

**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc - Teleconference
July 6, 2004**

**Topic: “A Bird's Eye View of the Public Health
Information Network (PHIN)”**

TO: Ad Hoc Listserve Members
FROM: Rupa Patel
SUBJECT: Conference call information and agenda.
DATE: July 6, 2004

The next EHDI Ad Hoc teleconference will be on Tuesday, **July 6, 2004** from 2:00 to 3:00 pm **Eastern** time. To join in, call: **1-866-842-6975**. You will be greeted by an automated voice and asked to enter a Passcode. **PASSCODE: 218840 (plus the # key)**. If you have any questions please contact Marcia Victor (MVictor@cdc.gov / 404-498-3035) or Marcus Gaffney (Mgaffney@cdc.gov / 404-498-3031).

An internet based captioning service will be available at no charge during this teleconference if requested. If you would like further information or to schedule use of this captioning service, please inform Marcus Gaffney (MGaffney@cdc.gov / 404-498-3031).

Powerpoint slides will be available soon on the National Center for Hearing Assessment & Management (NCHAM) web site: <http://www.infanthearing.org/checkpoint/cdc/>
Username: cdc
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Agenda

I. Welcome

II. Tom Savel, MD (Centers for Disease Control & Prevention): Public Health Informatics Network (PHIN) Defined -PHIN Standards Working Group.

III. Elizabeth Seeliger (Wisconsin State Department of Health): “PHIN From a State Program's Perspective.”

IV. Questions and Discussion

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>> **RUPA PATEL:** Good afternoon everyone of this is Rupa from the CDC. I'd like to welcome all of you to this month's early hearing detection ad hoc teleconference. The presentation is called a bird's-eye view of the public health information network, or PHIN as it's commonly called.

I'd like to ask everybody to please mute when you're not speaking. Please don't put your phone on hold when you leave the room. Instead hang up and call back. We've had some problems with messages and music coming on when people do that.

There will be a transcript of today's call posted on the EHDI website. And in addition, I'd like to let everyone know there will be a follow-up phone call after this call that will go into more detail with the technical issues of PHIN.

There will be a special topics call on August 24th. Please save your specific technical questions for that phone call.

Today's speaker is Dr. Tom Savel, member of the public health information network standards working group. He has overseen implementation of outpatient medical record systems and development of clinical software for hand-held devices. His presentation is called PHIN defined.

Tom will give an introduction of PHIN and discuss its various components.

Can the captioning service hear me okay? (Yes, I can).

Okay. Without further ado, here is Dr. Tom Savel.

>>**TOM SAVEL: COMMENTS UNAVAILABLE**

For information about PHIN, please visit the following website where copies of presentations from the May 2004 PHIN Conference can be found: <http://www.cdc.gov/phin/04conference/index.htm>

>> **RUPA PATEL:** Elizabeth and Lilah will now begin their talk. After they finish their presentation, we can take questions. Okay. From Wisconsin we have Elizabeth Seeliger, program director of Wisconsin sound beginnings, and Lilah Katcher, who is project manager of WeTrack surveillance systems.

The title of their presentation is PHIN, public health information network, a state EDHI program perspective. Elizabeth and Lilah will discuss the benefits and challenges they have faced in implementing a standards based system.

>> **ELIZABETH SEELIGER:** Thank you very much, Rupa.

To all my fellow state EDHI people, I hope you had a really relaxing Fourth of July weekend and you're going to try to stay with me today. As it's kind of a tough way to get back into the swing of work.

I don't know what Tom's background is but mine is certainly not data system development. So I've started out my presentation with an acronym glossary because it's taken me a long long time to try to remember what all of these different things stand for. At any time during the presentation, you can go back to the first slide which helps to redefine some of the terms that I might slip in and throw in there.

Okay. Wisconsin's EDHI data and tracking system is called WE-TRAC. And it is a part of the Wisconsin Public Health Information Network.

Tom did a really nice job of laying out the PHIN umbrella as he called it. But it's really, the way that we look at it is the PHIN is really a portal into a bunch of different applications that Wisconsin is developing underneath that PHIN umbrella.

Some of the examples of those for Wisconsin is we have what's called a Program Area Module, which is just each different programmatic area has their own data collection system. But again, they all abide by the same standards, and so that we can all have easy access, I guess, if we need to, and share data.

So we have West Nile virus. We have our SPHERE network, which is our MCH data collection PAM. We

have birth defects surveillance, and there's been many others.

So the PHIN helps to bring together the National Electronic Disease Surveillance System, that base system that he was talking about, all of those PAMs, and then we have very close collaboration with our State Lab of Hygiene, which is our laboratory reporting, and our Health Alert Network.

So it's kind of the platform for all of the different systems to work together.

This is the next slide, a really complicated technical schematic of how the PHIN acts as a portal for all of those other modules.

If you want us to go over that after we're done with the presentation, we're happy to do that. It's just in there for reference mostly.

So Rupa had asked that we go over the benefits of being a part of the health information network.

I'm going to start with kind of the generals first and then get more specific.

The biggest benefit that we have found in being part of the PHIN is that you seem to get just more bang for your buck. We seem to have gotten a lot of enhanced technology and enhanced functionality because we're a part of something bigger.

And we also had the opportunity to not have to make a hundred percent of the decisions, the technical decisions, because we had a framework laid out for us.

The positive effect that we have seen on system development is that we have shared resources. So every time you set up a data silo, especially if it's a web based data silo, you have to think about the hardware, the software, the network, security, all of that kind of stuff.

We've been able to share some of that burden across the different PAMs.

Then we have shared functionality. So we have a common user directory. We have commonalities between our reporting mechanisms. And some of the other code that is in our system.

I'm going to talk about how that benefits our users in a little bit.

We have shared policy development which was actually, I think, quite a great time saving. So we have a user agreement and a confidentiality statement, and we had the benefit of Beverly Dozier from the CDC help review those policies.

And now we're looking at using those policies across all of the different PAMs and generalizing them so that we don't have to keep reinventing the wheel for common agreements.

Then we can take advantage, like I said, of predetermined standards without worrying about being out of compliance. So West Nile and birth defects and WE-TRAC all have to look at how they are transmitting data and whether or not that's secure according to HIPAA regulations. We have the ability to function under set standards and protocols that we know are HIPAA compliant. So that's been a huge benefit for us.

Integration obviously has positive effects on cost. I think that we're going to see the benefit of that over the long term. Again the security and network services, software maintenance and upgrades. We had an example of that happen last week where a piece of the software was upgraded or a newer version was installed. And to us and to our users, we never even noticed that that happened. It was all done behind the scenes. But in the long run, it makes, you know, the data transmission faster and it makes the system work a lot better. And that's transparent to us, which is really nice.

The hardware and maintenance of hardware, there are shared servers that were bought for the PHIN network. So far we have not had to pay a hosting fee. Eventually that might happen. Again, we've been told that it's based on use. And our system is a pretty low volume system compared to some other PAMs. So our cost should be less because of that.

And things that we've never even had to consider except to know that it's been done for us and it's secure and it's really good. And that is things like disaster recovery in case something should really bad should happen like the building that the servers are in should burn down or something. We have constant data backups and we have off-site backup. So we feel pretty secure that where our data is going, it's very protected. And that's a really important benefit of the PHIN.

We also have standardized reports and analysis.

Integration has a positive effect on usability. I think that's really important. A lot of the users of our WE-TRAC system tend not to be very techie kinds of people. Some of the nurses who input information into the WE-TRAC system were pretty anxious about having to be on a web based data and tracking system.

But once you get them trained on to your PAM, if they have to use a different PAM, like the health alert network or the NEDSS system, there's so much commonality in the look and feel across the PAM that the users are a lot more comfortable. They don't have to relearn so much. And it also benefits our program staff because many of them had already been trained through the health alert network. So that when we came in

and did the training, they were like, oh, yeah, that's easy, we've done that before.

So there's a reduction in training and technical support needs.

We also have the benefit of having high volumes of user feedback, not only on the WE-TRAC system but kind of on the look and feel of the whole public health information network.

So we feel like it's more solid because we have so many different kinds of users looking at kind of standard systems.

And it really allows myself to look at more of the programmatic needs rather than, again, to have to concentrate on the technical infrastructure and design, because the PHIN folks have taken care of that for us.

Sustainability is probably on our minds with grant funds ending and things like that. So to be part of the health information network has given us a lot more executive buy in. We have a lot of support to make sure that this whole PHIN thing works.

WE-TRAC is a module underneath that. So we therefore have support in making sure that WE-TRAC works, and we feel lucky for that.

We have already gone over the cost sharing.

If you can show that there's cost savings within a larger network, you're less likely to have your system fail or be discontinued or something like that.

And by being able to share data and have common reporting mechanisms, we look to the future to be able to eventually really look across different data sets and to be able to show positive outcomes from each of our different initiatives. But then to be able to cross compare data, we should be able to really get back to our stakeholders and funders and other parties with the benefit that our actual programmatic efforts are making because we have the ability to track outcomes and to collect data really effectively.

So that's kind of the really general overall benefits that we have found in being part of the PHIN network.

One of the things that I didn't say was that we were able to use some of that BioSense money that you heard about earlier to actually buy some of our rural hospitals computers and to get them hooked up with Internet connectivity. Because again, the larger network, the PHIN network, needed to be able to gather real-time data from those entities.

So we didn't even know that that was happening, but by the time we got out there to train them on WE-TRAC, we found out that they, that they already had the computers, they already had the connectivity, which saved us a big headache. So that's just another example of how it's been beneficial to be a part of the PHIN.

Next I'm going to go into a little bit how WE-TRAC fits into the CDC PHIN, architectural specifications and standards. A really big mouthful. I'm going to try to keep it not very technical. The slides can get kind of technical. So if you have questions about something that's on the slide that I don't go over today, please feel free to e-mail me or Lilah.

So, each of the slides, I want to explain the structure to make it easier to understand, has the same title of how do WE-TRAC, how do WE-TRAC, implement the standards. Then there's an italicized statement. And that is the actual PHIN standard. Then bullet points are how we track within that standard.

One of the standards is there needs to be manual data entry for event detection and management. We have all kinds of points at which we have data entry into the WE-TRAC system.

So we use the blood card as our main transmission of initial screening data into our system. So hospital staff manually enters that information on the blood card, goes to the state lab of hygiene where they manually enter the results into their database. Then WE-TRAC users can manually update that information and enter test results for outpatient screening and diagnostic audiology. So they can make online referrals and enter test results via the WE-TRAC system.

WE-TRAC also exceeds the standard by automating event detection so that if the event is that a child does not pass their newborn hearing screening, that referral will go into a hospital's queue, and there will be an e-mail message that generates to alert the hospital that that event has occurred.

The next PHIN standard is that there's directories of public health and clinical personnel. And I had alluded before to the fact that we have a shared user base.

That's somewhat correct. We do have some shared and common users across the PHIN and birth defects and some of the other PAMs. But we also have very unique users in that audiologists tend to first be coming onto the network because of WE-TRAC. But if for whatever reason there's an outbreak, as meningitis or something like that, and they want to know which audiologist has seen kids for hearing loss as a result, that would be information that might be available to the greater public health information network.

Probably the most important part of this slide is that, again, we have access to all of the WE-TRAC

nurses. But we also have access to the greater PHIN and user directories.

So if we ever needed that, we do have access to that.

>> **LILAH KATCHER:** I'm going to jump in at this point. And that is that one huge benefit of being integrated with the public health and clinical health directory of the PHIN is that the PHIN staff do some of the administrative work. And authorizing and giving someone initial access to the PHIN. So that takes some time in that area off of WE-TRAC program specifically. Thanks.

>> **ELIZABETH SEELIGER:** That's a great point, Lilah, thank you very much for jumping in on that.

The next slide talks about the automated exchange of data between the public health partners. WE-TRAC those out. We have automated messages from our state lab of hygiene to our University of Wisconsin that houses our servers and our databases.

And the messaging technology meets the CDC standards so that if, for example, CDC decides that they want us to message information on the incidence of hearing detection in Wisconsin someday, we will hopefully have the mechanism to be able to do that very efficiently.

Methods data is available to us at the programmatic level as well as to all of our users, physicians, audiologists, and eventually birth to three program.

And it's all using kind of the similar mechanism. So it's very flexible and can be change pretty easily depending on need.

The next one is management of possible case and contacts. And of course that's what we really want to be able to do, is to find out how these children are progressing through kind of this complicated continuum of hospital screening all the way to early intervention.

So WE-TRAC does allow for pretty sophisticated case management. The options vary with the user role. And what that basically means is, first of all, what is your job title, are you an audiologist or are you a hospital nurse or are you in an NICU.

Then we have also three levels of use of the system. There's just the user in the hospital, then there's usually an administrator at that organization. So there's one person that's in charge of making sure that staff are using the system appropriately.

Then there's WE-TRAC administrators, which is myself and Lilah, who are able to kind of look at all of the parts of the system.

We can track provider contacts such as screening, transfers and referrals. And one of the documents that I included was a child's chart. If you look at that, you can see that we can track, we can find out where the baby was born, where the baby was screened, what day that they were referred for outpatient screening on. We can track transfers, in and out of NICU and back and forth between organizations.

So the benefit is that if a child gets stuck in the system, if they have been rescreened but never made it to diagnostic audiology, we have the ability to see who was taking care of that child last and who should be taking care of them in the future.

The secondary benefit is that we can track which providers have experience with caring for a child with hearing loss. We haven't done anything with that information currently but there's been a lot of asking from parents who have kids who are deaf and hard of hearing, do you know of a physician in my area that's ever dealt with a child who uses sign language or things like that. So in the future, it gives us that ability.

We also have a confirmation of hearing loss and referral form which gives us a lot of information that's necessary for tracking and follow up.

And we also have a medical home pop-up so we can see really pretty good information about who the current primary care provider is. And we ask for that information to be constantly updated.

Next one is public health information dissemination and alerting. Again, we have the ability to generate reports to stakeholders. We have e-mail notification that can alert users to new efforts.

We have time-out alert so if a child gets stuck in a part of the continuum and we don't get information that they have moved on and that somebody else has taken responsibility for them, there's a time-out alert, electronic referral alert.

If a clinician enters a refusal of hearing related care, an automatic alert in the form of an e-mail will be sent off to the child's medical home so that the PCP will know to follow up.

And then Lilah and I have administrator queues which allow us to also have alerts set up for lots of follow-up and other kinds of events.

Analysis and visualization. This is one of the great benefits of being part of the PHIN because there's

pretty complicated reporting functionality that's part of the PHIN service.

We're in the process of looking at that reporting functionality. We have what's called level one reporting functionality right now which means basically we have tables of semi-canned reports with pop-up definitions.

And I have included one of those as well, which includes hospital birthing unit as compared to the statewide average.

We have reporting for each of the different kinds of organizations. So if you're an audiology organization, then a specific kind of report would be generated for you.

But because we're a part of the PHIN, they have looked at developing common functionality across the PAMs that will allow us to do much more flexible reporting and really look at our data much more closely, such as drill down reports which would allow us to put in specific criteria, for example, if we wanted to know how many kids were born with profound unilateral hearing loss maybe in the right hear or something, we would be able to drill down that way to get that kind of a report.

And then again, there will be access, hopefully, to charts and graphs as well as global information systems, which would allow for that sort of map to see where there's pockets of kids with hearing loss.

Those are things that we would probably not be able to afford to develop ourselves with just, you know, with just CDC funding to the EHDI program. But because we're a part of the PHIN network, we can be, you know, involved in setting that up so that it meets our needs as well as the birth defects registry's needs, as well as the server or PAM'S need.

Again, that's kind of something that we get because we're part of the PHIN network.

IT security, critical infrastructure. Very detailed standards came out from the PHIN and the health alert network about security and the infrastructure. And again, WE-TRAC has been able to take advantage of a really thorough security infrastructure that was created for the PHIN. And there's some different security jargon underneath.

We have gotten a ton of benefit from being connected with the PHIN. Also some challenges. Some probably very similar to what any other program that's developing a data and tracking system goes through.

But specific to being part of a much bigger network is that we all have to share resources. So the benefit of sharing resources, you get to develop one piece of code that actually fits amongst all of the different PAMs or some of the PAMs, and you don't have to pay to redevelop that code. But the challenge is that you also have to develop some sort of sharing of knowledge between programmers, you have to share the programmers themselves as the PHIN grows and grows and grows. It's almost hard to keep up with the staffing needs as far as the IT staff goes to be able to develop all of the different PAMs.

Overall system stability, that's getting much better. I have that the PHIN is evolutionary, not revolutionary.

Basically what that means, the PHIN is developing over time. And as changes are made to the PHIN, sometimes they trickle down and affect our small little PAM.

And so there needs to be really consistent communication between the people at the PHIN and the people who are working on the HON, and us who are working on WE-TRAC, both coming down from the PHIN and then coming up from WE-TRAC.

For example, if we have a system demonstration and they are planning on taking the whole PHIN down for an hour so that they can, you know, upload a new version or something like that, it's difficult because we may not know that that's happening or we may not have told them that we have a demonstration.

So that's getting better. But that's probably the biggest challenge. The bigger the system gets, the more critical communication is and the harder it is to keep all the players informed and on the same page.

In order to take advantage of things like the system development pieces or if you want to make sure that you're not developing a piece of code that somebody else has already developed, you need to have coordination. You also need to have communication so that you can let people know, oh, I'm working on this. I think that your PAM would fit really well into here.

Like I said, that's getting better.

So, we're going to continue to prioritize amongst and then between the PAMs.

That's important. And then coordinate careful change management. It's easy to say we want it this way and then to find out that that doesn't exactly mesh with something that somebody else is doing. We have to be careful how we change things.

And then we're just, again, trying really hard to implement effective ways of communicating with one another to make sure that we all work together, which is really, I think, the ultimate goal of the PHIN, is to make sure that all of these different program area modules are able to communicate and work with one another, and that we can share resources really effectively.

That's all have I to say. If anyone has any questions, I'm happy to take them now or to receive e-mail.

>> **Unknown Speaker:** This is Shelby ??? in California. I really enjoyed that. I think you've done a lot of work in putting this together. It sounds very exciting.

I had a question about reporting cases of deafness. Sounds like at the moment you have a good forward tracking system for children who fail the hearing screening program. But do you have anything on the back end where audiologists will send you reports when they diagnose cases of deafness even if they didn't come through the infant hearing screening program?

>> **ELIZABETH SEELIGER:** Yeah, I'd be happy to respond to that.

We have, I think you have a sample of our confirmation of hearing loss report form. And that is made electronic. So that if you go through the WE-TRAC system, there is a way to enter all of that information right into the system. And it doesn't look anything like the piece of paper that you have in front of you.

>> **UNKNOWN SPEAKER:** Right.

>> **ELIZABETH SEELIGER:** Instead it's automated.

However, audiologists do also have access within the WE-TRAC system to something called the forms tab. They are able to get onto the system and submit a confirmation of hearing loss form from the system or from outside of the system by just saving it onto their desktop and submitting it.

We are looking at the next year of developing something called the cast add function where we'll be able to search the system, see if the baby was ever in our system, and if not, add all of that information separately.

Does that answer your question?

>> **UNKNOWN SPEAKER:** Yes. And do most of your audiologists, are they set up to do this? Are they part of the network?

>> **ELIZABETH SEELIGER:** Well, we have been in pilot for just a year or so, just getting all of the kinks out of the system. And we've been in pilot with about 11 hospitals. And their audiology staff and a few primary care physicians. We're looking at going statewide at the end of the summer. However, the audiologists do have the confirmation of hearing loss form and have been using it for a while now.

>> **ELIZABETH SEELIGER:** Thank you.

>> **UNKNOWN SPEAKER:** I have a question. And actually, maybe Tom can have some recommendations.

What, who, or what division, is there a central organizer, decision maker for PHIN, assuring that all the people are at the table when major changes are occurring.

Our challenge is between the birth defect, the blood spot, the hearing, NEDSS, we're spread across divisions. We're spread across cities and buildings. And no one person is our champion.

So how do you guys do that?

>> **ELIZABETH SEELIGER:** I can definitely share our perspective, but I'm not sure that it will be the same across all states.

I think that we were actually very lucky. We have one man named Larry Hanrahan, who started out in, boy, Lilah, if you know, please jump in. He was involved officially in the national electronic surveillance system, some the NEDSS effort, and was the PI on the grant for the bioterrorism money. That came from CDC. So whoever was the PI on that grant might be a good person to start out with.

And then he's been setting up sort of steering committees and making sure that people are all on the same page.

But we had stars in alignment because WE-TRAC was one of the very first PAMs to kind of get going within our health alert network before it was even the PHIN.

So we were able to really make the system work for us, I think, because we were one of the first horses out of the gate.

However, there's been, you know, there's been some drawbacks to that as well in that we had to kind of invent the wheel the first time. And all the other PAMs have kind of been able to take advantage of that.

>> **RUPA PATEL:** Can you say that one more time.

>> **UNKOWN SPEAKER:** One of the groups that will use this, hopefully, would be physicians.

>> **ELIZABETH SEELIGER:** Right.

>> **UNKNOWN SPEAKER:** How much input have they had?

I know in our state, I think we could have done a better job in finding out what would work for them before we designed.

>> **ELIZABETH SEELIGER:** Right. We actually have tried very hard to get physician feedback. And that usually comes mostly through our advisory committee where we have a family practice physician as well as a pediatrician, or EDHI champion, and the physician that works here.

But the module that's been created for our physicians is not yet fully developed. We have a medical home, a way to keep medical home information and a way to alert the medical home if the follow-up care is needed.

We also have just in time information that we've developed that can be sent along as part of WeTrack or can be accessed by the physician, so right at the time they get a referral or get a confirmation of hearing loss for a child that's in their practice, they can access information about what the next steps should be or what they should be looking for.

So I think that it's not the most developed part of our system, and we'll be looking into enhancing that as we go. But I think it's pretty good. And the physicians that have had feedback on it seem to really like it.

Now, the thing that they would like even more is that if, as part of the public health information network, they could access the whole child health profile. And we are not at that point yet in Wisconsin, although we'd like to see it.

>> **UNKNOWN SPEAKER:** You mean like immunization, hearing.

>> **ELIZABETH SEELIGER:** Right, blood spot.

>> **UNKNOWN SPEAKER:** Blood screening and genetic.

>> **ELIZABETH SEELIGER:** Yeah. We would like to go that direction. That seems very consistent. If there's a way to allow a physician to have a peek at all of the information on a particular child like that, that they would be much more likely to use the system than if it doesn't.

>> **UNKNOWN SPEAKER:** I'm a chapter champion, and that's what I hear from my physicians in Oregon too.

>> **ELIZABETH SEELIGER:** Yeah. Or if there's a way to develop a module of their electronic, I don't know what they are called. They basically don't have paper charts.

>> **UNKNOWN SPEAKER:** Electronic medical records.

>> **ELIZABETH SEELIGER:** Right. If you can make it a module of that, which seems even less likely than trying to make it a child health profile.

Hopefully that answers your question.

>> **UNKNOWN SPEAKER:** Gives me the status. I think it would be a huge benefit if these were more active rather than, you know, passive in their delivery information.

>> **ELIZABETH SEELIGER:** I would agree. And we need to keep our minds open. And we're constantly looking at other ways to make that happen as other funding sources come down, you know, and as other

initiatives come down. We're watching like the autism initiative very closely to see how that might impact physicians.

You know, yeah, I think we have to keep our mind to that goal.

>> **RUPA PATEL:** I'd like to thank our wonderful speakers for presenting on this call and for everybody for calling in.

If you have any other questions, I'll give you Tom, Lilah and Elizabeth's e-mail addresses. And I hope you found this teleconference helpful.

The next ad hoc teleconference is on September 7 at two. We'll send an announcement and information about the topic close to be the date.

Thank you, everybody.

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