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>>John Eichwald: Welcome everybody. On behalf of EHDI here at the Centers for Disease Control in Atlanta, I welcome you all to our teleconference on Standards for Electronic Transmission of Newborn Screening Records. I'm John Eichwald, the team lead for the CDC-EHDI program here. Our other presenters today are Dr. Anna Orlova and Dr. Terese Finitzo.

>>[*Steve Richardson, CDC EHDI Health Educator, gives logistical instructions on how to participate in the teleconference*] ...to keep the lines free of interference, we will be Handling questions electronically today. Please look at the top of the tool bar and click on Q&A. You will see a note pad area you can use to type in your Question. When you finish, press "ask" to send it to the presenters. At the end of the presentation, they'll answer as many Questions as possible from the list.

Other useful documents can be found on the same tool bar. At the right, you will notice an icon with three pieces of paper. Clicking on this handouts icon puts you in touch for useful documents for download including acronyms used in today's Presentation. Click on the box you want and download to receive a copy.

The icon of a spiral notebook next to it on the tool bar holds useful web links and email addresses for you to copy. If you have technical problems during this session or if you don't have a link to the visual portion on the web, please Email me at this address, [srichardson@cdc.gov](mailto:srichardson@cdc.gov). This session will be recorded, visual and audio and be available later on the web. Please remember the questions that you're submitting are for the public. They're public questions, so bear that in mind as you do and we'll get to as many as possible at the end of the program. Now, I'd like to turn it back to you, John.

>>John Eichwald: Thank you, Steve. Before I begin my part of the presentation, I just want to give a short biographical background.

Dr. Anna Orlova is at Johns Hopkins and Clinical Associate Professor at the School of Public Health and Health Sciences, University of Massachusetts, Amherst. Dr. Orlova is with the National Library of Medicine. She started her informatics career at the Scientific and Technical Institute in Moscow, Russia, where she developed a large scale information system. Her informatics is in electronic health records, applications for health and information technology standards.

Our other presenter is well known to the community, Dr. Terese Finitzo, the chief executive officer for oz systems, a pediatric audiologist with experience in clinical and Research background in EHDI. She's a member of both ASHA and AAA and has served as program Director of the pilot project for newborn screening when it was developed and the development of the ASHA model build to assist states to pass effect EHDI legislation. Served as a member and the elected chair during the development of the JCIH position statement and introduced the concept of benchmarks and quality indicators as measurement tools for EHDI program assessment and improvement.

I'll talk about some of the activities we have been involved with in the last year and a half, and, first of all, why do we want to have standards in newborn screening? Newborn screenings will help us streamline management and operations, increase performance, hopefully will have a

major impact on reducing loss of follow-up and improve documentation on appropriate services, overcome problems in name changes for parents, guardians and for child and for identifying the medical home. It will help us securely access data via the web from many different locations, provide clinical decision support for second stage screening and diagnostic testing, complete data to consultants and specialists, help integrate newborn screening into the longitudinal electronic health record of a patient and provide access to *diodinoside (phonetic)* data to provide clinical and qualitative research.

I want to talk about different groups that have been working in the advancement of standards for newborn screening, the American health and informatics community. The health information panel. Work going on for codes for EHDI and the impact of the American Recovery Investment Stimulus package on these activities. To start with the American Health Information Community. AHIC was charged in, a federal advisory committee charged with making recommendations to the Secretary of Health and Human Services to accelerate integration and adoption of AHIC through networking capabilities. Several groups belong to AHIC, a strong representation from government, Health and Human Services and within that from the Centers for Disease Control and Prevention. There are professional organizations including the American Academy of Family Physicians. There were representatives of fairly high level business Organizations including Intel, Wal-Mart, Blue Cross/BlueShield Association.

The main product of AHIC is the development of use cases, or what some people might consider white papers. Each of these used cases describes how information should be moved. It talks about the stakeholders, the scope, the issues, the obstacles and discusses different system scenarios. There are several AHIC use cases that have been developed. You can see on this slide. There were use cases developed in, also cases in and, and some of these include Public health case reporting, personalized healthcare. In the work has been developed, is moving forward on the development of a use case for newborn screening.

In this work from the AHIC in February, AHIC provided recommendations to then secretary Leavitt to talk about how the issues of newborn screening could be addressed, and this included both for newborn dry bloodspot and for hearing. Almost a year later, the first detailed use case was created; it addressed the ability to order and communicate results from screenings in clinical domain from dry spot and EHDI. An accompanying document created at this time and it is the Screening coding and term knowledge guide that had actual Screening technologies identified both for *tandem mass (phonetic)* and EHDI.

The use case again communicates how screening case results will be communicated, confirming test results ordered, how results and information specific to referral and the management of the patient, how information is reported to public health, how the screening order and -- is communicated -- the results are communicated from screenings in various clinical domains and how to share the identified newborn screening information without requiring additional data collection or entry.

That web link at the bottom is to the specific use case. On a link under the note page, you can copy that if you want to capture that link to the use case. This is one page out of pages developed for the use case. I don't expect you to read any of this. The one thing I wanted to point out is you will see other Use Cases newborn screening refers back to. So there's a very coordinated effort between the use cases that have been developed.

The term knowledge -- coding and terminology guide, the documents -- the coding and terminology guides identified gaps in coding, *[word]* as it referred to EHDI. The web page for the terminology guide at the bottom of your Slide and you should be able to copy it to your notes page.

The AHIC was passed to a different committee HITSP. AHIC is part of the American National Standards Institute under the contract of Health and Human Services. The purpose is to take the data standards out there, integrate the standards and harmonize them. And to develop standards to enable widespread interoperability among software and as they interact in regional and health informational networks. Membership includes members of standard development organizations. I've listed other standard organizations that's part of HITSP, other government members, and professional organizations including the American Academy of Pediatrics.

At the bottom, the Public Health Data Standards Consortium. The big shift is the government sector. You can see the large number of organizations involved. National association of chain drugstores, Quest Diagnostics, University of Missouri, WebMD. Again, just this major shift from government involvement to private sector involvement.

HITSP is this harmony of standards and the purpose is to identify a pool of the standards, identify the gaps where they exist, identify where there are overlaps, and make recommendations to resolve these gaps. And, so, they create these extension gap documents. And the main product of this is the interoperability specification. Within this are a number of smaller documents that are constructs that help the existing standards satisfy the Use Case. Then all the standards are taken and instructions put to test by vendors.

The process is HITSP recommends the standards to the Secretary of Health and Human Services. The secretary accepts them for a period of time; I think it's generally a year. This gives the vendors time to refine instructors to comply with the standards and one year later the secretary of health and human services officially recognizes them for use in federal applications.

I don't expect anyone to read this slide here. When a specification is needed, it will occur in several different places, so we can borrow from these other interoperability specifications to fulfill the needs of the Use Case. Just to give an example of how it works for newborn hearing Screening, we took the AHIC use case and we took that and started moving forward to develop the interoperability specification, identifying transaction packages. We have branded any LOINC codes. [ *technical difficulties* ] as part of the stimulus package, provisions include that electronic health records should be developed for every person in the United States by, that there's a nationwide exchange of information, that privacy and security is independent [word] to this technology development.

Anna. I'm sorry. I tried to open this presentation before and it somehow stopped with tend but not the beginning. Bear with me here. We're on slide one right now.

>>Dr. Orlova: Good afternoon. Thank you for your time to attend this session. It's very important for us that we were able to talk to you about this project that public health data consortium is working on with integrating healthcare enterprise as well as state and representatives from four state health departments as well as the international community on newborn screening.

Public health data consortium is a membership based on nonprofit organization of state, local, federal, public health, professional organizations, health academia, Healthcare members and individual members who are interested to move forward with health information technology for Public health. So what you see here in this presentation is the project that we have been working with the support from the health researchers and services administration, and the title of the project is Standards for Public Health Data Exchange. It's called informatics of domain. It's what we're focusing on and I'll tell you about two other projects covered by this initiative.

The presentation that you will see today was developed by Terese Finitzo and myself, and we were serving as the lead core authors of the white paper we will be presenting to you. We'd like to thank the French Minister of Health and PHDC as they [cooperated] greatly in the document

we're presenting today to you: why are vendors and the consortium interested in this screening? That's what we will try to convince you by the end of the talk today.

We'd like to present you the way how vendors develop standards and how it's related to your particular domain. We also will be doing this presentation today for you because we want to solicit broader participation of public health community and clinicians in a review in this White Paper that we are releasing. This webinar is the first one in the series of webinars that will be held by the consortium during the month of June.

About this white paper, just to assure that the broad public community can send out your input. This input is so important because we need to make sure that various aspects of newborn screening and hearing screening, the way you see it from the state health agency, will be addressed in this presentation. And we believe that we have a way to capture this to develop a robust product.

I would like just to acknowledge in the beginning of my talk several activities that have been done before we started working on this project. Why we're selecting newborn screening? This is because, first of all, because the newborn screening and (*inaudible*) are the first two encounters in addition to Immunization performed at the birthing facility within hours of the birth of the child. And this represents the first encounter between clinical and public health information systems. Also, your community has very extensive experience using information systems for your individual programs. Your community also invested a lot in the effort to standardize this exchanges of information that maybe right now sounds like state-specific, but the work that you already did is actually enabling us to move ahead with the national use case because we believe that the content for both newborn screening and bloodspot screening and hearing screening is pretty well defined within the community and we can really deliver and explain well to vendors what we need from these exchanges.

Another reason for focusing on newborn screening, of course, the national health information agenda that includes this newborn screening use case. I would like just to clarify here the point of the relationship between the national use case and activities that would be done by HITSP as well as the activities that were described to you here.

HITSP is the organization that harmonizing standards. The steps HITSP is doing the conducting the requirement analysis of the use case where they're reviewing and selecting appropriate standards. They exercise that we conduct in this white paper is going over the possible information exchange standards that could be applicable for newborn screening and hearing screening in the national use case. That's what we did. We basically forwarded the national use case in terms of the activities and processes conducted by clinicians, and we went through the exercise of identifying what existing standards can be used or suggested for harmonized interoperable specification to be developed later this fall by HITSP. I myself am a co-chair of the HITSP population perspective committee and one of the co-chairs responsible for the development of the national interoperability specifications for the work that we're doing right now. It's very important for HITSP because of these delays in work on the (*inaudible*) case.

We'll conduct an analysis under the project and leverage information solicited through this white paper in the national specification. That's another reason -- this is another reason why we are looking now for very broad review of the white paper to make sure that public health community could provide its input in our work and then the input also can be presented at the national level at HITSP. This work started in.

In fact, with this diagram that, if you can see, me and Dr. Terese Finitzo put together. This was a project funded by (*phonetic*) at the time, developed a system of how record systems and public health systems can exchange information. This was presented in at the Health

Information Management Systems Society meeting and it shows that information if collected in the hospital at birth, it can be simultaneously sent to the stand-alone public health registry that you see presented here. That was very successful demonstration that we build for to show the visibility of working in this direction and the link of public health and electronic clinical based systems.

What did we do between and now and what progress did we make in trying to make this vision to be a reality? I think our main lesson over these four years was basically the realization that it's not enough to work within just the public health community. If we're going to exchange data with clinicians, we have to go beyond public health community and engage in discussions, clinicians and health information with vendors. The issue of talking to ourselves within the public health community is not easy because you know that building the consensus of common knowledge in data exchanges between public health programs is a very difficult topic.

But in order to make our systems to be a part of the emergent health information exchanges, we need to go through this process to understand interactions between public health systems and within the health department and the cross health department. We need to understand common knowledge and data architecture for the systems and define the common needs on behalf of the public health in the exchanges. Working with clinicians would mean that we have to define what are those needs in the systems will be to ensure they in fact collect data of interest to us. We need to better understand interactions between clinical care and public health systems in terms of the information exchanged.

As well, this is a repetition from the previous slide, but you may glean with me that the commonalities between data, data architecture and public health and clinical systems are very important to precede. We have to begin working with vendors, not one by one, but we have been doing this for several years, and the result of that are stand-alone interoperable systems. We need to assure that all vendors can support multiple needs of multiple health programs, so we need to know better the tools.

We have to be able to communicate needs for interoperable electronic health records systems to them as well as non-ehrbased applications that we may need to have such a survey. We also have to be able to participate in the design of the information systems under development in the nationwide health information exchange initiative.

What are these vendors? Here's a list of vendors involved in health it. Just looking at this list, you realize how difficult it is from public health to begin approaching the individual vendors saying we need certain capabilities in your product to support our needs. The answer to the question how to communicate is a founders group. This is showing the provers and developers working together to deliver interoperable health information systems in the enterprise and cross care setting. Integrated healthcare enterprise is organization of Electronic health record vendors and professional organizations that are called sponsors in this organization. You see how professional associations already collaborate to make sure that they meet in the electronic records systems. You will see when you review the paper at newborn screening conducted outside of this country and you will see how we were able to include it in our description of newborn screening activities, information from Austria, Germany and France as well as incorporate their data needs in our common data needs.

The slide I showed you before was from this organization because all the vendors participate in IHE and will be able to produce them. They produced a technical document, health it standards. The documents within IHE fall into white paper, technical profiles and content profiles. We're working on the white paper. The document will look like this, describing the vendor community. The needs for information exchanges in this particular domain, explaining what the domain is about, what the process is about.

Then based on this explanation, the vendors will develop what's called integration profiles and content profiles and the documents would start looking like this, like on the right, with complicated diagrams that users have difficulty understanding but making sure that we describe the process correctly. We have this breach right now and you will see in the presentation how our simple diagrams that describe our work process can be, in fact, built into the technical documents that we will show you.

Okay. Just only also for to take a moment to tell you about content profiles. A content profile is a technical specific case that looks like this, describing the content of the information exchange. If the integration profile is something that connects on this right side, these boxes called interaction profile, what's within the line is described in the content profile. So very limited data that we conducted in the white paper effort will be used to develop the content profile for Information exchange. But you see here is what we would like to see with regards to newborn screening in February. This is a *connect (phonetic)* demonstration.

Much standard organization develops standards but only it conducts this exercise when various vendors are constructing trial implementation for potential solutions before they go into real world operation. This is how many domains. Information exchanges on cardiology, patient care coordination, radiology. We would be very happy to see if newborn screening will be added in here.

I would like to finish the presentation with the organization -- of the organization with this slide that public health was added to the list of domains because two Years ago, consortium was invited to form public domain. Public health activities in the last two years at IHE are growing. In, we first developed white paper building information systems interoperable for public health, explaining to vendors what public health is. We also worked with the North American Organization of Central Cancer Registries and CDC on the cancer pathology integration profile. We work with immunization on their immunization demographic profile.

With the support from HRSA this year, we're working on service oriented for public health white paper which is the common architecture that may one day fill the needs of the solution.

A few comments about the white paper effort that's being conducted. The goal of this effort was to specify to electronic health records vendors the need for electronic exchange. We focused on newborn bloodspot screening and hearing Screening only in this effort. The method that we used, being used in several projects funded by HRSA at the consortium where we used the informant to document the process of electronic health records in newborn screening and hearing activities. We use the functional requirement analysis document to specify data sources and data needs in this effort. The target audience for this document is public health professionals and clinicians involved in newborn screening, record systems vendors and public health system vendors Involved in the domain. The project team included the consortium, myself and Terese presented this and IHE laboratory committee.

Here you can also see the health departments that helped us provide an input in describing these health information exchanges and are from Alaska, Iowa Maryland and Texas and three European countries, France, Germany and Austria.

With this said, I would like just to conclude my portion on this presentation and then give the floor to Terese Finitzoto go over the details of what's being developed. Thank you.

>>[Steve Richardson] Dr. Terese Finitzoto, could I just break in to remind people that if you have questions, please look at the toolbar at the top of your screen, the fourth item from the left, Q&A, and please feel free to click that open, type in what looks like an email and click "ask" to send it to the presenters and we'll get to those things at the end of the presentation. Thank you, go ahead, please.

>>Terese Finitzo: Thank you. Given that our EHDI programs are in the limelight, something that certainly surprised me at first, what do the three of us see at our role representing public health with the clinicians from the professional organizations and the bigger vendors John and Anna described for you?

First, we want to maintain any CDC and HRSA priorities in EHDI. CDC's recent grant direction talks about knowing the status of every rent birth and the hearing status of every occurring birth during an individual child record. Therefore, we didn't want the future -- and I put that in quotes -- to require the hospital to send only aggregate test results to public health that seemed inconsistent with some off the priorities we all have been working on for more than a decade.

Secondly, we wanted to assure that the quality initiatives you undertake to improve your programs not be weakened in this effort. Some states have certification or compliance programs in which rules that operate how your hospital should perform and we wanted to make sure that those went forward and that you certainly -- that they would be no worse and hopefully better as John described, the whole reason for standards is to make things better.

Third, to maintain your jurisdictional autonomy, and that is important given that IHE is both international as well as national. So not only did this -- did the use case have to be palatable for different states within the U.S., but it also had to be okay for France and England, both, which have very different systems.

So the goal, then, was to maintain the flexibility that you have now. You also, different states have different needs, and it's these needs that drive your priorities. And, so, it seemed important to us to keep that autonomy and flexibility for you. That certainly was the message we got from some of the states that we spoke to as well.

So the purpose of this part of the presentation is to give you an overview of the EHDI component of the newborn screening use case. The focus here will be on EHDI. We want to introduce the word "functional requirements" and also introduce them to you for the newborn hearing screening systems to define actors, because you're going to see them as you read the white paper, and actors can be both business actors and technical actors.

Finally, to review, we'll not call it a "dumb-down," but a simplified version of the EHDI use case you are going to see on the IHE web site, as well as to take a look at some of the use case diagrams and then to review your next steps. Functional requirements for this project meant documenting the work processes at the hospital by public health and the PCP primary care provider medical home. I put medical home in here because it's one we know in the U.S. It won't be in the white paper because it's not an International term, but I assured Anna, everyone in the U.S. knew that and was comfortable with it.

Secondly, we want to specify functional requirements meant Specifying information and data, and that includes high risk Factors, contact information. Basically, your program requirements. Some of you include high-risk factors as information you want. Others don't. So the important point is making sure we could be inclusive and include the information that was needed. Specifying how the hospital electronic health records system needed to function for EHDI to be successfully completed in your state, and finally specifying what Electronic Data Interchange -- that's what EDI stands for -- is needed by the electronic healthcare systems, because it's system, not just a record or a form from a electronic healthcare record System.

But what the hospital are needing to communicate with Stakeholder systems including the EHDI information system And the PCP medical home system. So business actors, business actors are people. Okay? They're the people, and they're the healthcare providers, and they're the healthcare providers at the hospital. Now, at the hospital, they might include the attending

Physician, the hearing screener, screening supervisor, and this is meant to be generic and inclusive.

Again, many of you told us that you used volunteers, your Hospitals used volunteers. You have contract people. You have nurses. You have different people or different types of roles,

Different types of personnel fulfilling these roles. That's fine. This just connotes who -- you do need a hearing screener. You have the primary care provider, the medical home Provider, the baby's pediatrician outside the hospital. In addition, another business factor involved is public health, and that's your -- your board hearing screening or EHDI program. Again, this is inclusive.

You told us you had contract people. Sometimes you had audiologists. This could include your clerical staff, staff, whoever is involved to run your EHDI program, this is an Inclusive list.

All right, you've got the consumer, and that includes the Baby and, of course, the baby's parents. Now, the technical actors are the systems, the electronic [WORD] records systems we have been talking about and that will be at the hospital or the birthing facility. Obviously, they're not always the same, because the hospital might not birth babies, but in this case we're talking about hospitals that do birth babies. You've got the hearing screening device which is actually involved in electronic communications in some states, in some countries -- England for one. Some U.S. states require this to be an active participant or have an active role in electronic communication.

You've got the EHDI information system at the department of health or at the hospital and the department of health. So this is an inclusive term as well.

You've got the primary care provider's electronic health record, and what's out of scope but that you will clearly be Hearing more about in the future is personal health records system so that we have to, in the future, keep in mind that data will likely have to go back or a report will likely have to go back to the baby's personal health records.

Finally, we've got this thing called a health information exchange. Anna's already talked about it some, but it's the one that confounds me the most. The world health information exchange helps a little. It's about moving clinical information electronically between different systems or within a system while maintaining the meaning of the information exchanged. When I read maintaining the meaning of the information, I had a "duh" moment, why would you not want to maintain the meaning? The point is it hasn't always been easy and that's what you see AHIC and HITSP and IHE working hard to make sure it is a critical piece because obviously maintaining the meaning is the most important component. It's obvious that it gets there as well.

Health information exchanges are going to facilitate the access and the retrieval of clinical data for safer, more timely and then you have all the great e-words -- efficient, effective, equitable -- patient center care. Who will be involved? These are some of the big guns. I see Microsoft talking about this, Google. John and Anna may have some and Dr. Zuckerman may know who may lead this effort in the future.

All right. This is a version of Anna's slide, but we updated it a little bit, and it's also very simplistic. I use that to mean really more than just simple. It's a naive representation, but I think it helps to show one key improvement in our effort, and that misinformation goes both from the birth hospital to public health and back from public health to clinical systems, and that's something that's really, really important.

Note in the upper left-hand corner under birth hospital there's something called a birth record. This doesn't reflect vital statistics, but this could be --And I've seen it in HITSP's internal and

child health use case -- this could be a notification of the birth that gets published or sent to the health information exchange to be made available to public health and anybody else who is authorized to see it. Now, what that could mean for us is really exciting, because, first and finally, we would have a good denominator. And with that denominator, we could then deliver care the way we need to, to our babies, and know that they all got the care. I'm going to show you how this world works in a minute, at least demonstrate a small piece of it.

All right. Use case description; we're all giving you our own definitions. Basically a description of user activity and the data that needs to be exchanged in a particular clinical scenario. For us, scenario is newborn hearing screening. But more importantly, it's the birth screening component of Newborn hearing screening, so it's not even the entire realm of what you and I know to be EHDI. It's just the first screening component because what we were focusing on is what these big electronic health records system vendors needed to do.

I lost my cartoon here. When you read use cases, I'm going to speak for me, but I have a feeling John had the same reaction when he first read his first one. Maybe Anna was intuitive about it and understood it, but somehow they remind you of this cartoon on the automatic back scratcher in which you kind of say wouldn't it have been easier to do this another way? But, again, I think that, as you saw -- or heard John talk about what the hopes are for standards for all of us who have been involved in EHDI for so long, and after you read them a few times, they begin to look a little and sound a little less like this.

Here's the use case. Notice at the top, this is for the birthing facility. Notice the numbers. Also notice they're not sequential because I've abstracted from the IHE white paper to pull out just some pieces of it. So let's take a look and see what it would look like and what you should comment on. The electronic health record system reminds the hearing screener that a newborn is due for hearing screening. All right, so this might be an alert, to-do list, a task list of some sort.

The hearing screener explains screening to the parents, obtains consent if needed again, no requirement to obtain consent. Many of you told us we don't need consent, we have consent refusal. This will be her jurisdictional requirements in your state.

The hearing screener enters required information into the electronic health record system or the screening device. This information is what you in your state say are required to effectively operate your EHDI program. Some of you have contact information, high-risk information; some of you want maternal data on these kids. That's going to be stipulated by the rules that are set up by public health. . . , the hearing screener performance the task using unapproved hearing screening device, and this continues with the birth facility, but you see the numbers change to , and that's because, right now, at least in the first three, We're talking about what the device does. The device generates the results. That's the part referred we're familiar with and something I learned recently in the potential LOINC codes and how they may be used in standards stations.

Hearing results are sent to the EHR. We're running short, so I won't read all of this. You can see the kind of thing that will happen.

Let me just touch base on the public health EHDI program. Again, go back to that first piece which is going to happen before the screening occurs. The EHDI information system is going to receive notification of the newborn's birth. That's your denominator. The EHDI information system could establish a newborn record if that's required in your state without hearing screening results. Might receive screening results from the ehr system, directly from the device or the EHDI information system might. Match the results and calculate outcome. Again, the outcome is more than the screening results and it's what you in your state say happens next. In

one state it might be send a risk factor letter out when the baby's two months old. In another it might be call the parent if the baby didn't get care for days.

>> Our presenters asked me to notify when there are five minutes left in the program. Thank you.

>> Okay. The PCP/EHR system has things that will happen as well, but I'm going to skip that slide. And then, basically, say here are some work flow diagrams. I've seen these because Anna showed you them before. These are the use case diagrams. You see the little actors, and you see the colors. It's color-coded. Blue being technical actors and the pale beige being the Business actors. Go through these. Every time I look at this, I think there are probably better ways to do it. I wonder if it needs some help. So a few things could be changed.

This is where we want your input as both Anna and John have said. This again is the work flow diagram. All these little xgss and pccs, these are the forms the Vendors will need to select from to meet the interoperability requirements, and to select from, not develop, because the whole goal is interoperability.

The data, we've begun to collect data from the various states on what you consider to be the important data that must be communicated. Here is a data mapping form. You can't read anything on this, but the goal is to get all the forms -- and we've gotten some of this information from hospitals and states -- all of the information that each of you collects that you need in a data map, concepts mapping.

This was Anna's slide she asks that I show you. All right. This is the post important slide, and it is because this road is not yet finished, and it needs your input, and that's really why we're here today is to ask you for your input.

Finally, you've got this up in the notes on the right that John and Anna have talked about. Please give us the feedback. Finally, I guess we can open it up to questions for a few minutes.

>> [Steve Richardson] Okay. And I think in answer to several of the questions can be one answer. People are very interested in getting a recording of the session or the slides in particular. I know I can say right away the recording of this session will be available as soon as possible after the session, and we can announce that to the usual list service for you to request that. It will probably be a good-sized recording, but you will be able to see the entire visual and audio program as it was presented today. I talked to our presenters. Will the slides be available in PowerPoint or some other format?

>> [Dr. Orlova] Absolutely. Yes from the consortium side, this slide that you see right now presented by myself and Terese is available for distribution.

>> [Steve Richardson] Okay, will the slides from the entire presentation be available?

>> Sure, that's fine.

I just wanted to make sure. So those things will be made available and be announced, too. That covers a number of the questions.

>> Another question earlier I think we should address. Unless somebody took it away or answered it for her. This really is about the screening, the standards really have not -- the referral to audiology, the diagnostics, the intervention, at this point in time, are out of scope. We are really talking about screening and providing screening from the hospital to the EHDI program and eventually back out to the medical home. Is that right, Anna?

>> Yes. This is Teresa. I skipped that slide that showed the data going back to the Primary provider if it's a medical home. But the point is, this is the birth screening component. It is a

narrow component for most of us when we think of EHDI but we want to move this whole initiative forward after we deal with screening. We certainly want to keep moving it forward.

>> I think, John, the idea of a health information exchange makes this the ability to communicate data from public Health back through the health information exchange to the authorized audiology care provider, the geneticist, the EMT, That's what this really is about is the standards that will allow state programs to do that.

>> Anna: when we are still on this page, I would like to show you again the international context of the activities at it. You see mother and child profile. This is, in fact, French profile sponsored by the French Minister of Health, where they are defining the information to be exchanged in their labor and delivery ward related to Mother and child's health.

>> [Steve Richardson] I think we've covered most of the questions because they were about getting copies of this rich information. I would like also to point peoples' attention once again to the icon that's on the right side of the tool bar, the yellow note pad icon called "shared notes." It has URLs to contact, to get copies of the white paper and to provide comments. It also has email addresses for our presenters today as well as other useful information. So please feel free to go to that, copy and paste that into your own files for future reference. Are there any further comments from our presenters?

>> Steve, I just would like to add here that on the slide that you see right now, the comments on our white paper should be submitted through online forum at this [http forum for radiology society of north America](http://forum.radiology-society.org) that sponsors Directivities. So the directions to get to the page may be complicated. If it's not easy to navigate, email me and I'll work with you to get you directions on how to do that. And my email you can find in the meeting notes -- in the Webinar notes section.

I would like to finish this up by giving my sincere thank You to both Anna and Terese for working in this area and today's presentation. Thank you.

You're welcome. Thanks very much for having us.

Thank you.

With that, I think we're done.

>> if you have any comments on improving the session, things You'd like to see done to improve it, let us know [gol8@cdc.gov](mailto:gol8@cdc.gov) much for participating today. Thank you all.

[End of event]