

DataSpeak: Vitaly Important: Improving the Timeliness of Vital Statistics to Advance Maternal & Child Health

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Program Transcript

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[slide 1]

Introduction

Ashley Hirai, Ph.D. – Health Scientist – HRSA, Maternal and Child Health Bureau, Office of Epidemiology & Research

Good afternoon. Welcome to today's program, Vitally Important: Improving the Timeliness of Vital Statistics to Advance MCH. My name is Ashley Hirai; I am a Health Scientist in the Office of Epidemiology and Research in the Maternal and Child Health Bureau which is the sponsor of the DataSpeak series.

The data and health indicators collected from birth and death records provide vital information to our public health programs. Vital statistics allow states to track fetal and infant mortality, adverse birth outcomes, maternal risk factors and other important health data. Improving the timeliness of these records is essential to making sure they are most useful for advancing public health efforts in real-time. At the bureau I provide data support to the COIIN or Collaborative Improvement and Innovation Network to reduce infant mortality which is a state-driven HRSA supported effort that depends on realtime data to drive real-time decision making and change to improve birth outcomes. If we want to maximize impact, we really simply cannot wait years to know if a strategy was not successful and needs to be refined, or if it was successful and should have been scaled up sooner. [slide 2] So, timely vital statistics are really key to this effort and **we are excited today to have 3 speakers who will describe how they are working to improve vital statistics timeliness.**

First, **Dr. Patricia Potrzebowski** from the National Association of Public Health Statistics and Information Systems will give us an overview of the efforts underway to make vital statistics more current and useful.

Second **Glenn Copeland** from the Michigan Department of Community Health will present a summary of the work in Michigan to develop provisional infant mortality statistics to inform and monitor prevention efforts as part of COIIN.

And finally, **John Paulson** from the Ohio Department of Health will discuss how Ohio compiles, augments and uses the data in its public health data warehouse. I will now turn the program over to our moderator Sarah Lifsey.

Sarah Lifsey – Analyst – Altarum Institute

[slide 3] Thank you. First, I would like to welcome our presenters and everyone who is in the audience today, thank you all so much for joining us. Before we begin our presentations, I just have a few pieces of brief technical guidance for you all. First, I would like to call your attention to the [DataSpeak website](#) which we hope you will visit after today's program. On the website, you will find [archives of all the](#)

[DataSpeak programs](#) going back to 2000. The slide on your screen shows some of the most recent programs that are available and the address you can use to access them.

[slide removed] I would also like to point out that you are able to download [today's PowerPoint presentations](#) and additional resources directly from the screen that you are seeing right now.

Once you are finished, you may click the continue button to proceed with the presentation.

Timestamp 02:46

Vital for a Reason

Patricia W. Potrzebowski, PhD – Executive Director of the National Association for Public Health Statistics and Information Systems

[slide 4] Hi, this is Trish Potrzebowski. We really appreciate the opportunity to talk with you today about the importance of timely vital registration and vital statistics and what we at NAPHSIS and at the State Vital Records Offices are doing to make improvements in timeliness of this data at the state level.

[slide 5] Vital records are the source of vital statistics data, and they are also the permanent legal records that document life events, births, deaths and fetal deaths, marriages and divorces. The legal responsibility for collecting vital records is a state function—not a federal function—and as such it is governed by state—not federal—statutes and regulations. The 57 vital records offices located in the 50 states, 5 territories, the District of Columbia and New York City, work cooperatively with federal agencies to provide data electronically for specific uses such as aggregating national vital statistics, issuing social security numbers, and promptly stopping benefit payments for deceased persons. NAPHSIS, the National Association for Public Health Statistics and Information Systems, is a nonprofit professional membership association for the 57 vital records agencies in the U.S. Our mission is to provide national leadership for both vital records and related information systems in order to establish and protect individual identity and to improve population health. Working with the jurisdictions to improve the usefulness of vital statistics is critical to our work. We all want to make vital statistics more accurate, more timely, and more accessible for the users of this data.

[slide 6] Vital records have 2 main purposes. The first is for legal and administrative uses such as proof of citizenship, age and parentage. In addition, vital records are used to obtain identity documents such as passports and driver's licenses, and to enroll in benefits, programs and settle estates. This is what the general public thinks of when we talk about birth and death certificates, but as we all know vital records are not just historical and legal documents, they are also the source of data used to calculate vital statistics, public health indicators such as life expectancy or leading causes of death. Because vital records represent people, the accuracy of the information collected as well as the privacy, confidentiality, and security of the records are critical. When you see a report on the number of teen pregnancies or the alarming increase in drug overdose deaths, or racial and ethnic disparities in infant mortality rates, or even the most popular names given to babies, you can be sure that all that data

comes originally from NAPHSIS numbers—the state vital records offices and this is why we say that vital records are called “vital” for a reason.

[slide 7] In 2013 NAPHSIS, with the support of the Annie E. Casey Foundation, released a report called “More, Better, Faster.” This report does not just identify problems, it also recommends improvements to better meet the needs for better quality, more timely vital statistics data that are more accessible and can more effectively be used to plan, monitor and evaluate public health programs. I wish I had the time today to go through all of the recommendations in that report, but I don’t, so I will encourage you to take a look at it on the NAPHSIS website. One key point of the report is that all data improvements require resources. Unfortunately, many state vital statistics offices are fully fee-funded. They receive no state appropriated funds, but their state legislators will not raise birth certificate fees, so obtaining resources can be a serious challenge which is why it is important for us to work with our data users who can help us advocate for better vital statistics. In the next few minutes, I want to quickly review what the jurisdictions in NCHS have been doing over the past 2 years to implement some of the report’s recommendations, focusing primarily on improving timely reporting, analysis of and access to vital records and statistics. Improvements to timeliness of vital statistics data are especially critical for public health data users like yourselves who want to be able to track outcomes and evaluate program efforts as close to real-time as possible. We can provide vital data to users faster by speeding up the process at several points along the way.

[slide 8] Data access as well as timeliness can be improved through the use of mailboxes set up for public health programs as part of the State and Territorial Exchange of Vital Event system or STEVE. STEVE is a secure point-to-point messaging system that is now operational in all of the vital records jurisdictions except American Samoa. It is used to rapidly transmit vital records data electronically between jurisdictions for statistical purposes. For example, when a child is born in a different jurisdiction than his or her mother’s state of residence, or when someone dies in a different state from the one where he or she was born. Cross-jurisdictional exchange of information is especially important when looking at the deaths of infants, because it helps to create a complete match birth infant death file which provides more information than the death certificate alone can provide including maternal risk factors and circumstances around the pregnancy and delivery. This interstate exchange is also critical so that vital statistics rates based on place of residence can be calculated. STEVE is also used by the jurisdictions to transmit vital records data to NCHS and it enables approved state public health program users to access vital records data as soon as they are available, rather than waiting for special extracts or reports to be created by staff in the vital statistics office. If you are interested in becoming an authorized STEVE data partner, please contact your state’s vital records office.

[slide 9] Having all births and deaths registered and processed through the use of electronic systems is another way to improve timeliness. To register a vital event, most, but not all, jurisdictions have electronic birth and death registration systems. Fully 98% of all births in the U.S. are reported to vital records offices electronically. On deaths, we are not quite there yet. This map shows the status of Electronic Death Registration Systems, or EDRS, in the jurisdictions. Currently 45 jurisdictions have EDRS in production; 3 are in the process of implementation: Tennessee, Colorado and Mississippi. One, North Carolina is in the planning stages and only 3 states—West Virginia, Rhode Island and Connecticut—are

not actively transitioning to electronic death registration systems. Electronic death registration systems go a long way toward improving timeliness of death data since the data providers, funeral directors, physicians, medical examiners, and coroners submit data electronically. These systems include extensive front-end edits to help ensure data quality. But just because a state has an EDRS does not mean that all medical certifiers submit data electronically. In many jurisdictions only a small percentage of physicians participate in the EDRS. Nationally, about two-thirds of all deaths are still filed on paper or through hybrid drop to paper systems that are not as timely or accurate as fully electronic death records.

[slide 10] Encouraging all medical certifiers, physicians, coroners, and medical examiners to submit death data electronically is a critical step needed to make vital statistics data more timely. We need to accomplish this step, so that we can achieve the 2016 performance objective to improve mortality surveillance as shown on this slide—a goal 3 initiative of CDC’s new surveillance strategy. To accomplish this objective though NAPHSIS and our member jurisdictions must collaborate with our public health partners both data users and data providers, we need your help. We just do not have the power or the resources to accomplish these goals alone. Vital records data users like yourselves are the best champions for improving vital records, and the user community is most likely to work with us to help obtain the resources to modernize and improve our systems if those improvements will help make the vital statistics data more useful to them. Once we have vital statistics data reported more quickly, the next step is to get that data in the hands of the users faster and in a more meaningful way. And that is also where the use of provisional statistics, which you will hear more about today, can really help. Thank you for the opportunity to bring you up to date on the improvements NAPHSIS and the state vital records offices are making to better meet the needs of maternal and child health and other public health programs for these vitally important data.

Sarah Lifsey

Next, I would like to turn to our second speaker, Mr. Glenn Copeland.

Timestamp 13:22

Provisional Infant Death Data—Recent Experiences and Accomplishments in Michigan

Glenn Copeland, MBA – State Registrar for the Michigan Department of Community Health

[slide 11] Thank you, I appreciate the invitation to talk, and what I am going to do today, is kind of go through the trail we have been following to try to produce much more timely and more accurate information on infant mortality in our state. [slide 12] When we started on this project, it was a couple of years ago, and we were actually going in the wrong direction. Our files had been historically finalized in June which allowed us to produce statistics within a fairly short period of time after that, in early-to-late summer. And then we took several hits. We were revising our systems, developing an EDR, modifying our web EBC, and debugging those systems, and it actually caused problems where the data were getting trapped and our ability to deliver data, despite becoming more and more automated, was

actually slipping later and later out. So, we definitely had a problem we had to get out of, and there were some things that sparked our interest in change.

[slide 13] One is, we had a very much data-oriented governor who was very into what he called scorecards, and he has a website that monitors statistics on all of his major priorities, and of course infant mortality is one, so he found our data so slow that he is using national projections based on NCHS data to display to the public what our infant mortality rate is, which in my line of work is very upsetting, because he obviously could not rely on us. So, it was very much a stimulus to make some changes. And then the CoIIN Project also came around, and it was very focused on making a difference with infant mortality, but also providing those working on the CoIIN Project with timely data on what is happening, and the ability to make adjustments to their policies and their approaches, so a good incentive again. [slide 14] And it turns out the CoIIN measures were pretty basic things. They wanted to know quickly what the infant mortality rate was on more of a real-time basis, neonatal mortality, post neonatal mortality and then getting into cause of death, pre-term birth—those kind of measures.

[slide 15] And in staring at that, we figured we could do something, so we felt that if we really focus in on just what these basic needs are we can do something despite all these problems swirling on around us and develop these rapid estimates with numbers and rates we thought we needed to be able to do that not only statewide, but by county, or by any of our 46 health jurisdictions, and we wanted the data by race. We thought we could also add to that, much more timely data on birth characteristics, and cause of death, things that would help them evaluate what is going on.

[slide 16] So, we definitely had problems and barriers. Our records of death at the time were still being filed on paper as they are today, but we felt there was a way around that. We had problems with our EDR system. We also still are only in testing to get the STEVE system up. STEVE is very important to us—getting those births and those infant deaths that are occurring outside of our state to be able to make sure our data are accurate. , the time, there were also issues where the National Center for Health Statistics had only recently taken over the responsibility for coding cause of death for the full country, but there were problems with the causes of death being assigned, and we were working our way through that problem as well.

[slide 17] So, we have made some progress, and we thought we had the tools to do that. First of all our electronic birth system is very reliable and timely. We get data very quickly, and it's very clean. So that was a very important point, that we had the denominators we needed. We were also already supporting the sudden unexplained infant death surveillance project going on in Michigan by routinely screening all the records as they come through to find infant deaths and forward them on to that group, so we could piggyback on that and, of course, EDR is continuing to improve which improves our ability to find these deaths quickly, and even though the national center had taken over the cause of death coding, we do have a trained nosologist on staff, a nosologist being someone who is trained and certified in coding causes of death.

[slide 18] So just as a little background, this is an old chart, but it shows the long process we went through to get our birth records automated. This is the percentage of hospital deliveries that were using

our web EBC product to record births, and you can see we hit 100% more than a decade ago. But what that means is 99% of our live birth data is available to us within just a few days of the birth. So, that is a handy thing to have. [slide 19] And this is actually showing the progress you can see as we moved from 1998 to 2000 to 2004, the red line shows what happens when you go to a web-based application and that is where we are today. So, that is why we can count on live birth data pretty quickly. [slide 20] Death data is a different story, this is showing the timeline for deaths to be processed and available to us in terms of months from the death, and we have very little data until between the third and fourth month and then further on out the data can trail in for over a year getting into our systems. So you can see the problem that we have with our death registrations, using this as the track that the paper will follow in getting our data together. [slide 21] EDR does a lot to solve that. These are some recent numbers. Our EDR deaths in 2003 are available to us within about 6 days compared to 178 days in 2013. We made a little improvement in 2014 on the paper side, but it is still 134 days on average and EDR is still hovering around 6 days, so it makes a big difference. [slide 22] The other point, though, is that we have a ways to go. As of end of 2014, just over half of all our deaths are being recorded through the system. It is not a mandatory system. We have a lot of selling to do to get people to use it, but we are very close, we think during 2015, to hitting somewhere between 80 and 85%. The best we think we can do, though, is about 85%, so there will always be this lingering problem with deaths that are filed on paper.

[slide 23] So, our approach has been to leverage that birth data and use it. We have real reliable data on births aside from the out-of-state deliveries within 60 to 70 days, and even doing that by county is quite accurate. And in terms of getting our estimates together we are using simply put “brute force” on the infant deaths, we are finding these documents, and we are actually processing them separately whenever we get an infant death reported, so that we are developing kind of a parallel system for these babies so we can do the data very quickly. We do not wait on NCHS, we do not wait on data entry, or any of that, to get our data for the measures we are after.

[slide 24] And we did release infant mortality data for 2013 in April, the first part of April, so just roughly 90 days from the end of the year, and we released a 12-month moving average through March and June, but we did find some significant problems with our first attempt. I am sure you have heard about the problems that Michigan has had, and Detroit has had, and it turns out while we are in the midst of trying to create these rapid estimates our Detroit City Vital Records Office was closed and taken over by the Wayne County Office, and in the process we had some 40 infant death records that were simply lost to the system or they did not materialize until well into the summer. So, we were releasing numbers that looked wonderful, but simply put they were wrong. We are solving those problems monitoring the data to make sure we are not having any gaps like that, although I think that was really the 1,000-year flood, but we do expect to have our 2014 data released in 2 weeks.

[slide 25] So, we do intend to keep doing this on a quarterly basis, and want to work from this point forward releasing essentially a 12-month moving number throughout the year at the state and the county level, and follow it up with more detail once we get cause of death and other birth characteristics by linking deaths to births we can follow up with that kind of information.

[slide 26] So, just in summary, hopefully I have shown that it does not just fall into place, if you truly want an estimate of what your final numbers will look like, it is not as simple as you might think, but there are ways to tackle it if you really focus in on very specific issues that you want to measure, and you have to leverage everything you have in order to do it. But, here again, the directions are all very clear—births have solved the problem—EDR has done a lot to help us pull this off, and it is simply is reducing the workload and the worry that we might not have all the data that we need.

Sarah Lifsey – Analyst – Altarum Institute

Alright, great, thank you so much for that. Just as a reminder, if you have a question for any of our speakers, you can submit it online at any time using the questions form at the bottom of the screen, and at the end of all the presentations, we will also provide a way to ask a question over the phone. So, I would like to turn to our final speaker, Mr. John Paulson.

Timestamp 24:23

DataSpeak: Vitaly Important: Improving the Timeliness of Vital Statistics

John Paulson – Data Center Supervisor – Bureau of Vital Statistics, Ohio Department of Health

[slide 27] Thanks Sarah, thanks for having us here this afternoon, and I look forward to sharing with you some of the things going on in Ohio.

[slide 28] Some of the stuff I want to talk about today, is I just want to give you an overview of our vital stat data collection system. I want to explain how Ohio collates that data and transforms it to useful public health data, and then I am going to describe our technique we use for getting this out to our public health users which is our data warehouse.

[slide 29] Just to show you briefly how these records flow, if you begin in the upper left corner of this slide, you will see that some event occurs—birth or death is what we are talking about today—it would also be fetal death, that data is going to get entered by a provider somewhere maybe electronically, maybe by paper, that entered data is going to be collated in a vital stat system in our state here it is our Central Ohio Vital Statistics Office. Then that data should get augmented in some ways and transformed, I am going to talk a little bit about that, and then that data needs to then be provided back to the users, and then turned into public health uses, so that is kind of what we are talking about today, and trying to help public health data users figure out ways to access that data in a timely way and use it.

[slide 30] So, just to give you some ideas about the time lags in Ohio here, as Glenn said, it is similar in Ohio with births it is very rapid, we are fully-electronic with the exception of home births, and those come in very quickly and they are available for analysis, like he said, within days. Deaths are not so quick, because parts of our processes are still on paper, especially for the cause of death statements. Fetal deaths is completely a paper system in Ohio, so in hospitals where the fetal deaths might occur or out in the field somewhere, the fetal deaths are going to occur that will then generate a paper copy

similar to what we had here 10-20 years ago with all the systems, and then those paper copies come into Ohio into our office for keying and so that is later yet. And then the orange bar at the bottom of this little table describes the difference between our resident deaths that occur in Ohio versus resident deaths that occur outside of Ohio. So, we are in control of the events that occur in Ohio, we have those, we need to get the others from our residents who are born or die out-of-state—those records are going to be owned by those other states—and that is where STEVE comes in it has sped up that process quite a bit, but there is still some kind of mopping up to do at the end of the data year or throughout the year to make sure you have all your records there.

[slide 31] So, just one example, sort of a high-level example of what happens with our death certificates, the death occurs in the upper left, a lot of that is going to get keyed by the funeral director into an electronic system, the demographics and some of the business aspects like burial permitting and things like that happen rapidly from the funeral director, but that then goes to what we call “drops to paper” for the cause for most cases. So, that now is a paper version of the death certificate. That paper certificate gets a cause of death entered on it by the certifier—a physician or coroner—and that flows to the local vital statistics offices where we have over 100 in Ohio, local vital statistics offices, that do their work locally with it and then what we call “file a certificate,” and then they mail the bundles of certificates on a weekly basis to us here in Columbus, Ohio at the central office. We key into our electronic system and reunite the paper information about the cause of death with the electronic record, and send that off to the National Center for Health Statistics from which we get the cause codes, and then at that point, when we get their cause codes back, which is sped up quite a bit with the national center, we get those back fairly rapidly and then once we fold those back into the data, the data is available for use. So that gives you a high-level view of how complicated this can be.

[slide 32] STEVE was already mentioned by Trish, so what STEVE is, is a filter that we as a state can send our records into and it splits it apart, it splits those records into first of all, all the records are going to go to the National Center for Health Statistics, because they are keeping the national statistics and all states submit data to them directly, but also in order to fulfill our need to share our data with states whose residents died or were born in our state, STEVE is a great mechanism for that, because it splits those records out to the states, and they can then pick them up through STEVE. So that has been a huge improvement.

[slide 33] STEVE is also there for, where it has been set up, it is there to help state offices disseminate subsets of their data to the different user communities that have been set up in STEVE. So a state would have to—if you were a PRAMS staff—you would have to get a mailbox set up in the state STEVE system in order for you to receive those records so that you can carry on your PRAMS study.

[slide 34] Now I am going to kind of shift into our data warehouses, and I am going to share with you what goes on with our data here in Ohio, and how we disseminate it to our users. When we surveyed our users which our primary ones are local public health, but we have hospital users and university users, we found out that they really wanted timely data delivered on their demand without waiting, and they really wanted timely data, and we were not living up to that 5-10 years ago. We needed to

automate the statistical file processing so that would free up our staff time here, and we needed a stable single portal through which to disseminate the health statistics.

[slide 35] For example, we have over 100 birthing hospitals in Ohio—those are shown with some marks here on this map of Ohio. We have over 100 local health districts—all of these places want our data back and it is too hard to do manually. We needed to set up a system for that.

[slide 36] So what our data warehouse does—is if you look at the green cylinder on the left—that would represent the electronic birth registration system. A hospital is going to key their data into that, so the birth weight of a child for instance gets keyed there. And that system is good for collecting data, but not so good for analysis, so we needed to build something outside of that environment for analysis and data dissemination, and that is our warehouse which is shown on the right. So it flows into the warehouse, gets supplemented along the way with—for instance—geocoding or transformation of variables and then it shows up in the warehouse where users can pick it up.

[slide 37] Some examples of the kinds of augmentations or transformations a state office might do and which we do are geocoding—taking the street address of residents for the mom for instance on the birth certificate and figuring out in more detail where she resided like a census tract or a school district something like that. We also supplement the very rich multi-race data we get in the certificate with a single race view, so that we can do our traditional statistics based on populations. Another example is where we assign cause groupings so that better sense can be made out of the causes of death when the ICD-10 allows for 8,000 or so different causes of death, we needed those grouped in a more meaningful, larger, more cruder groups, and then we augment the datasets with new indicators like maybe a low birth weight indicator or a neonate, post-neonate death indicator, or an indicator that describes whether an induced birth at a certain gestational age was without medical indications.

[slide 38] Some of the features of our warehouse are—we have a public version which anyone can see for instance at a library, at home, which does not have as much information in it. We have a secure version, which requires each user to be specifically authorized to a dataset by a data steward and with a data use agreement ensuring that they abide by our policies. The warehouse has been developed with lots of different funds primarily the Vital Statistics Fee Funds, but also the SSDI has contributed to that. So we have one warehouse that is built for multiple datasets, and data stewards in each of the data types control the access to their datasets and by getting multiple datasets in the warehouse, we hope to be able to cross-fertilize between datasets. So, for instance, generating infant mortality data which would benefit from both births and deaths.

[slide 39] I am just going to show a few slides of what our warehouse looks like if you had access to our secure site. So you get into a front page that would look something like this [slide 40] and at the bottom of that page you will see different rows representing different datasets in the file. The starred ones are ones that are vital statistics related which include birth and death here in Ohio in our warehouse.

[slide 41] I should mention that the death is not fully online yet, we're very close to releasing it, but we have been working very hard on it in the last 8 months. This is after one has gotten into the live birth, what we call a live birth part of the warehouse and that would pull up and it includes births back to 2006

and is going to contain 1.3 million, or more now, records and this represents a data view of those 1.3 million records, of course that is a lot, and people do not typically want the data going all the way that far back, [slide 42] so you can filter down this data view by using filters built into the warehouse. In this example, I have filtered down to just 2015 births, and mothers ages 15 to 17, and in February, when I ran this, that took the number down to 133 from whatever that was, 1.3 million, in the earlier view.

[slide 43] Probably more frequently used by our epi users around the state are our download files. [slide 44] In the birth download file we provide annual download files and so these are resident live birth data, not identified, but will provide the user a row-level data say for instance county of residence, infant's birth weight, things like that, so then they can run their analyses as needed and then they can download this as needed and it refreshes on a weekly basis right now. It refreshes on Sundays. So when you come into work on Monday, you can download the latest data.

[slide 45] The warehouse also provides the ability to pull reports, here is an example of a low birth weight report.

[slide 46] The download dataset is used by many users—well over 150—I would say right now. Here is an example of where one of our partner agencies, the Ohio Perinatal Quality Collaborative is trying to improve birth outcomes in hospitals, has been tracking births induced at 37 to 38 weeks with no apparent medical indication for early delivery trying to get those births moved back in time, and this chart showing the decline in the frequency or the percentage of those over time shows that their project has had an impact, and they have used our birth warehouse data to track this. So, it saves them a lot of data collection time for that.

[slide 47] This is just an example of deaths just a look, in this case, of unintentional injury deaths in Ohio among 0 to 14-year-olds using provisional 2014 vital stats data, and I put it in here as a warning to users that if you look at this slide notice how it is dropping at the end of the year, that may be a seasonal thing but it might just be a relic of taking longer for data to come in. So, there is a whole science about when is data complete enough to be used when you are talking with real-time data it is something that you are going to have to educate yourself about, and vital statistics officers are trying to do a better job of developing policies and procedures for ensuring that users do not make mistakes by using too timely data to come to conclusions.

[slide 48] So, I believe this is my last slide, but this is our vision. We have built the birth part of the warehouse; we are very close to being done with the death. We are going to attack the fetal deaths here hopefully in the next year or 2. But by having these datasets in one place now, we are hoping to provide these linkages between datasets to generate some very neat, useful analysis that will not require somebody to put all the datasets together, rather you would be able to download these and run with them at a local level. [slide 49] Thank you very much.

Questions and Answers

Sarah Lifsey

[slide 50] Great, well, thank you so much, and thanks again to all 3 of our speakers today. It has been a very engaging program, and we already have some questions coming in via the text box at the bottom of the screen. As I mentioned at the beginning, we are going to be taking questions both online and on the telephone, so to post a question online, just enter your question in the field at the bottom of the question's box, and hit enter. And if you would like to ask a question over the phone, just press *1 to indicate that you have a question, and the operator will let us know that there is a question, and indicate to you when you can ask your question. So, while we wait for folks on the phone to join the queue, I am going to start with some of the online questions that have come in. And the first question I have is for any of our speakers.

How can county public health departments get access to STEVE?

John Paulson

I can take a crack at that. I am not sure about that. That is a good question. The sharing is state to state, so this would be somebody within a state at a county that wants to get their records through STEVE—let us say their resident records.

Patricia W. Potrzebowski

Yes, I agree with you, John, this is Trish. I think the best way to do that would be through your state health department in your state, and talk to them about whether or not you would qualify as a data partner. If you are a public health agency at the local level, I really personally don't see a reason why that would not work, but I think it would depend on each state to determine who can access the records through STEVE.

Sarah Lifsey

Okay, great. The next question I have is from Lauren who asks,

What efforts are underway specifically aimed at improving the timeliness and accuracy of the fetal death data, and are there any recommendations that the speakers have for improving the quality of the fetal death data?

Glenn Copeland

Well, I can speak to that, this is Glenn Copeland, and we have incorporated fetal death reporting in our automated web EBC, so we get probably 60% of our reports through that system, not necessarily as timely as birth records.

One of the reasons we get timely birth records is because hospitals need to actually prepare the birth certificate, and present it to the mother before she is discharged, so they have quite a strong incentive to get at least the legal portion of the record done very quickly. There is no such incentive with a stillborn, and we do have chronic problems with them on a number of fronts. They are underreported. We need to routinely review the number of reports by facility to find facilities that are not reporting in the levels we expect, and we need to follow up with them. The other significant and chronic problem is that roughly 2/3 of the still births have a cause of death that is very nondescript. We have made, as a nation, a radical change to the way we collect fetal medical information trying to identify what might have led to the death. I do not know that there has been any great success to that. So, getting cause of death, knowing the etiology of why a pregnancy did not succeed is still a lost art, and I guess it is more than just the reporting and the record keeping—it is also the medical knowledge we need to develop to do a better job with that. But that would be my quick thumbnail impression, is we are working hard to make sure our accounts are accurate, but there are still issues with the quality of the information on cause of death.

John Paulson

The only thing I would add to that, is that the number of fetal deaths is about the same, at least in Ohio, is about the same as the number of infant deaths, and as infant deaths, the question I am sure everyone knows this, but as infant deaths decline, we need to be watching whether the fetal deaths are rising. And, I know in Ohio, it is slower and not as of high quality of data in the fetal death as there is in the birth and the mortality file. I know that we are going to try to get resources to move the fetal deaths into the warehouse which I think will help us here in Ohio to disseminate that data to users.

Patricia W. Potrzebowski

And this is Trish, let me just confirm what both Glenn and John have said they have made good points, but from a more sort of national perspective, what we are seeing is the number of fetal deaths is very low, and it is very difficult to find the money in a state to develop and implement a very expensive electronic reporting system that could theoretically improve the timeliness of the data, because if you only have 1,000 or 1,500 in a state, and that is a fairly decent-sized state, but some states where you have a much smaller number, it can be a real challenge to get the resources. We have had a lot of trouble just getting all the states on the 2003 standard certificate of birth, and the standard certificate of death—fetal death—which sort of follows along that model, was probably less of a priority for a lot of states, although I think they are almost all there now, but it is really a challenge to get the data both faster and better-quality data, and I think it will continue to be a challenge.

Sarah Lifsey

Great, thank you all so much. I do not think we have any questions on the phone yet, so I am just going to continue with the questions that we have received online. The next question I have is from Claudia in the Kentucky Vital Statistics Office who writes that

Despite STEVE, the transferring of out-of-state records is still not being performed in an effective and timely manner for all the states which is affecting the ability to do a better job on having complete records to offer the different users of the vital statistics office. She asks how could this be controlled or regulated.

Patricia W. Potrzebowski, PhD

Let me try that one. So, yes, STEVE does exist in every state, but some states are very slow at even getting the records in. So, I know of one state, well, a couple of different states, and I do not know if any of them border on Kentucky, but a couple of states where I'm aware that the death records in particular are maybe 6 months behind or even longer, so that is a real concern. Until we can all get the data more timely we cannot share more timely. I do think that the whole issue with states using STEVE is going to continue to improve, but it is clearly something that—and this is a really good point and I am really glad you brought this up—because this is something that we need to continue to promote full use of STEVE by all the states.

John Paulson

This is John from a state that does border Kentucky, and I know Kentucky has had a problem with getting those data into STEVE. If the data when it gets sent to NCHS does get split to states, I think there are some options in there about whether the states will actually get them by default, and for here it is an IT issue as well, I need assistance with that, but I do think STEVE is the way forward, and I think that is the best way to get the information, and I am just speaking for Ohio here, but I know we can do better with getting it to the other states.

Patricia W. Potrzebowski

I just think if you have a problem with a particular state, probably the best way is to talk with them directly.

Glenn Copeland

This is Glenn, and I would add one other thought, and that is that states are being urged not only in terms of cheerleading, but with some financial incentives to make sure we get our data to the federal National Center for Health Statistics timely through STEVE, and I think that impetus will translate over time over the next 2 or 3 years into everybody putting the right priority on it. I have got to say that I do not think any state is slow and sluggish and not on time because of indifference. There are a lot of challenges to pulling this off. I mean, to get births and deaths registered, we work with thousands of people who are filling out these forms, so it is really quite a challenge, and then the IT that was just mentioned by John, is really quite a challenge as well. These are not simple solutions. They take a lot of highly-skilled people. But, I do think we are on the right track, and I think we will see a lot of these problems look old-fashioned in a few years.

Sarah Lifsey

Great, thank you. Kind of continuing with the theme of NCHS, I have a question from Ron who...

wants to know more about NCHS coding for all of the causes of death in the whole country and wants to know when did that start and how was it done previously?

Patricia W. Potrzebowski

Let me start that, and Glenn and John you can jump in if you have anything to add. NCHS started doing the national all the coding in, was it in 2013? Does that sound right?

Glenn Copeland

I think it might have been 2012.

Patricia W. Potrzebowski

2012, okay, so they have been coding the causes of death for the last several years. Previously, each of the states had their own nosologist who did the coding. Part of the concern about the reason why NCHS actually switched it to doing at the national level is, because a number of the states were having problems maintaining the level of expertise that is needed amongst nosologists, and think about a small state that might only have 1 of these people, and then when they retire it really takes a long time to train a new person. So, a number of states were already having NCHS do their coding, and so they decided at that time that they could do it more consistently, and really faster, at a national level, they could make sure that they had the data faster if they did the coding.

Glenn Copeland

Yes, that is a pretty good summary, Trisha. It really happened rather suddenly, but definitely smaller states had a problem. When we first started doing the coding here in conjunction with NCHS, we actually at one point had 5 nosologists, all of whom were trained and certified by NCHS, but as the years went by they developed MICAR and then super-MICAR, so we have these automated systems for doing the coding, and we were down to the point where we needed maybe 2 people to do our nosology coding, but right now we only do it for our own purposes. It is not something that we have to do to end up with finished files, although, I can tell you because we were doing parallel coding we were able to help identify some of the systemic coding problems with the national center early on when this started, that I think they have resolved at this point. But, yes, it is the way things are done now. We send off the medical information, and then we retrieve back the coded causes of death.

John Paulson

In Ohio, we switched in 1999 to the national center coding those for us, and that did coincide with our loss of trained nosologists, and what we get now from it though, is we sort of have that backup at the national level, and we also have multiple causes rather than just the single primary underlying cause of death which we had prior to 1999.

Sarah Lifsey

Great, I kind of have a follow-up question to that from Sutida,

is there any part of death coding that is done locally or at the state level or cause of death coding?

Patricia W. Potrzebowski, PhD

Yes, there are several states—and I cannot recall offhand exactly who they are—who still do cause of death coding at the local level, so in that case, they basically believe that they can do it faster and better, and they have the nosologists and the resources to do it, so they continue to do it. It would be interesting to do a comparison.

Sarah Lifsey

Great. So, my next question I have is from Will, and I think this question is in reference to Glenn's presentation.

Why do you expect an 85% limit for EDR? In California, EDR is better overall, and why wouldn't everybody adopt it?

Glenn Copeland, MBA

Well that is a good question. I think the success does vary from state to state, and I hope I am wrong. I hope we can get higher than that, but we do have some resistance to it in our state, use of the system is voluntary, we do not have any statute to compel its use, and I doubt that we ever will. The other thing we have here is that we do also, much like John mentioned, have local registrars, and their use of the system is critical, but also voluntary. We cannot force them to use that system without invoking a constitutional problem—it is called the Headlee amendment—which would essentially mean we would have to pay them to use it, so it is not just a logical process, it is also a political one. But I do think that, much like I showed you with births', that as time goes on and as it becomes kind of the way things are done, we probably will inch well pass the 85% that I am hoping to see in the next few years.

Patricia W. Potrzebowski

This is Trish, let me just add a little bit more from the national perspective. There are several states in which submitting data electronically by the funeral homes, physicians, coroners and medical examiners is required, either amongst all certifiers or in some states where if a physician certifies more than a minimum number say, 10 deaths a year, then the next year they have to submit all of their records electronically. But also, for instance, California, I believe is 100% electronic, but the physicians, medical examiners, and coroners are not all submitting the data electronically. In California, most physicians use what is fax attestation, which involves the record being faxed from the funeral home to the physician, and the physician completing that record, and then doing a voice attestation before it goes back to the California Health Department. That is a great system for timeliness. What it lacks; however, are front-

end edits, in other words, if the physician puts in information that may be nonspecific or may be lacking information such as cancer, but without mentioning the site of the cancer, or the type of cancer, then there is no way in the fax attestation system for that to be caught before the record is filed, so it means that it takes time for those to go back and do a query. So, there is a little bit of a limitation on that method.

Sarah Lifsey

Okay, great. Well, I see that we are just coming up on 2 o'clock. We actually have quite a few questions that we did not get a chance to get to, and I want everyone to know the answers to the questions that we were not able to address during our Q&A period will be posted in writing along with the program archives and that archive will be available on the [DataSpeak website](#) in the next couple of weeks so that you can access it at your convenience.

If you think of any more questions for our 3 speakers, you can submit those to us via email over the next week using the email address you see here dataspeak@altarum.org, and before you go, we would like you to know that we will be broadcasting more DataSpeak programs in the coming months, and announcements about those programs will be sent out via email to everyone who registered for today's program, and will also be posted on the DataSpeak website.

[Questions and Answers submitted after the presentation are available on the [DataSpeak archive](#).]

[slide] The last thing, before you log out, we would appreciate it if you took a moment to provide us with feedback on today's program. We really like to get your input on the session and your recommendations for future programs. It is a [short survey](#) and if you click on the link on your screen right now it will open in a new window.

And last of all I would like to thank everyone who attended and especially thank our 3 speakers—Patricia, Glenn, and John—for giving their expertise to us today.

Today's program is now complete.

Thank you everyone for joining us, and have a great afternoon.

About DataSpeak

The MCHB's DataSpeak webinar series is dedicated to the goal of helping MCH practitioners on the Federal, State, and local levels to improve their capacity to gather, analyze, and use data for planning and policymaking. DataSpeak is funded by the MCHB's Office of Epidemiology and Research.

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