

# DataSpeak – Health Information Exchange Transcript September 14, 2009

## Participants

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Kelly Cronin, Director, Office of the National Coordinator for Health Information Technology (ONC)  
Debra Bara, Associate Director of Programs, Public Health Informatics Institute  
Ellen Amore, Rhode Island Department of Health  
Gretchen Noonan, DataSpeak Moderator

## Presentation

### Mary Kay Kenney

Good afternoon. Welcome to today's DataSpeak Web Conference on Health Information Exchange. My name is Mary Kay Kenney, and I'm a Statistician at the Maternal & Child Health Bureau's Office of Data and Program Development. The DataSpeak series is sponsored through the office's Maternal & Child Health Information Resource Center.

Today's program will focus on the electronic exchange of health information and how the MCH community can utilize new funding and technology in this area. Our first presenter will be Kelly Cronin from the Office of the National Coordinator for Health Information Technology, also called "Onc" or O-N-C. She's going to begin the program by discussing recent legislation that has created new guidelines and funding related to health information technology.

Our second presenter will be Debra Bara, Associate Director of Programs at the Public Health Informatics Institute. She will discuss issues that MCH agencies and organizations need to consider when preparing to electronically share information.

And our final presenter today is Ellen Amore from the Rhode Island Department of Health. She will discuss their State-level experiences with implementing a health record system. She will provide examples of data—of child health profiles and discuss benefits of the system and barriers that they have overcome.

It is now my pleasure to introduce Gretchen Noonan, the Moderator for today's program. Gretchen, I will now turn the floor over to you.

### Gretchen Noonan

Thank you, Mary Kay. First I'd like to welcome all of our participants today. We're excited that you could join us. But before we begin our presentations, I have some brief technical guidance for everyone in the audience. For those of you—excuse me—for those of you who are on the phone, please know that your phone line will be muted during the presentations. After the presenters have finished, we'll have a question-and-answer session. You'll have the opportunity to ask questions through the telephone Operator, who will come on at that time to provide instructions.

You can also post question online at any time during the program. Simply enter your question in the questions box located on the left side of your screen and hit "Enter." If you're logged in via the Internet, a

feedback form will be provided at the end of the presentation, and we would really appreciate if you could take a moment to complete the brief form.

If you encounter any technical problems during the presentation, which we hope isn't the case, please feel free to call the MCH IRC Help Line. That number is 202-842-2000.

Now, I'd like to quickly let everyone know about some features about the DataSpeak Web site, which we welcome you to visit after today's program. For everyone's convenience, additional resources on the topic we have today have been posted on the Web site, including some of those that our speakers will highlight in our presentations. And you might also be interested to know the archives of past DataSpeak programs going all the way back to 2000 can be found on the Web site, and the address, I think, is there on your slide. And the archives are offered in several different formats, including full multimedia archives with sound and the text-only transcripts.

Finally, I'd just like to let you know that copies of the presentations are available to you right on your current screen there. In the presentations box, just click on the presentation materials there and click "Save to My Computer," and a separate box will pop open, and then I'll give you instructions.

Now, I'd finally like to turn to our first presenter, Kelly Cronin from the Office of the National Coordinator for Health Information Technology. Welcome today, Kelly.

### **Kelly Cronin**

Thank you. I wanted to try to spend the next 13 or 14 minutes or so quickly going over some slides. And it's a lot of information, but I'm going to go through it fairly quickly and then hopefully be able to address any questions you might have at the end of the call.

So just to start, I wanted to focus on the following things. There's a lot in the Recovery Act, and the Health IT Provisions of the Recovery Act are called the HITPC Act. And the things that I'm going to focus on today are around national coordination, the payment incentives coming from Medicare and Medicaid, and then some of our priority grant programs that we're really focusing on developing right now—and then also give you a heads-up about some things that will be coming out in the near future.

So the monies that were allocated to the Office of the National Coordinator for Health IT were \$2 billion. And we're looking at this primarily as monies that will be in support of the meaningful use incentives that will be coming from Medicare and Medicaid, which will be going to eligible providers at both Medicare and Medicaid—to a variety of doctors and hospitals that are meaningful users of electronic health records, which I'll talk about a little bit more in a second.

But in terms of national coordination, the HITPC Act does establish ONC as a permanent organization. We were created under the last administration by an executive order, and we're now codified. It's also established two Advisory Committee meetings, a Policy Committee, and a Standards Committee, and the products coming out of those committees are going into or being considered for regulation around the incentives and also regulation of certification and standards that are necessary to make electronic health records and health information interoperable across the system.

We also need to be updating a strategic plan by statute now and appointing a Chief Privacy Officer. And we have new authority established which allows us to provide governance or ensure that there's governance for a Nationwide Health Information Network that will allow for secure and appropriate exchange of information across the health care system.

**Gretchen Noonan**

Does the Act offer any sort of incentives to providers for participating?

**Kelly Cronin**

Yeah, the—what a lot of people have been interested in since the Recovery Act was signed was roughly \$45 billion of estimated incentive payments from Medicare and Medicaid, which many of you have probably heard about. So this means either a hospital or another type of eligible provider will be a meaningful user of electronic health records to receive those payments. And by statute, there's a few things that these meaningful users must do in order to qualify for these incentives, and that includes the use of a certified electronic health record; exchange of health information, not just from perhaps a patient to a doctor, but really across health care providers—really, this is getting more to care coordination and improved quality. And then the ability to report quality measures to an outside party is also a requirement. And this will all be finalized through a rulemaking process, and CMS is expected to publish a formal definition of “meaningful use” for the purposes of the incentives by the end of the year.

**Gretchen Noonan**

Great. Can you tell us about some of the specific requirements of the Act—I'm sorry if you hear sirens behind me—and the opportunities that it provides?

**Kelly Cronin**

Right. Well, first I'll give you some context around what we thought to be really the short-term prerequisites for widespread adoption of health information technology, really, through these incentives. We thought that a certification program is really critical to make sure that these electronic health records that will be adopted can be implemented and able to share information across the system, but that really clinicians and hospitals must be able to have support to be able to integrate these tools into the care delivery process.

There's a lot of challenges within small doctor's offices, within different types of hospital settings, to really make this work in a way that is really seamless with the care delivery process. So, you know, considering workflow and considering the clinical needs up front before these tools are acquired and as they're implemented is really critical. So to provide the support that's needed across the system to make it helpful is really one important prerequisite.

Another one is really to make sure that the technical, the policy, the legal, and the financial supports are available to make sure the information flows across the system. There's been a lot of silos in our fragmented system, and the software investments that have been made, particularly among some larger hospitals, have not really resulted in information sharing across public health and across different providers who provide maternal and child health services. So in order to try and break down these barriers and create network services where this information could flow more as it's needed from a clinical or public health perspective, there's a lot of sort of foundation that needs to be laid from a policy and a technical perspective.

And then, finally, we need a skilled workforce. So we need to be able to make sure that the highly skilled—either clinicians or technical experts are available to help physicians in hospitals or help public health agencies do the critical upgrades and adoption work that's needed to make all this pull together. So we'll be looking to implement new programs that will help develop a skilled workforce.

And so, the priority grant programs that really focus on these prerequisites are the Health Information Technology Extension Center Program, the State grant programs to promote health information technology and what we're refer—that's what the statute says; we refer to it as the State HIE Cooperative

Agreements Program—and then finally Information Technology Professionals in Health Care or Workforce Program. And I'll talk a little bit about these in the next few slides.

This is a snapshot of two of the bigger programs that we've already announced in the last few weeks. These comprise roughly \$1.3 billion out of our \$2 billion. The regional Federal program will have three rounds of applications as a competitive process. And the thinking behind this is that there's several places across the country that have already formed strong collaboratives and can offer helpful assistance to the primary care physicians as they make decisions on which electronic health records to implement and actually do the implementation support work.

So the very early deadlines to September in making awards by December for this initial cycle is really geared towards those collaboratives that are already—that already exist and that are already advanced enough that they could be targeting and delivering services to primary care physicians in a given geographic area. There'll be approximately 70 awards, but I think it's really going to be based on how many awardable applications there are through these three funding cycles.

And then the State HIE Program is roughly a \$564 million program that will be awarded to all States and Territories—those that are eligible applicants and submit awardable applications. It's similar to the regional center program. It'll be a 4-year performance period, and we have already received letters of intent and hope to be making awards by January.

#### **Gretchen Noonan**

And if we could talk a little bit more about the State HIE Program, which you just mentioned, can you tell us what the purpose of the Program is and what the State's role is in the Program?

#### **Kelly Cronin**

So the primary purposes are to facilitate and expand the secure electronic movement and use of health information among organizations according to nationally recognized standards. And this is really from the statute. But specifically, we're looking at governance, policy, and technical infrastructure that's really critical to enable standards-based HIE. It's going to be essential that there's a Federal-State collaboration, because there's a lot of complexity to making this happen that really requires both Federal and State authorities and strong leadership on both levels and a multistakeholder effort in pulling it together in a way that works across a State and across regions.

So public health needs to be involved. We need health care providers, hospitals, physicians, health plans—really it's a multisector, multi-State culture effort to pull this together. And the cooperative agreements will develop on—will focus on developing the statewide policy infrastructure, the governance needed for accountability of health information exchange, the technical infrastructure, and business practices needed to pull this all together.

And the State role is really primarily a critical leadership role, so the Governors are expected to appoint State Health IT Coordinators, which will be high-level government officials who will be charged with not only State government coordination of health IT and health information exchange, but also really work across all of the health care and public health stakeholders in pulling together State strategic plans and operational plans. But specifically, States will be expected to use their authority, their programs, and their resources to determine the roles and responsibilities of a State-designated entity if they choose to use a public-private partnership or not-for-profit organization that would be multistakeholder to really develop the capacity. They would be expected to—or they are expected to develop and implement the plans, as I mentioned; develop State local directories and enable technical services; remove barriers in creating—create enablers for health information exchange, particularly among labs and hospitals and clinician

offices and other important training partners. They need to be ensuring that there's an effective model for governance and accountability such that there's trust in the system and that information is being exchanged in a secure and appropriate manner and, you know, those authorized to participate are the ones who are actually receiving data. A coordinated approach with Medicaid and other State public health programs is important. And they also need to be developing or updating their privacy and security requirements to make sure that data can not only flow appropriately and seamlessly across a State but— or within a State, but also eventually across States.

And there's a lot of coordination that would be important with federally funded programs, which we will be enabling from ONC. And this next slide gives a lot of details around the different federally funded State-based programs that are required to be part of the plans and the thinking going into these applications. So there's CDC programs, epidemiology and laboratory capacity, cooperative agreement program, long-term care programs, maternal and child health systems development initiative program that HRSA administers—I'm sure many of you are working with—and then there's other Federal agencies that are important to coordinate with, given that VA, DoD and the Indian Health Service have facilities across States and need to be considered in terms of how they will become part of a statewide approach to health information exchange. And then, of course, there's other Recovery Act programs, like broadband funding, that really need to be considered as well, since that will enable connectivity across the State, particularly rural States.

So in terms of special populations, the program does require that when States are planning and implementing a project, they think specifically about the medically underserved populations. Newborns, children, and youth, including those in foster care, must be addressed. The elderly need to be addressed—persons with disabilities, LEP, and those with mental and substance abuse disorders, and also those in long-term care.

So, just to give you a quick preview of some things that will be coming, as I mentioned, CMS will be defining meaningful use by the end of this year through a notice for a proposed rulemaking. That will initiate the rulemaking process, which will be then finalized prior to the implementation of the program in 2011. And then adoption of standards and certification criteria relevant to meaningful use and statutory requirements is by the end of this year through an interim rule that ONC will be putting out. We'll be updating our strategic plan, and then we'll also be announcing new grant programs but also awarding quantitative agreements for the two big programs that I mentioned earlier.

So we have a lot more information on our Web site. I'd, you know, encourage all of you to monitor what's going on to the extent that you're interested. And you can also always e-mail me or ask me questions if there's anything that I didn't cover or that you'd like to know more about.

**Gretchen Noonan**

Great. Kelly, thank you so much. And I just want to remind everyone that Kelly's slides are available on your screen right there, and they're also available on the DataSpeak Web site, and she'll be with us for the Q&A at the end of the program.

And now I'd like to introduce Debra Bara from the Public Health Informatics Institute. Hi, Debra.

**Debra Bara**

Hi.

**Gretchen Noonan**

Thank you for joining us today. One way that public health agencies have been preparing to share information electronically is by integrating their child health information systems. Can you tell us what that means?

**Debra Bara**

Sure. Well, what we mean when we talk about an integrated child health information system is one that's able to produce what we call a consolidated record. And if we think about the way most public health agencies have access to data right now, each program has its own database. And what happens in an integrated system is that somehow, they're able to gather the information about the services that an individual child has received from that public health agency and combine it into a consolidated record.

So that's the first thing. The second thing is that there's the ability for what we call this bidirectional exchange of information. And what we mean by that is that the child, for example, shows up in a pediatrician's office, and they need a lead screen repeated, or they need an immunization that day—that the pediatrician is able to administer that and then provide that information back to the public health agency, and other people who have need of and legal access to that information would be able to view it.

The third thing is that the information is available at—in real time at the point of service. So it's not linking datasets for the purpose of doing some sort of retrospective analysis of data. It's actually something that's happening in real time, and it's regardless of the software and the hardware between those two entities.

**Gretchen Noonan**

Okay. What's the rationale for integrating child health information systems, from your perspective?

**Debra Bara**

Well, there's quite a few drivers for developing these integrated information systems. And the first one is just the expectations of the public. If we think about our lives today—I'll give the example of—if I decided at the end of the call today that I wanted to fly to Hong Kong tomorrow, I could go online, buy my ticket—when I get there, if I decided that I wanted to do some shopping, I could use an ATM card, plug it into a machine—it connects back to my bank account in Atlanta, where I live, and I can get money in the currency of the country that I'm in. And if I buy something, I can track it during my stay there through, you know, FedEx or some service like that.

So we live in the information age right now, and there's a high expectation on the part of the public to have that information available at the time when people need it. The second thing is this development of the e-health movement, which is one of the cornerstones of health care reform, and a big part of that is going to be the health information exchanges that have been alluded to earlier today. And Kelly Cronin also, in her conversation, talked about meaningful use; that's going to be a push for more exchange between public health agencies and clinical care providers to exchange information.

So those are some of the sort of broad rationale. But when we think about public health specifically, this concept of the child health profile was developed by HRSA really as a vision for providing that kind of timely, accurate, and very individualized information to clinical care providers, like pediatricians and audiologists, at the point of care. So we really need to focus on being able to create those kind of consolidated records.

And to be able to provide such a record allows for what I call the actualization of the medical home: taking the concept of the medical home and making it real. And if we look at the definition for "medical home," information technology can help us a lot in achieving the number of objectives around continuous care, comprehensive care, and coordinated care.

### **Gretchen Noonan**

Okay, and I understand that your organization has done some research on integration. How common is it for public health agencies to undertake integration of their information systems?

### **Debra Bara**

Well, we have done some research. In the winter of 2007/2008, we conducted an assessment to learn more about what public health agencies were doing around this topic. And we developed a 24-item online survey. We partnered with AMCHP on this project, and the sample was drawn from a list of MCH Directors that they provided us that included the 50 States; eight U.S. Territories; and Washington, DC. We were really pleased with the response rate of 70 percent, so we had 41 responses; 39 of them were included in the final dataset.

And what you see on the screen here represents the categories. The blue area there indicates 18 States already had, at the time of this survey, integrated some or all of their child health information systems, with three more planning to do it in the next year, which is the red, and 10 more that were planning on integrating their information systems within the next 3 years. And when we look at the program areas that were most frequently cited, we see that the newborn screening program's immunization and vital records were the top ones. And this sort of documents the level of activity by program areas reported by the respondent.

And this finding about which program areas were most frequently integrated wasn't really surprising to us, because they share some common characteristics. And the first is that they're all recommended as essential services for infants and children. All of these services are carried out in the newborn period. And they're time sensitive. There's possible long-term consequences if the recommended actions aren't performed in a timely action. And both clinical care providers and public health programs share responsibility for their implementation. And that's one of the key points, I think, about the importance of public health agencies and clinical care providers being able to exchange information in order to improve child health outcomes.

In addition, a lot of these services are mandated by State. And we've been involved with one other—one additional research project, and this was undertaken to study how health information exchanges, immunization information systems, and these integrated child health information systems could work together to improve health outcomes.

So right now in the U.S., most providers have access to their State's immunization information system separately as a stand-alone system. And many areas with the health information exchanges are working to do the same thing that we're trying to do with the integrated information systems in public health, and that's to consolidate information and deliver a more integrated view of patient data at the point of care.

So the Public Health Informatics Institute, where I work, worked with the Regenstrief Institute in Indianapolis to try and answer the question about—"Can these entities work together, in this case specifically to improve immunization practice?" And as far as we know, this kind of work hasn't been done at other places in the United States.

So the project documented data flows and the business processes required to exchange and synchronize immunization information across the electronic health records; the health information exchange; and the IIS, the information system for immunization. And this project really uncovered a lot of the complexity that goes on with policy, legal, and technical issues required in creating such an integration and documented

this in a report. And the plan right now is to vet that report as a way to advance the national discussion on how to address some of these challenges.

And the other research that I talked about will be published—the survey that we did will be published in the *Journal of Public Health Practice and Management*, I hope, in November. And that's a summary of the research that we've done.

**Gretchen Noonan**

Great. And I believe that you have your contact information there for folks if they want.

**Debra Bara**

Thank you. I do.

**Gretchen Noonan**

Great.

**Debra Bara**

Yeah, and I'd be happy to answer any questions during or after the presentations.

**Gretchen Noonan**

All right. Thank you so much, Debra. I appreciate it.

I'd like to introduce our final speaker for today, and that's Ellen Amore from the Rhode Island Department of Health. Hi, Ellen.

**Ellen Amore**

Hi. Thanks and greetings from Rhode Island, everybody [laugh].

**Gretchen Noonan**

I know you want to talk about the KIDSNET information system today. So what—why don't we start with the—what is the purpose of KIDSNET?

**Ellen Amore**

Basically, KIDSNET is an example of a State public health program that integrates and exchanges children's preventive health care information. And we share it with authorized users to make sure that all kids receive public health services.

**Gretchen Noonan**

Okay. So it's not an electronic medical record, like you would—

**Ellen Amore**

It is not. It is a public health program.

**Gretchen Noonan**

Right, okay. And so, why did Rhode Island decide to create this integrated child health information system?

**Ellen Amore**

Well, back in the late '80s, early '90s, our Maternal and Child Health Title V Director had many requests for developing new or improved data systems, including a push at the national level to develop an

immunization registry, which Rhode Island did not have at the time. The families and health care providers were telling us that they were frustrated with the communication and access to information coming in to them from multiple categorical programs. So pretty much, we pooled the limited resources we had and created an integrated system.

**Gretchen Noonan**

Great. And you know, what public health programs are affiliated with KIDSNET?

**Ellen Amore**

Currently six programs send data in on all children that were born or receiving universally required services in Rhode Island. And these are the birth certificate, the three newborn screening programs, immunization, and lead screening. And then, for those who participate—WIC; Early Intervention, which is our Part C program; and home visiting program—they send data to us directly. The birth defects and foster care programs send info to KIDSNET, although most of that, users cannot—most users cannot see that information.

**Gretchen Noonan**

Okay. So we know who's sending you information, but in what form does the information come in, or where does the KIDSNET data come from?

**Ellen Amore**

The KIDSNET—it basically comes in in a hybrid way. Most of the data comes in electronically from the various maternal and child health programs, and then KIDSNET warehouses selected fields from those program databases. A few programs, like the immunization registry, actually have their whole database built into KIDSNET. And then, in addition, primary care providers send immunization data electronically from their electronic medical records, or they send it in on paper for data entry here. And audiologists can enter diagnostic information themselves directly into KIDSNET if they choose to do that, or they can report on paper as well.

**Gretchen Noonan**

Okay, great. And now, who uses the information that comes out of KIDSNET?

**Ellen Amore**

That is a growing list. We have various different categories of users. Mostly they're maternal and child health programs, and they're community partners that help them coordinate and assure public health services.

**Gretchen Noonan**

Okay. And as you just put that up there, what sort of information is available on each individual child through KIDSNET?

**Ellen Amore**

Well, we do have this sort of child health profile that Deb Bara talked about. And the information available from the entire child health profile depends on the actual users' profile—what they're allowed to see. So you can see on the left-hand bar—users will see various different data categories that they're—that they actually are allowed access to on—from their profile. What you see up here is a primary care provider's profile, so they have access to quite a bit of information, but other users would have a smaller list in the profile that they could see. If a category is grayed out, that means there's no information available in KIDSNET for that particular child.

**Gretchen Noonan**

Okay. And I know you're going to show an example of detailed data that's part of a child health profile; is that correct?

**Ellen Amore**

Right. So if they go to that left-hand bar, they can then click on any one of those categories to get more details. So here's an example of—if they clicked on the hearing assessment tab, they would come to some more details. They would see the newborn screening results, recommendations and risk factors from the newborn screening, as well as diagnostic audiology test results and information about the tests that were done. If they actually were an audiologist, they would be able to enter new data right in through the screen.

**Gretchen Noonan**

Excellent. And these can be printed, correct? You have a summary report?

**Ellen Amore**

Yes, all of the screens can be individually printed as well as—we have a summary screen, where they can get an overall summary that includes the information that they have access to, or—this is an example up here now of the newborn summary report. A lot of times, primary care providers don't always have the maternity hospital information—the discharge information when an infant shows up for care in their office. And this printable report summarizes the newborn screening, immunizations, and home visiting referrals that occurred prior to discharge.

**Gretchen Noonan**

Okay. And from your experiences thus far, what are some of the benefits of data integration?

**Ellen Amore**

We—there are numerous benefits. Some of them include the ability to look at populations. So obviously, from public health, that's very important—not just looking at individuals. We can look at all kids in a particular provider's practice or who live in a town or, of course, at the statewide level. We've definitely increased our capacity for outreach—the collection of demographic information that we can share so people know race, ethnicity, and how people live—those kinds of things. And if one program finds out that a child has a new address, that then gets shared so that we're able to maximize our capacity to reach kids and their parents.

We've been able to do—like I talked about earlier, the providers wanting to have a single point of access for—to look at the information and to communicate it for the most typical programs that are part of maternal and child health. And so, that's been very beneficial. And then we're able to support the different maternal and child health programs in medical homes out in the community.

**Gretchen Noonan**

And we're going to come back to medical homes in a minute, but first I was wondering if you could tell us about some of the challenges that you faced with integration?

**Ellen Amore**

Sure. Challenges are many [laugh], as with anything. It's really been a challenge to make and market our business case to the various different categorical programs—and we got a lot of assistance from the Public Health Informatics Institute around that—and then to be able to take those categorical programs and blend the different funding streams in an integrated product. So that's something that we've had to

deal with and we continue to do. It's also been a challenge to acquire and retain expertise in a State personnel environment, particularly around the information technology area.

The reason we're not convincing people, or providers in particular, but also other programs, to use KIDSNET to its fullest—the sort of meaningful uses of the system—but to actually go in and use it to its full potential—was a challenge, particularly in the beginning. And we ended up developing a provider relations model, similar to the drug company reps that go out. And those provider relations representatives go out, and they train providers and other users and help promote KIDSNET and help them understand what the full potential is.

Data quality and data standards are things that we—issues that we work on constantly. The matching and deduplication of the system, getting the data in there in a timely way, making sure it's accurate, and a way we can communicate with electronic medical records—that's all a challenge that we work on regularly.

And then I would say magical thinking is a big challenge that we face, in that—what I mean by that is, there's this sort of magical thinking on the part of many around the willingness of very, very busy people to actually use and contribute data to the system. And just because we build it doesn't mean someone will use it. There's a lot that needs to go into the marketing and the training on the system and the incentives for people, because we're all struggling to try and manage our time.

**Gretchen Noonan**

And how do you use this KIDSNET data to impact or measure population health?

**Ellen Amore**

The actual uses of the data are endless, and we're always having a great time using it in new and inventive ways. But besides use by the medical homes, which has been a primary initial emphasis, we've developed newborn screening and immunization quality assurance protocols. We've helped with program evaluations for various different programs using the data. We have school entry forms that doctors can use to get kids into schools, to print out when they don't have an electronic medical record that prints out a prepopulated form. We've also looked at various medical home characteristics in our State.

**Gretchen Noonan**

And if you'd like to continue with medical home here, can you give us some examples of measuring the medical home indicators?

**Ellen Amore**

Sure. With KIDSNET, it's really—there's a number of indicators, but KIDSNET is best-suited to look at really the—how continuous and comprehensive care is, since we're collecting services that kids have received.

**Gretchen Noonan**

Okay. And you have some measurement of medical home at the statewide level from the integrated data?

**Ellen Amore**

We do. One of the fun ones that we've looked at recently was—we took a look at some key immunization and lead screening services in one birth cohort. And taken separately, those services have good statewide coverage rates, and we're doing very well, and we're very proud of that. But when you look at it together, you see that only about a quarter of this particular birth cohort had every single service by the recommended age, so that clearly there's room for improvement in terms of getting every kid all the

required services on time. And so, that's just one kind of fun way that we've looked at it, and then there's others that we've done as well.

**Gretchen Noonan**

I want that graph [laugh]. And it's a good way to end right now. Ellen, thank you so much.

**Ellen Amore**

You're welcome.

**Gretchen Noonan**

And I'm sure that the audience appreciates hearing from your experiences today, and I'm guessing they'll have some questions.

I'd like to, again, thank all of our presenters, Kelly and Debra and Ellen, for the great information that you've provided. And we're now in the question-and-answer portion of the program. And I see that we've gotten quite a number coming online here, so—and we did end a few minutes early, so we might have time for a few extra questions more than we usually do.

As I mentioned at the beginning, we're taking questions online and on the telephone. To post a question online, you just enter your question in the field at the bottom of the questions box there on the left and hit "Enter." And our Operator Latanya, are you there?

**Operator**

Yes, I'm here.

**Gretchen Noonan**

All right. Can you tell any of our telephone participants how they can ask a question on the phone?

**Operator**

If they would like to ask a question on the phone, they just press star-1 on their telephone keypad. And if they're on speaker phone, they will have to pick that up and press star-1 to enter into the queue.

**Gretchen Noonan**

Okay, so star-1 to enter into the queue. And while people are doing that, I'd like to introduce my colleague, Jennifer Decker. She's with us to help moderate the online questions that are coming in. Jen, do you want to start off with one of the online questions from our audience?

**Jennifer Decker**

Absolutely. Thanks, Gretchen. We have a question from Jeffrey: "Will standards for electronic health records be established so that health systems can cross-communicate?"

**Gretchen Noonan**

Would Kelly or Debra like to answer that?

**Kelly Cronin**

This is Kelly. I can start to answer that. We have been working over the last 4 years to harmonize technical and—the different types of standards that are needed to both communicate information and also make sure that you use sort of consistent terminology, such that information can be interpreted from one computer to the next. So we have had that effort going on for 4 years, and we're now in a phase where we're going to be regulating that there be compliance with these standards. And initially, they will be very

much tied to sort of eight areas that are identified by statute, but also really connected to what's important to achieve meaningful use of electronic health records. So there's a lot of work that has gone on in recent years, but there's now a much more focused effort to figure out what specifically will be required for interoperability—so sharing of information across health care providers, across public health, but also really tied to this concept of meaningful use.

**Gretchen Noonan**

Great, okay. Jen, do you want to go ahead with another question from online?

**Jennifer Decker**

Absolutely. "How can MCH makes sure it becomes part of the State HIE program activities in their respective States?"

**Kelly Cronin**

I would say that contacting your State Health IT Coordinator is one way to ensure that the priorities are addressed. I think I mentioned that there are requirements to make sure that child health is addressed in the plan and the applications. So they should be looking to—the State Health IT Coordinator should be looking out to reach—reaching out to the maternal and child health contacts in their State. To the extent that they're not—or perhaps these individuals are just getting identified—they may not have had time. So I would try to—if you haven't been actively engaged, try to find out through different contacts in your Department of Health who is the really big key point of contact either for the Governor or for the Department of Health to play that coordination role, because in order to be an eligible applicant for this cooperative agreement program, they have to have someone appointed. So they're—if they're not identified yet, they will be by October 16, or at least a temporary person should be identified by the time of the application. So I would just encourage people to be proactive about reaching out to them.

**Gretchen Noonan**

Great. Latanya, do we have anyone on the phone who wants to ask a question?

**Operator**

No, we do not have anyone on the phone line as yet.

**Gretchen Noonan**

Not yet. And that was star-1, correct, to get in the queue?

**Operator**

That's correct.

**Gretchen Noonan**

Okay. Thank you. Jen, why don't you go ahead with another question from online?

**Jennifer Decker**

Great, thanks, Gretchen. This is a question for Ellen: "In KIDSNET, what access do parents or patients have to their data? Is there a mechanism for communication between patients and providers?"

**Ellen Amore**

At this point in time, the only access that parents have to KIDSNET would be through their primary care provider so that they could ask their primary care provider, "What information is available on KIDSNET on my child?" And part of our agreement with the provider is, they are required to supply that information to the parents. We also communicate with parents when their child is enrolled in KIDSNET so that they

make sure that they know that they're in the system and that they also have the right to opt out of the system. But at this point in time, we have not given them direct access to the information, and primarily that's been because we didn't have an easy way of authenticating who the parent was, and so initially we never set it up that way. We do, on the long-term planning, have that under consideration, but we haven't done it yet.

**Gretchen Noonan**

Okay, great. Jen, do you want to go ahead with another few questions?

**Jennifer Decker**

Sure. "Ellen, can you track an individual child's progress on your system?"

**Ellen Amore**

We can look at an individual child and see what services—that they have had and that they have not had, if that's what you mean by "tracking an individual child." So we can also see when they will be next due for an immunization, so we have the—an immunization algorithm that looks at what immunizations they've had, when the next ones are due, and which ones are overdue.

**Gretchen Noonan**

Okay. Jen, would you like to read another one?

**Jennifer Decker**

Sure. "What is the relationship between the child's health profiles that were demonstrated and an electronic medical record? How are each used?" [Pause] Is that question [laugh, indiscernible]?

**Gretchen Noonan**

Anyone can speak—go jump right in [laugh].

**Ellen Amore**

Well, the child health profile that's in KIDSNET is the health profile from a public health standpoint: that we have an integrated set of information on that child. What would be in an electronic medical record might be considerably more information at the provider's office that has information that is every lab test that they've ever had and, I don't know, what medications they're currently on. So in our child health profile, we just have certain selected public health pieces of information. And those—the electronic medical record sends information to KIDSNET for that, and the users can look at it. And ultimately, as the health information exchange activities in Rhode Island progress, we may—there may be much more of the bidirectional exchange of information between the individual record at a doctor's office and what's in KIDSNET. Also, in KID—in the electronic medical record, just the doctor using it there has access to that information, whereas within KIDSNET, the child's health profile is available to all authorized users at various different locations throughout the State that are responsible for helping coordinate care and provide services for these kids.

**Gretchen Noonan**

Great. I'm sure that a lot of people were hoping for that clarification, so that's very helpful. Latanya, do we have anyone on the phone?

**Operator**

No, we do not have anyone on the phone.

**Gretchen Noonan**

No? Okay. We have a quiet bunch, but we have plenty coming in online. So Jen, did you want to read another question or two for us?

**Jennifer Decker**

All right. We have a question for Kelly: “When will the workforce program applications be sent out?”

**Kelly Cronin**

Well, we have not yet announced the workforce program. So once it is announced, there’ll be a clear time line associated with the application process. So I would just keep a lookout from ONC, and there likely would be press releases around the announcement, and that should provide you with the information that you’d need.

**Jennifer Decker**

Okay. We have a couple of questions for Ellen about assigning IDs, and I’m going to do my best to combine them: “You have several agencies that are linked in or hoping to link in. What ID numbers do you use to make sure everyone is on the same page, and how do you ensure confidentiality?” And one person asked if you’re still using probabilistic matching.

**Ellen Amore**

Okay, that’s—so there are several questions. Let me just write those down. “Probabilistic...” [Pause] Okay. I’m trying to take those in that order. So in Rhode Island, as many other places, we had a lot of discussions about a unique child identifier and master patient indexes and ways to link, etc. But KIDSNET has been around since 1997, so we—there—a lot of that discussion hadn’t even begun at the national level. And as we had discussions here, it became more and more clear to us that those discussions were going to go on, and we needed to forge ahead in the meantime.

And so, what we ended up doing was, we collect every ID that comes in as far as our linking. We—if it’s coming from a program, we collect a program ID numbers; if it’s coming from a doctor’s office, we collect medical record numbers or—I mean—or the hospital—we collect medical record numbers. And we keep all of those within KIDSNET so that when we get future communication from those systems, we know what the program ID number was, and it helps us match. But we do try and match on the usual demographic information: the name, date of birth, the mother’s name—we look at address; we pull those in.

And we do have a probabilistic matching. We have deterministic matching, which—for those who don’t know, that means exactly—the first name matches, the last name matches, the date of birth matches, and the program ID numbers match. But probabilistic matching is a more sophisticated way of looking at it, and we do do that as part of our matching, where if it’s a definite match, there’s a very high probability—you know, top 20 percent or so—that this is a match. The match gets made automatically.

If there’s a very, very low likelihood that this is a match, like “No way; there’s different date of birth, different name; this kid just doesn’t exist in KIDSNET,” then we automatically create a new record for KIDSNET. And for those that are in that little gray area, where it’s not definite, I mean, one way or the other, then we have to have human review of those. So obviously, those are the most costly to us in terms of the matching, but we do do that.

And then I think there was a question about confidentiality. And confidentiality is maintained through—we have the Confidentiality of Health Care Act, which allows us to share this information for the purposes of care coordination, but—so that anybody who’s involved in care coordination for a child has the right to this confidential information. We have disclaimers on the screen when you log in to say that you accept

that this is confidential information. And you know, they have to—by u—by logging in, basically you're accepting to keep the information confidential for the purposes that are in the agreements. And then each program and user has an agreement with KIDSNET that they sign so that each program is only allowed to use it for the purposes listed in their agreement with us.

think I got everything there [laugh].

**Gretchen Noonan**

Is that all of it, Jen? [Pause] Jen, are you there?

**Jennifer Decker**

Yes, I'm sorry.

**Gretchen Noonan**

No, that's fine. You want to—I think Ellen covered everything there, so if you want to, go ahead with another question.

**Jennifer Decker**

Great. "There is no commercially available product that can accommodate public health and primary care data. For example, our local health departments deliver primary care as well as more traditional services, and interoperability of these datasets is needed. What is being done at the national level to facilitate this?" [Pause]

**Gretchen Noonan**

Again, any of our presenters can feel free to jump in. Is Kelly still on the line? Kelly, are you there?

**Kelly Cronin**

Yes, I'm sorry; I got distracted. But I think they're talking specifically about the lack of an electronic health record; is that right? I do think that there are some electronic health records that are attempting to capture data that's relevant to both clinical care, primary care, and public health needs. And CCHIT has been working on a certification process specific to child health, so I think, in that process, they've been contemplating needs relevant to growth charts and immunizations. And as those requirements get rolled out, you know, there should be a higher bar than to be—if you want it to be a certified electronic health record in a primary care practice that offers pediatric care, then, you know, they would be looking for sort of the baseline requirements that would be needed for both the clinical care and public health aspects of pediatric care.

So while I think maybe there aren't, perhaps, immediate options known to the person who posed the question, I would encourage them to look a little bit harder about maybe what—check CCHIT's Web site as to what would be the current certified EHR vendor list. I don't know exactly where they are in their child health module. I haven't looked—or haven't gotten an update on that in a bit. But certainly, the meaningful use criteria relevant to immunizations and other public health requirements will also drive and create a higher bar for the certification process relevant to public health and primary care.

So I would continue—I would just encourage them to look for options among vendors bef—and also make sure that the requirements are explicit. And if they're not the purchasers, then whoever is the entity acquiring that electronic health record—for them to be very clear about what their business needs are as they shop around from vendor to vendor. And they're more likely going to get what they need if they're very clear about their business requirements.

**Gretchen Noonan**

Great. Thank you, Kelly. Latanya, I just want to check in with you one more time and see if we have anyone in our phone queue.

**Operator**

No, we do not have anyone at this time.

**Gretchen Noonan**

No? Okay. Jen, I think we have time for one or maybe two more online questions.

**Jennifer Decker**

Great. “Do you anticipate that data will be integrated through HL7? If not HL7, what technology would be used?”

**Gretchen Noonan**

Ellen, I know you mentioned that on one of your slides. I don’t know if you feel comfortable taking that question or...

**Ellen Amore**

Well, sure. I mean, it’s hard for me to predict what will happen at the national level, because there are various different data standards for use. I know that KIDSNET is using HL7 data standards wherever possible, and we’ve created initially a guide—an HL7 guide for submitting immunization data to KIDSNET. And we’re trying to work on getting a similar thing going for submitting height and weight data and body mass index data—and try and look at what’s available out there. So I’m hoping that that will be the way to go, and—but it’s hard for me to predict.

**Debra Bara**

Gretchen, this is Deb Bara. We also worked last year with a group of folks, including Ellen and probably some other folks that are on the line today, to document the business processes for newborn dried bloodspot screening. And that’s one of the things that we’re working on—HL7 implementation guides—to be able to share the results clinically between laboratories and hospitals—the results of the newborn dried bloodspot screening. And I think this is one the areas where there’s still quite a bit of work to be done, not only in public health but in health care as well, but more so on the public health side and specifically around MCH kinds of services. They’re coming out very slowly but one at a time.

**Gretchen Noonan**

Okay. Thank you. I think we have time for one more question, Jen, if you want to go ahead with that.

**Jennifer Decker**

All right. We have a question from Amy: “Is there any information on KIDSNET that is not accessible to the medical home? And if so, why is it not available?”

**Ellen Amore**

Yes, there’s several pieces of information that are not available. We do a newborn developmental risk assessment that has a lot of information about the mother: you know, the mother’s history of drug use and tox testing during the delivery and those sorts of things. So what’s available to the medical home is a summary of newborn things—you know, newborn risk factors that would include—it would just say “parent characteristics,” but it’s not going to go into a lot of detail, and those are around privacy issues. If the mother has HIV, we leave it up to the hospitals to get, you know, whatever appropriate consents are needed, but we don’t provide that information directly.

And also, foster care information is not directly available to the primary care providers. If they bring them—if a foster parent brings the child in, then they're able to tell the provider directly, "This child is in foster care." But other than that, there's reasons why we don't. Also, information around adoptions are not readily available to everybody, because those are often legal issues that we're not allowed to disclose—things. So for the most part, primary care providers have almost—access to almost all the information.

**Gretchen Noonan**

Okay, great. It is a little after 3 o'clock, so that's all the time we have for discussion today. If anyone in our audience thinks of more questions, you can submit them to the e-mail address on the screen there; it's [mchirc@altarum.org](mailto:mchirc@altarum.org). We will post the questions we had during the Q&A period, as well as the answers to any unanswered questions, on the DataSpeak Web site along with the program archives. And those will be on there in the next few weeks, and we'll get a notification out to you when that's available.

And before we go, we'd like to let you know that we'll be broadcasting several more DataSpeak programs in the coming months, and announcements about these programs will be sent out via e-mail to everyone who registered for today's program. And they'll also be posted on the DataSpeak Web site.

Before you log out, we would really appreciate you taking the moment to provide us with feedback on today's program. You can do so by—I believe you click on the evaluation link there, and a short survey will pop up for you in a new window.

I want to thank our presenters and everyone who had joined us today, and our program is now adjourned.