representatives from behavioral health with those from physical health care, and the goal was to discuss ways to integrate health records in a way to guarantee privacy protections for mental and behavioral health data but not reduce the quality of health care for members of those populations. And it's an important and difficult conversation, but it's happening and it's happening in the light of day. And we saw a number of other states also engaged in discussions on the issue, including Wisconsin and Indiana. But by far the greatest impact of the project to date has been, at least it's been reported, is that disparate groups are now talking with each other about privacy in the open in a transparent way and that has served to strengthen relationships, particularly between state agencies and other stakeholders.

The project has also helped states establish a privacy and security foundation which can be used to develop new health IT efforts. So many initiatives are going on, it's hard to know what's driving what. But clearly the states have noted that this contract is helping to drive other efforts. They reported increased engagement of stakeholders in the development and continuation of other health IT projects in the states. As the state teams have developed their privacy and security solutions and implement them, they decrease barriers for other health IT and HIE efforts in their states. We have 14 states that have indicated that the project has increased support for upcoming health information exchange efforts and in some states Health information Exchanges were already in the development process when the project began and in others they were just emerging. In the states where the development process had already begun, the project seemed to provide some clarity and focus. In states where Health information Exchanges are just beginning, the project has demonstrated that privacy and security issues can be addressed even among stakeholder groups with disparate interests.

23 of the states referenced increased awareness of privacy and security issues among stakeholders as a key component of success in the development and sustainability of their other key projects with 10 states indicating that the collaboration has been significantly enhanced as a result of the project and that stakeholders are better prepared and better educated to move forward and engage others in their planing for new opportunities. Overall, the project has provided states with one of the states called Activation Energy that was required to engage stakeholders. And the teams have repeatedly remarked on the momentum that has been built

around Health Information Exchange and the project's ability to drive new work. So early engagement with stakeholders has enabled and supported the implementation work that is underway and the state teams expect that to benefit their new work in 2008 and beyond.

What does lie ahead? Tying back to our goals, once again we need to continue to work to adopt and implement common solutions and the state teams, armed with the knowledge of the privacy and security landscape within each start, will work together to develop a comprehensive approach in seven key areas that the leaders of the state teams have identified. In 2008 we will incorporate the work of nine additional states and Guam into the Collaborative. We have a nationwide effort going forward. There is a list of key areas identified and more details will be revealed about two of the groups here, the Consumer Education and Engagement Group and the Harmonizing State Law work group. The work, going forward, will be guided by a steering committee made up of the co-chairs in each of the collaborative work groups so all of the states will have input into the work of all of the other groups. And that will facilitate communication and knowledge transfer between and among states so that we don't have the creation of silos and we don't codify variation by having the states going off and working independently. We have them working together in a shared and cooperative way. The process will be open and the state teams will be looking to expand their reach both within their states and nationwide as it goes forward. And it really promises to be a productive year in this area. Links exist to where all the information can be found including links to the participating states so if you have questions or information, you can go right to the state you're interested in.

We want to make sure people understand that in those six areas previously mentioned, there is always going to be some level of crossover and RTI is going to be doing a great job of coordinating that among the different groups as everyone comes up with different issues that may be common over the next year. This is an overview of the next steps that are coming up for the consumer education and engagement piece of the Collaborative's work. When we set about our work we decided we needed to focus on the outcomes first. What do we want to do with this, given the time period available. What are the privacy and security issues? What are the process steps? What are the targeted population subgroups or how do we get there? What are the kinds of tools that we, as a group, will consider as we are engaging and educating consumers? Who are the partner groups? What kind of measurement is going to be used to determine our success? And overall, what is the plan going to be?

First, we developed our outcomes. At the end of 12 months we will have established a replicable process, and replicable is an important piece of that, that increases the engagement and understanding of targeted consumer population subgroups in privacy and security issues in HIEs - the goal being that although there is a limited number of states who are involved in the effort, any state or any local, regional organization can use this process that we are testing to do outreach and engagement with their local consumers. We came up with several particular privacy and security issues that we felt we needed to address as a group. And much of this is based on the previous HISPC work. Many of the states involved in this particular Collaborative have done some work on consumer education engagement. The first one is one that has come to the fore in the work that has been done thus far. We need to be able to define and describe the importance of health information exchange primarily because it's so misunderstood currently in the field. There is also related to that understanding how health information flows. And when we talk about this in the context of this Collaborative, we are trying to explain to consumers and engage consumers in a way that helps them understand what does happen through a paper process and what does happen through an electronic process, and conversely what doesn't happen in those two processes.

We need to, since there are a variety of states involved in this Collaborative, distinguish between what is information control, what is information ownership and what is information access and be able to explain that in the context of what consumers need, as well as defining and describing other uses of information that may be involved in Health Information Exchange. And finally, one

of the big issues that we found through the previous work under what we're describing as HISPC One here, is identifying patient preferences for that. What exactly do consumers want out of this new world order of Health Information Exchange?

What kind of steps are we going to use to get there? The first is inventorying existing material and initiatives. There are a fair number of organizations that have touched on different pieces of consumer engagement and education. We want to make sure that work isn't lost in our attempts to move consumer education and engagement forward. For example, the national organizations that have done work on this, the state level involvement that has occurred thus far will all be put into the inventory so that we are able to piece through what has already been done, what hasn't been done, what needs to be developed and how, if any, evaluation has occurred - putting that into the mix. The second is a literature review. The initial attempts at this show there is very little literature out there specifically on Health Information Exchange and as a result, the focus has been broadened to the larger issue of consumers in general. What do we know about consumers? What do we know about working with consumer groups, working with consumers individually so that will be incorporated into what's there as well. Similarly, a fair amount of research and implementation pieces will be done so that sample documents and sample processes will be easy to extract from this Collaborative. Any state or local organization out there can say, "I need a document as a basis to work from that does this" and they will be able to reach into the Collaborative and find that document. Or they may say, "We know we have a particular type of consumer out there, we don't know anything about that particular type of consumer so where's a process we can use that may have been successful in engaging that consumer group?" We also expect to do a fair amount of analysis as to whether these materials, documents and processes work within our local constituency organizations so that we can feed back into the loop what is and is not working on the ground. Finally, our attempt in less than a year will be to refine those processes and make them work better locally.

One of the areas that we're most interested in; is the handful of projects that have been out there that have focused on general consumer information. What we know is that the consumer, as we think of the consumer, is not necessarily a monolithic type. One of the things we want to be able to do is within our states pull out, in addition to the general consumer focus, pull out specific subgroups that will be of benefit to a multitude of states or organizations or localities as we move forward. So each state will be able to define, prioritize and select population subgroups to make a decision about which subgroups they're going to focus on. Some examples of these types of subgroups that we have been thinking about are ethic subgroups, age subgroups such as seniors, the very young or a particular age group. Are there cultural subgroups? Particularly out in the West, Native American culture is something that needs to be taken into consideration. Regarding health status, do people with chronic disease have a different view of health care and health information than people without chronic disease. And the standard urban/rural dichotomy, there are a wide variety of states and some folks need to be focusing on one and some folks need to be focusing on the other.

Some of the tools that we're expecting to be able to use are diverse. We did discover, because this is a federal contract, that we need to be very careful with surveys and focus groups. We have agreed as a group that when we do surveys and focus groups to inform the decision-making process within the Collaborative, we will not be using HISPC funds for that. Those funds will need to come from elsewhere. We will also be using the standard tools of meetings with large and small groups, summits that may be taking place among constituency groups, material review and dissemination. There is a lot of interest in videos, DVDs, public service announcements and other visual tools that can be used; and subsequently being able to distill all of that into toolkits that work by population group, by area, by substance so that others may use this information over the long term.

Who are some of the partner groups that we have decided to identify in this process and engage? There are a myriad of laundry lists. Anybody is a consumer of health care. So in a first national

look, we specifically wanted to focus on some consumer groups that we knew were very active in these areas: AARP, ACLU, National Alliance for the Mentally Ill, National Council of La Raza, the National Urban League as examples of the kinds of organizations that will work. In Colorado there are additional organizations. We are fortunate to have the Colorado Consumer Health Initiative, an umbrella organization for many different consumer groups in the health care arena, so we're lucky to have them as one of the partner groups we will be working with. Other local communities may have a similar organization as well. We also wanted to be clear about this and RTI has been very accepting of the idea that each state is going to have a different framework for this kind of work. There are different partner groups in different communities that operate better or worse in different states. But our goal as a collaborative and as an organization and process that's going to be beneficial to everyone, we'll try to include as many of those as possible.

Regarding measurement, what are we going to measure to say whether we have been successful in producing this consumer education and engagement process? Our first measurement was increasing consumer engagement and increasing consumer understanding and increasing the likelihood of consumers participating. As an example, measurement is where our challenges came up. That's one of the things we've really tried to narrow in on is what are the challenges of all of us working together. An example of that is we have currently two states in particular that are looking at personal health records as their model. The majority of the other states in the Collaborative are not looking at personal health records as their model state-wide. Some are looking at opt-in models, some are looking at opt-out models, but our commonality of measurement is the likelihood of any consumer participating in any one of those. So whatever our state model is, participation is the goal for that. We also are focusing on, and this is a challenge, where do we find our baseline. How are we going to start the measurement? What is measurement? Is it a presumption of no knowledge? Is it a presumption of something else or do we have hard data that we can use to start that measurement off and then remeasure at a later point?

The plan is we have 12 months to do all of this, which the good news is many states in this Collaborative have done a fair amount of work already. In order to make that happen, we are being very collaborative across all the states in doing joint investigation. We all within the Collaborative will be working together to gather the information, review the information and consolidate the information in a way that may be helpful. We will also be doing concurrent replication across the states, so we'll all be working at the same time in our own frameworks to test the materials and test the information that we have. And we think that's going to work pretty well for the outcomes of the Collaborative because we have an incredibly broad base of states that are involved. If you look at this list, you can see east and west, north and south, urban and rural. You can see a lot of different kinds of states that are participating in this Collaborative that probably have similarities to your own state and that was our goal.

And we also expect to, over that 12 month period, be able to compile that information in a way that is useful to others, as they proceed down the road and become more engaged with consumers within their process. So again, the goal at this point is that at the end of 12 months we will have established a replicable process that increases the engagement and understanding of targeted consumer population subgroups in privacy and security issues in Health Information Exchange.

We learned very early in the initial stages of the first phase of HISPC the power and benefits of the interaction of the states and we are very much looking forward to continuing that process in 2008.

Regarding harmonizing state privacy law collaboration, the following is a little bit about the background of the Florida HIT initiative and our involvement in the HISPC project in phase one. Then there will be an explanation of the objectives and processes planned for the harmonizing state privacy law collaboration. Next will be a discussion of Florida level objectives concurrent

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with the collaborative objectives, all the states have their own objectives that dovetail, depending on their various positions entering the Collaborative that they hope to achieve during 2008.

First it must be emphasized that the HISPC project for Florida has been integral to our overall strategy in the state to promote Health Information Exchange. Our current strategy is to remove legal barriers to Health Information Exchange in Florida law that we find are not appropriate and in some cases are carryovers from past years that are no longer applicable in an electronic environment. We are also working very diligently to promote the adoption of electronic medical records, including electronic prescribing. We are going to be participating in another collaborative, the Provider Education Outreach Collaborative and we see this as being very beneficial to our initiative in that area. And also we continue to support development of local Health Information Exchanges and promoting uniform privacy and security standards among those Health Information Exchanges in Florida.

Florida is one of the original states participating in the HISPC Project. We found in our statutory analysis through that effort - findings similar to other states that there are inconsistent and fragmented laws that exist. We found both at the state and federal level there is a lack of a standard requirement for when to use patient consent and we found among health care providers that there is a fear of violating laws and rules and possible litigation based on the sharing of data and some concern that there is not a clear understanding among all providers about what the standards are. And also there is concern about follow-up liability issues in the sharing of data. So there is a very conservative behavior due to lack of clarity about the applicable law, sometimes a lack of clarity of the facts that leads to concerns about which laws would apply. And we also found in that phase that providers are very concerned about providing necessary health care and they are very adept at working within the constraints they must deal with with the existing law. It is correct to say there is a great deal of need for education and really interest among providers on being more informed about the laws that operate in this area.

As part of the original HISPC Project, each participating state developed an implementation plan to address improvements and solutions to some of these privacy and security issues that are barriers to electronic Health Information Exchange. Florida developed an implementation plan that had four goals. The first goal was to establish uniform privacy policies for electronic health information to attempt to provide greater clarity that would assist health care providers in the appropriate exchange of health information. We also set a goal of ensuring the creation of secure health care information exchange through a technological infrastructure. The third goal goes back to education, which would be to raise awareness of the benefits of electronic health information, that it can be more secure when properly used. The fourth goal is to participate in national forums, which this Collaborative is part of that goal.

During 2007 we had an opportunity through the HISPC Project to begin to implement some of the goals of our implementation plan and we took that opportunity to reconvene our legal work group which had been quite active in 2006. We extended the analysis that was performed in the initial phases of the HISPC project. And we took an additional step, which was to take that analysis and review the findings and really look at it in the context of priority recommendations. We developed criteria to evaluate the analysis and determine those barriers that were most problematic for Health Information Exchange. And we also were very ambitious, also developing initial draft legislation to incorporate those recommendations. In addition, as part of our objectives, we developed a risk assessment tool focusing on security. We held community forums between agencies and local Health Information Exchanges, the RHIOs in Florida. Again, through those educational forums, we repeated the findings in the initial phase of the project, the awareness on the part of providers of the need for greater education and really learned again that they are very much aware of the laws they operate under and are very sensitive and concerned about staying within the requirements as best they understand them. We also did some outreach with consumer state leaders that were identified by the RHIOs and found also that consumers have a lot of interest in the development of electronic Health Information Exchange. And they are

pretty aware of the benefits and pitfalls of electronic Health Information Exchange. And we have both information to impart and information to learn from engaging consumers. Finally, we have participated in the development of the Collaborative proposal with other states that are interested in harmonizing state privacy laws.

The type of analysis done in Florida in 2007 was an extension of the analysis from 2006. We went beyond the 18 scenarios originally laid out for the project. We took a broader look at the issues. This was not a preemption analysis, although a preemption analysis comparing HIPAA and state law is a very good start. Our analysis looked at both the private and public sector. We have seen very good analysis in the public sector but it's really important to look at both state and federal law. The more you analyze, the more there is to analyze. The basic framework used, because all of the states involved in the Collaborative have done their own analysis within their own state and this is an opportunity for us to bring these different analyses and approaches together to compare and contrast, take it back to the individual states and really improve on the process. We looked at issues of ownership and control, patient consent and access, redisclosure - very much a concern of providers - and emergency access. We looked at where in Florida law the law actually addresses electronic transmission and electronic signatures and where it does not.

What was very interesting with the work group, after we had performed the analysis, we took a step back and asked the question, what legislative action would have the most impact and what options are supported and feasible. We were really looking for low-hanging fruit if there is such a thing in this area. We asked what are the key barriers to organized Health Information Exchange and RHIOs and we asked what are the key barriers to public sector participation, which is often more in the regulatory arena. Not all barriers are equal and we wanted to go over our opportunities to make some changes right away. The legal working group came up with three key recommendations in 2007. One was to reconcile our hospital licensure statutes and medical practice statutes. The medical practice statute allows certain exchanges among practitioners that is not always allowed by the hospital statute. And there does not appear to be any basis for this, other than historical, which goes back many years. We also looked at the clinical laboratory statutes, which puts limits on what practitioners can exchange, that is inconsistent with what is written in the medical practice statute. And we also began to focus on the need to develop a more uniform patient consent process that would be geared toward an electronic environment and that would actually occur within an electronic environment. We were very happy that we do have legislation that was introduced in Florida to incorporate the first two recommendations and we're monitoring that legislation in the session that starts in March. So we're very excited about that.

Moving into 2008, our Collaborative has developed - and these are our overarching objectives for the Collaborative but highly ambitious objectives - which are to create and use a consistent analytical framework. We will be working to develop a framework that allows us to serve as a tool for common language across the states because this area can be very complex and it's a barrier just getting oriented to the different states and how their statutes are structured. We will also be working to develop priority recommendations for reform with the expectation that we will begin to align state solutions and possibly, if there is the opportunity, develop a demonstration law in 2009.

The process we will follow is in phases. We will begin by using the processes that the states have already done, gathering the information. Then we will develop the analytical framework in phase two. The states will have an opportunity to go back and revise their original analysis using the input of all the states collectively. That's the power of the collaboration. The third phase will be an opportunity to assess what that complete analysis put together. In the fourth stage, we will document the process and issue a report because we want to be able to allow the other states to benefit. We have eight states participating in this Collaborative and the expectation among all these collaboratives, the ones we're participating in and the ones we're not participating in, that we'll be able to gain from their achievements. We recognize that there are various challenges.

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The biggest challenge to our group is that we have been very ambitious. Having just worked over the work plan, we have been very ambitious in our timeframes, but having worked this group, they are very creative and we have every confidence that the objectives can be met.

Why are we going this multi-state collaboration, focusing on harmonizing state privacy laws? Why doesn't the federal government solve the problem for us? We are following what is happening at the federal level and there are a lot of good proposals being considered. Even if those were enacted, there are obviously issues to be resolved at the state level, regardless. Just as there is an opportunity for collaboration among the states, the experience of doing this analysis, the analytical work and consensus building can have a spillover effect for other states and for those working at the federal level to develop solutions.

As part of the collaboration, as we move through 2008, working at the Collaborative level those in Florida will be taking back the information gained from the work of the Collaborative, what is learned from other states, presenting it to the legal work group in Florida, getting their reaction, taking that back to the Collaborative and through this process we will begin to work toward common goals and solutions. To some extent, this depends on what happens during the legislative sessions, depending on how we emerge from the 2008 session, we will draft a more complete piece of legislation to go forward in 2009.

The states participating in the harmonizing state privacy laws collaboration are shown. Kelly Coyle from Michigan Public Health Institute, is co-chair with Patty Campbell, with the Idaho Department of Health and Welfare. We are very much looking forward to getting started on our collaboration.

In answer to a question regarding whether the Primary Care Association in Florida is involved in the Collaborative and if there are any federally funded grant programs like community health centers in the southeastern region that are involved in the Collaborative, there is a steering committee in Florida. Originally it was the governor's board. There has been a change in the steering committee recently but we do have representatives of federally qualified health centers involved in the new and old steering committee. The Florida Association of Family Practitioners are involved in the process. HRSA provides grant funding for community health centers and they do periodic reviews on the health centers and they do have a charge from President Bush to have electronic medical records implemented in some form by 2010. The issue is funding and in answer to whether there is any funding available to point grantees toward, since it is a limiting factor for grantees, one of the activities for the Agency for Health Care Administration that has the lead in Florida, is that it tries to provide technical assistance on its Web site and make stakeholders working in this area aware of grant opportunities. They also try to coordinate some of those activities also and can be contacted in this regard. It is anticipated that there may be federal assistance for FTAC's in Florida from the Collaborative and the staff can be contacted to learn what grant opportunities are available. This varies among the states regarding how help can be obtained.

In answer to a question about how the other states are participating in the work going forward, we are working to put agreements in place with 22 states and two territories that adds nine states and one territory to the mix. They are all working on one of the seven Collaborative's work groups. The whole focus this time is on this collaboration. However, each state also is maintaining their steering committee and connections within their own state. They also have decided on which focus area to work on this year, based on the concerns and needs of the particular state. So they're really playing two roles this time. They're furthering the work in their own state and working collaboratively going forward.

In answer to a question about how do we help to incorporate the new organizations into the mix when we have the 34 original states and territories who have the benefit of almost two years of work on this, we have brought them into the planning process during the course of the past six

months between June and December. States and territories interested in getting involved in the project have been working to plan and make decisions about which focus areas the project should focus on and which groups they want to participate in. We will also be providing them with additional support to help them form their steering committees and catch them up with some of the benefits that the other states have had from their longer participation. There are a few others beyond the 44, including the District of Columbia and a few other states, who are interested in staying involved and engaged in a little less active role at the time. And largely that's due to resources and whatever is going on in their environment at this time. But if anyone needs and wants to stay engaged, we will be providing opportunities for them to do that at a level they are comfortable with until they are in a position where they may participate at a greater level.

In answer to a question regarding the consumer engagement piece how national consumer groups such as AARP, ACLU and the National Alliance for the Mentally Ill are being engaged right now considerable interest has been shown at the state chapter level but it's unclear what these groups are hearing from their national organizations, when we started looking at this information trying to see what was out there, the consensus was that there was not so much connection between the state and national organizations. That is a function of several things. One, there are national funders who have been funding national efforts. In some cases those national efforts have been separate from the state organizations for whatever reason. When we got together as a group, our decision making process was by and large each state in the group is going about things very differently in trying to develop their Health Information Exchange framework. And as a result, the national associations really were not significantly helpful so what state organizations and groups were trying to do because it was very cookie-cutter. It was at such a high level, it didn't have any "legs" on the ground in each state. The decision was made to continue to work on the state level as opposed to working at the national level. But that will mean that we will have some back-and-forth as we progress through the process. Any information regarding this situation is helpful. It would be enormously helpful to the states to have a clear picture of where some of the key national organizations are on this emerging issue and what kind of guidance is being passed to the state chapters. The interest level among these groups is growing and there is a sense that they are hearing more from their respective national groups.

In answer to a question regarding how the HISPC work aligns with the NHIN (National Health Information Network) and how the work through HISPC, which is looking at state laws, lines up with the DURSA (Data Use and Reciprocal Support Agreement and one of the outcomes of the NHIN phase two), it has been at the forefront in terms of how these two projects align. There are a number of other projects that ONC is in charge of or leads and other projects that colleagues in other operating divisions in HHS run that need to be coordinated. These are two difficult puzzle pieces to fit together and they obviously need to be put together at some point. That's something that is being worked on behind the scenes at ONC. The NHIN has gone through its next phase in what is dubbed the trial implementations and they are working with HIEs in nine different areas. There is some overlap between the particular states that represent the HISPC initiative and those that are part of the NHIN trials. We're working toward putting those two together and feeding information back and forth between the two. The DURSA group underneath NHIN is working at a feverish pace to put together an agreement that can be useful for the trial. There is a companion collaborative, an inter-organizational agreements group being run through HISPC. There is a very concerted effort being made to make sure the two groups are synergistic and that when the DURSA group reaches a point where it has to get its phase rolling, we can shift some of the unresolved or state-specific issues to the inter-organizational group at HISPC. Information can also be fed back and forth regarding what the other states that don't overlap with any of the NHIN participants from the HISPC side to make sure that they are aware of the challenges that are out there. We're burning the candle from more than both ends and it's a good thing. It's a lot of work and is very complicated.

In answer to a question regarding a proposal by Ohio, which has significant support and encouragement from California and other states, to create an interstate compact as a mechanism

for exchanging data across state lines without necessarily having to have uniform laws across those states, a collaborative is looking at the idea.

In answer to a question regarding four hospitals in New Hampshire and Vermont who formed a consortium to try to improve transferring health and imaging information among themselves and whether there are any recommendations for currently available resources to set up guidelines to look at privacy issues versus the ability to share information, both states have participants in the Health Information Security and Privacy Collaborative. The University of New Hampshire and the Vermont Information Tech leaders have available contact information.

In answer to a question regarding Florida's HISPC state team around the risk assessment tool for RHIOs and whether this objective was met and could be shared, we developed a risk assessment tool that was presented in November in its initial phases. The plan is to eventually put it on the Web site. The initial tool focuses on security requirements and is considered an educational tool that can be useful in educating stakeholders and board members as they get involved in Health Information Exchange. It is not really considered a substitute for professional advice in the area of privacy and security. There are plans to continue to develop it and the privacy and security Web site with a number of tools. It is not currently up on the Web site but there is an intention to put it on the Web site and work on more of the privacy issues and try to develop a crosswalk tool between federal and state law in the 2008 project.

In answer to a question regarding harmonizing state privacy law collaborations and whether there are plans to translate some of the laws into everyday language that consumers can understand, it isn't something that has been discussed but it is an important consideration. A formal suggestion would be appreciated to make it part of the thinking process.

In answer to a question regarding the interstate compact idea, Ohio will lead the research along with California.

The National Association of Health Underwriters has HIE as a priority issue on their national legislative agenda that has filtered down to the West Virginia chapter which will be involving local agents in the work.

In answer to a question regarding whether there has been any work on developing model statutes for states to use in governing Health Information Exchange, it has been thought about but there is a desire to be very prudent in the process. The focus in the 2008 phase is to create a common analytical framework to develop priorities. We are not ready to crack a model law at this time but we may end up there. It has been monitoring the HISPC from the beginning and believes more groundwork is needed before model laws are drafted. AHIMA has been spending a fair amount of time trying to figure out what the common set of policies should be for Health Information Exchange. The Consumer Engagement and Education Collaborative considered what can be done but so many states are at different places right now in their development and going in so many directions, it isn't clear whether there is any one statute or set of policies that is going to address everyone's issues.

In answer to a question whether the scope of the HISPC funding includes funding for the construction of security, privacy and patient consent management infrastructure, it doesn't. It is used to fund the states to continue with the policy and legal work, so it's not an infrastructure funding mechanism. We're not giving money to buy hardware or software. It's more focusing on the policy aspects and what else needs to be done.