Perinatal Periods of Risk: Using Data and Community Involvement to Prevent Infant Mortality

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JOHANNIE ESCARNE: Good afternoon. On behalf of the division I would like to welcome you to this webcast titled "Perinatal Periods at Risk: Using Data and Community Involvement to Prevent Infant Mortality". Before our presenters are introduced today I would like to make some technical comments. Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentation. You don't need to do anything to advance the slides. You may need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window. A 12 second delay typically provides optimal performance for the audience. We encourage you to ask speakers questions at any time during the presentation. Simply type your question in the white message window on the right of the interface, select question for speaker from the dropdown menu and hit send. Please include your state or organization in your message so we know where you're participating from. On the left of the interface is the video window. You can adjust the volume of the audio by using the volume control slider which you can access by clicking the loudspeaker icon. Those of you who selected accessibility features when you registered will see text captioning beneath the video window. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your responses will help us plan future broadcasts in this series and improve our technical support. Today we have a couple of speakers and I will have Commander Madeline Reyes introduce them.

MADELINE REYES: Good afternoon. For the past ten years the interagency agreement between the CDC and HRSA has supported further development and implementation of the perinatal periods of risk. PPOR. PPOR is the community-based tool increasingly being used by Healthy Start to investigate community interventions to prevent poor perinatal outcomes. It provides a framework, steps and tools for extracting as much information as possible from vital records data and utilizing it to prioritize prevention activities. The overall intent of the PPOR approach is to provide a simple method that can be used by communities to mobilize and prioritize prevention efforts. I will now introduce our speakers.

Our first presenter today is Dr. Kasehagen. She serves as an epidemiologist to CityMatCH and a doctor at the University of Nebraska Medical Center. She has a masters in anthropology from New Mexico state university. And a Ph.D. in epidemiology and biostatistics from case western reserve university in Cleveland, Ohio. Our next presenter is Carol Gilbert. Ms. Gilbert is the health data analyst at CityMatCH. She has a Bachelor of Science in mechanical engineering from the University of Nebraska in Lincoln and a master of science in mathematical statistics from the University of Iowa in Iowa city. We'll now begin our presentation.

LAURIN KASEHAGEN: Thank you, Madeleine and Johannie for the opportunity to present about the perinatal periods of risk. In the event you haven't heard by CityMatCH it's a membership-based organization for urban Health Department professional responsible for maternal, child, adolescent health and its mission to improve the health and well-being of inner city people. Our objectives are to provide a general understanding of the perinatal periods of risk approach including the purpose, expected outcomes, analytic methods, resources and requirements for using, as well as a description of the six-stage approach. The next slide. So why do we need the PPOR approach? Infant mortality is affected by a woman's health and healthcare before, during pregnancy, labor and delivery and by the baby's healthcare after delivery. And now we know that a woman's health during her whole lifetime and even her mother's health can affect the health of the baby. We also know that infant mortality prevention must go along way before an annual visit to a woman's OB/GYN. Overweight, diabetes, and where she lives and the systems that surround her must be taken into account. Next slide. This figure on the slide may look familiar to you even though it's for a place called Urban County, USA because many communities share the problem of racial disparities in infant mortality. We know that in many cities infant mortality rates are very high. Almost as high as they are in some developing countries. For African-American mothers the rate is two to three times that for white mothers and even when overall mortality decreases the disparity usually does not. The depiction of a higher infant mortality rate from year to year for African-American infants may look like a rates in your community and the infant mortality rates among white non-Hispanic infants pulls down the overall mortality rate and maybe it seems like it's the problem in you are been county isn't so bad. We have to remember that the infant mortality rate is truly an indicator of population health and that doing the things we do to decrease infant mortality rates tend to improve the health of mothers and babies within the whole community. Next slide. So Bill Sappenfield and they had a better understanding approach to understand infant mortality in their communities. So our expert consulted with their expert because they knew that the causes of perinatal death are closely related to both age at death and birth rate and why not use both

pieces of information to learn more about why babies are dying? Next slide. So a six-stage PPOR approach that follows the general community planning cycle was developed. The stages include readiness, assessment using the PPOR approach, planning new prevention activities or modifying existing activities, and implementing those plans, evaluating and monitoring intervention efforts and reinvesting that success to assure community -- continued efforts within the community. Next slide. To help us better understand PPOR we're going to start with how fetal and infant deaths are categorized and counted and how it's used to better understand the problem of infant mortality in the community. At the end of this presentation we'll talk about the other stages of the PPOR process. Carol is now going to talk to you about that thing called PPOR. Carol.

CAROL GILBERT: Hi. The PPOR approach, the first big difference between PPOR and traditional infant mortality analysis is that PPOR examines fetal and infant mortality in two dimensions. Let's see what we mean by this. Next slide. The first dimension is birth weight. At the top we have extremely low birth weight babies which is about the size of a quarter container of milk. The second important dividing line is the low birth weight line or 3.3 pounds. The third division is low birth weight less than 2500 grams, and babies born 2500 grams or larger form the last group on the bottom. And for those of you who don't think in metric, 7 1/2 pound baby weighs 3,400 grams. Next slide. Our second dimension is the age of the baby or fetus at death. PPOR analysis does not include deaths that occur after the first birthday. This is just like an infant mortality. It doesn't go past the first birthday. Starting at the very right if the baby dies after the first month and before the first birthday it's a post neonatal death. If the baby is born alive and dies in the first month -- early feet all deaths are defined in the 20th to 28th weeks. The late are 28 weeks on. This carries into spontaneous abortions on the far left if they're not recorded, which they aren't if they happen at home especially, they cannot be included in our analysis. Next slide. Some of you might be wondering why we include fetal deaths in an infant mortality analysis and this is a good question. We have some good answers for you. First these deaths can be very sad for the families. Second, many people don't realize how common fetal death is. In fact, there are roughly as many fetal deaths as infant deaths excluding the miscarriages. Third, fetal deaths are an important picture of maternal and child health and provide us with a lot of information about mothers, their communities and health systems. The use of this information is another big difference between PPOR and standard infant mortality analysis. Next slide. Remember the PPOR examines death in two dimensions. Here they are again. The two dimensions put together now to form a grid of boxes which are called periods of risk, going across we have the early fetal death, neonatal and post neonatal deaths. We have extremely low birth weight, very low birth weight, and higher birth weight deaths. The experts

use statistical methods to combine the periods of risk if they had similar causes of death and similar maternal risk factors. If the boxes are that much alike they don't need to be analyzed separately. Combining them into blue, pink, yellow and green boxes simplifies our work without losing important information. As you can see, we end up with four periods of risk. Next slide. With four periods of risk were given labels that suggest the primary preventive direction for the deaths in that group. Notice that the blue box does not include deaths that were less than 500 grams at birth. Those experts found that there is inconsistent reporting for the very smallest fetal and infant deaths not only across the U.S. but even at the local level. Sometimes even between two different physicians in the same hospital. It's not possible to make fair comparisons if reporting is inconsistent and that is why those very tiny babies are excluded from our analysis across the board. Next slide. Remember that the dividing lines have been chosen so that deaths in the same period of risk in the same little box had very similar problems. They had both similar causes of death and similar maternal risk factors. The important point here is that since death within one period of risk has similar problems, they will also have similar solutions. Next slide. Each period of risk is associated with its own set of risk and prevention factors. For the maternal health and prematurity period, the blue box on top. Prevention may need to focus on chronic diseases or behaviors like smoking; drug abuse or they may be improved women's access to specialized perinatal care. For maternal care the pink box next down prevention may need to focus on quality of prenatal care or referral of high-risk pregnancies and good medical management of conditions like diabetes, seizures and post maturity. For the yellow box newborn care the focus may need to be on advanced neonatal care and treatment of congenital anomalies. For the infant health box, the green box, communities may need to focus on prevention of sleep related deaths such as SUID or suffocation and access to a medical home, injury prevention or infection treatment. Next slide. The four periods of risk in PPOR provide a simple framework for thinking about data. The PPOR framework helps us to use the data instead of just looking at it and feeling overwhelmed or suffering from what we call analysis paralysis. PPOR helps us to prioritize and focus our efforts where they have the most impact. The framework allows communities to use other information, too, all the data and information that's available. Next slide. We use the periods of risk we start by sorting the deaths. This is sort of like a quiz so good luck. Our first example is a baby girl who weighed 2,499 grams of birth and died when she was 22 days old, which period of risk will she be sorted into? Start by thinking of her birth weight of 2499 grams. She's more than 1500 grams so she needs to be in the bottom row. Now her age of death, will it tell you whether it's the pink, yellow or green box? The answer is on the next slide. She was larger an 1500 grams she's in the bottom row not very low birth rate and not a fetal death, but she didn't survive

past the first month because she died at 22 days, she goes into the yellow newborn creative risk. Next slide. Here is another example. We have a boy who died before delivery. He was a fetal death. His weight at delivery was 1,590 grams. Which period of risk will he be sorted into? Answer is on the next slide. Since he was a fetal death he belongs in the -- he goes into the pink box maternal care period of risk. The last example is a baby girl who weighed only 1820 grams at birth and survived 47 days. Which period of risk does she belong in? The answer is on the next slide. Since she weighed less than 820 grams she is in the very low birth weight category for the top row. The only box she should be in that row is the blue box, the maternal health period of risk. I hope that this sorting of deaths makes sense to you. That's what PPOR is based on. Now we'll have an example from a real community. Next slide. Community stakeholders in an Urban County that we'll call Urban County sorted the deaths from a four-year period and their resulting PPOR map looked like this. Next slide. There were 97 deaths in the blue box in the maternal health and prematurity period of risk. Some of the pink box, 44 deaths in the yellow box, the newborn care period of risk and 47 deaths in the green box, the infant health period of risk. You might be asking yourself whether these are high counts. It looks like a lot of babies to me but then it was a four-year period. I hope someone is thinking right now what's the population of Urban County? When we're using numbers we need something to compare the numbers two. The number we need in this case to answer our question is how many pregnancies did Urban County have during this time? Go to the next slide. PPOR map of fetal infant death at the top and if you were asking that question, pat yourself on the back because that's a good question. There are a total of 23,282 fetal deaths and live births that fit the PPOR criteria. That is our estimated number of pregnancies that we're going to compare and use as our denominator for computing PPOR rates. Next slide. To calculate a mortality rate for each period of risk, which is what we need to do in order to make comparisons, Urban County divided each count by that same denominator, 23,282. Then they multiplied by 1,000 because infant mortality rates are traditionally expressed in deaths her thousand because tiny members with a decimal point zeros are how to read and think about. In the blue box they started with 97 deaths divided and multiplied by 1,000 to get the rate of 4.2. There were 4.2 deaths for every 1,000 live births and fetal deaths. Next slide. Urban County went on to do the same calculation in every period of risk and produced this PPOR map. Of course, the period with the most deaths also had the highest rate because all the rates were calculate Wednesday the same denominator. The advantage of rates is now we can compare to other populations with a different number of live births and fetal deaths and this is a good time to stop and ask if any questions have come up so far.

JOHANNIE ESCARNE: There haven't been any questions.

CAROL GILBERT: All right. So the next slide says quick side trip number one, before we talk about comparisons we'll take a quick side trip to learn how Urban County found out about those deaths in the first place so they could sort and count them. Next slide. The U.S. vital records system is the answer. We have a death certificate created every time a person dies in the United States and death certificates are made when a feet -- fetus is delivered. Is every single baby really included? We believe even home deliveries are always given birth certificates but generally every baby is recorded at some time. However, we know some of the very smallest infants and fetal deaths may not be reported in the vital records even when state laws and hospital policies indicate they should be. Next slide. There are some rules about which deaths we count. First, when the baby was born the mother had to be living in the city, county or neighborhood we're studying and the baby had to be born during the time we were studying and had to die before the first birthday. Because of variations in reporting for very small babies they don't count them in they were born under 500 grams or before the 24th week of gestation. This ensures that we can make valid comparisons and as you'll see, PPOR is all about comparisons. Next slide. Back to Urban County's PPOR map of fetal infant deaths and the lovely map they made. I hope you are looking at that 4.2 and wondering how do we tell whether 4.2 is a high rate or not? PPOR answers this question in a practical way. We use a reference group. A real group of mothers who experienced these low mortality rates. We calculate the rates in each period of risk the same way we do for our city population. Next slide. Here are some examples of reference groups that might make sense. Educated black mothers who live in your state when the baby was born. Or white women who lived in affluent neighborhoods or sister city when their baby was born or well-educated white non-Hispanic women over the age of 19 who resided in your city when the baby was born. Whoever they choose this group must be defined in terms of population characteristics obtained from the birth and death certificates. It shouldn't be the presence or absence of risk factors. It has to be a realistic populations that has normal risk. The reference group is about justice. We make the assumption that if the reference group population has low mortality then our study population should be able to reach the same goal and doesn't that make sense? Why should our community accept higher mortality rates? One key part of PPOR is that the community stakeholders group gets to choose the reference group and they choose it because they believe their own community or study population should be able to reach that same low mortality rate. Next slide. Urban counties stay colder. The U.S. 2000 to 2002 records group fetuses of non-Hispanic white mothers who were 20 years old or more and had 13 or more years of education. They had one year past high school education. Next slide. Here we see the PPOR map for that U.S. reference group that Urban County used. You can see that the rates are lower than Urban

County's map reads. Our next step would be to officially compare these rates. Next slide. Comparing the study population to the reference population is done by a complicated mathematical formula called subtraction. You don't need a computer. Most people's cell phones do subtraction. The blue box -- in the blue box you start with 4.2 which was Urban County's rate and subtract 2.2 which was the rate in the reference group's red box. The difference is 2.0. There are 2.0 excess deaths for every 1,000 in urban counties in the blue box. Next slide. The same calculation is done for the other three periods of risk. The result is a new PPOR map of infant mortality. The mortality gap, the difference between Urban County and the reference group represents excess mortality or preventable deaths. The pattern of excess mortality is not the same as the pattern of mortality in the first map. The excess morality map on the right, the pink and green boxes are similar in the mortality map on the left but the gap map on the right you can see the green box is contributing more to Urban County's deaths than the pink box in. In Urban County the blue box is contributing to most for mortality and excess mortality. Next slide. If the number of deaths is sufficient we can create a PPOR map for any sub population and again to explore disparities or gaps. Here we see there is a gap in urban counties and they're widened in the blue and green boxes between the Blacks and the whites. Next slide. Urban County estimated the number of preventable deaths for each period of risk and overall. In the blue box they started with the 2.0 excess rate they had calculated and multiplied by that same denominator they used before and divided by 1,000 to get 46 potentially preventable deaths in that period of risk. They calculated others with the same formula and added up the excess rates in the four periods on the left at the bottom to get 4.4 overall excess mortality rate and added up the excess numbers of deaths in the four periods of risk after bottom on the right to get 103 preventable deaths in that four-year period. Now that is a kindergarten class each year of deaths that could have been prevented and were sounding less abstract at that point at 4.4 excess rate we had before. Next slide. Whether you use rates or numbers it's easy to see now which periods of risk have the most preventable mortality. A simple calculations show you that 70% of the excess mortality in Urban County walls in the blue and green box put together. Urban County can focus on those two periods of risk. They do have some excess deaths among still-burns in the pink box and deaths of larger newborns in the yellow box but the data indicates they don't have much to gain by focusing on those boxes so they'll focus on the blue and green boxes first. Next slide. Success. Urban County celebrated their success. They got their hands on their own vital records data, did the math and completed phase one of PPOR analysis. One part of their payoff was that remember those lists of causes and prevention activities we showed you at the beginning? Well, Urban County had now eliminated two of those four lists that they might have had to investigate. There is not much excess

mortality in the pink box so they would -- they're choosing the other two boxes. In contrast the blue box the reference population probably has something going for it that Urban County doesn't have. The green box also has some more room for improvement. Back to the slides. Another payoff for every, was that their stakeholders understood where the numbers came from and what they meant and why they should focus on the blue box and the green box. Next slide. Every data source has issues and this is no exception. Some stakeholders simply do not believe in infant mortality stays advertise particulars. They might see that their community has high rates but not personally know anyone who lost a baby or know of many deaths in their community and not believe it doesn't happen everywhere. Stakeholders may be shocked by the numbers and they may just need time to get over it. Sometimes stakeholders are right in their concern and there is something wrong with the data. Data quality needs to be checked. For example. Even if a few deaths don't have the birth weight information that will make the PPOR rates look artificially low because those deaths can't be sorted into the PPOR map even though they really did happen. It's important for many reasons to listen to and address the data concerns that your stakeholders address throughout this process. Next slide. So Urban County did celebrate these successes but the stakeholders knew they couldn't stop there. Each person now had her own ideas about why this excess mortality was happening but there was really a long list of potential causes and solutions and they knew they had to do some more data analysis to figure out what was really causing this excess mortality and not just each go by their own opinions. Next slide. And this is another good time to stop and see if questions come up since the last break.

JOHANNIE ESCARNE: Yes, we did have one question. That question is what resources are available for communities who want to use PPOR to impact IMRs?

CAROL GILBERT: Well, we will actually get to that answer if you mean what programs for interventions to design; we have a lot of those on record at CityMatCH. We do work with local city and county health departments who have a lot of good ideas and there are other sources, too. We will go over some of those resources at the end and some are available from AMCHP and CityMatCH. Also data sources, we'll talk about those, too. And I think I'll wait, then, other than vital records we'll talk about at the end. We'll get to that question. So now we should be on the slide that says she's got to be kidding, there's more? So if you feel like this little one, be assured that the additional work to come is worth it. Go to the next slide. There are three helpful steps in phase two analysis. We have a three-step strategy to help prioritize. Among take list of potential risk factors. The first is to identify the most probable causes or mechanisms for excess mortality. Once you've found the most probable cause to look at the risk

factors for that cause by comparing the prevalence of the risk factors from the study population to the test population. Then the impact of risk factors. Instead of going through each of these in detail they theoretically we'll show you how Urban County did it. Next slide. The details of what happens in each step of phase two analysis will be a little different for other periods of risk. We're going to show you the green box period of risk for Urban County. But the strategy is going to be the same in the other periods of risk. Even though no two phase two analysis will be the same. Strategy is what we'll focus on here. The next slide. Phase two analysis examples should be the title. What are some of the causes of death in this infant health period of risk, the green box? If the baby is not born very low birth rate and made it through its first month what typically causes death at this point? These are some of the causes. Fluid, suffocation, drowning, car accidents, congenital anomalies can be big issues in this point. Go to the next slide. Our job is to pick from that list and in the infant health period the best way to investigate the causes of death is to use the underlying cause of death ISCD codes from the death certificate. There are thousands of causes of death but there are only dozens that typically happen to infants so you can look at the frequency of how many times each of those occurred in your study area. If you look toward the bottom of the page, what Urban County found was they saw a lot of R95 cause of death codes, the codes for SIDS. In Urban County, deaths case reviews found that suffocation deaths were often misclassified as SIDS cases. Since it's impossible to tell from the code itself whether they were misclassified or not, Urban County decided to deal with this problem by combining sleep and suffocation death codes into one category called sleep-related deaths. Including causes of death both vary by who is doing it. It is worth investigating what causes are listed in your community and what those actually mean by consulting with the death review, your state's child death review teams. The infant mortality review teams or you may be able to talk with death scene investigators about how that's done. Next slide. Step one. Urban County grouped the causes of death into five categories besides the sleep-related deaths. Congenital anomalies, ill-defined, mostly heart and breathing related. Infections, injuries and perinatal conditions. Then they calculated the mortality rate for each cause group the same way we've calculated them for the boxes in the first phase of analysis. Here we see that the sleep-related group of causes amounts for most of the difference between our study and reference population. This is a big deal. It's not always this clear but it was at that time. Next slide. We have another success. Urban County stakeholders have discovered that most of their infant health period of risk excess mortality was due to sleep safety issues. They celebrated their success. They had eliminated many other causes of death from their study and they knew they would have the biggest impact by focusing first on risk factors that could cause s*id and sudden unexplained infant death and suffocation.

Next slide. Urban County stakeholders each had their own ideas of why babies were dying of SUIDs and suffocation. They knew they had to check the numbers. They dug deeper and began step two of their phase two analysis. Next slide. This is a list of known risk factors for sleep related deaths and SUIDs. For almost two decades there have been campaigns to caregivers not to put babies on their stomachs and smoking near the baby has been linked. People advise them to put the baby on their back with no blankets or pillows. Many deaths have been attributed to sleeping with a parent or siblings and parents using drugs have been linked to deaths and how death scenes are investigated will result in the mortality rate you'll find when you do PPOR. For each risk factor Urban County stakeholders tried to find data from their study population. Vital records data provided some of the answers. Other courses of data that might bury from city to city might include surveys, Healthy Start data, medicate and private insurance data, hospital discharge data, child death review systems and Fetal Infant Mortality Review information can also be helpful. Next slide. We're still on step two investigating the causes of SIDS and one of the big causes, of course, is smoking. Maternal smoking information is available from birth certificates and in some surveys. Smoking is generally underreported but if it's underreported by the same amount for both groups it still gives us a general idea what the disparity in smoking might be. It looks like Urban County moms were likely to be smokers than the reference group moms. Smoking could have contributed to their excess mortality in that SIDS related, sleep related deaths. Keeping on with step two, PRAMS is a CDA investigation of new moms. This data provided county level PRAMS data. They were as likely to be sleeping on their back as the best states that reported PRAMS result. Tummy sleeping was less likely to be contributing to the gap. Notice, we don't have PRAMS data for the national reference group that Urban County had used. Those green bars are overall state rates of back sleeping. It is possible that the reference group would have a higher rate. Often when we don't have exactly what we want he we use the closes substitute but we have to understand the limitations. Next slide. Step two other important information. Child abuse investigators who are contracted by the county to investigate infant deaths to the police were actually members of the stakeholders group and they reported that couches, blankets and parental drug use had benefactors in several infant death cases that called SIDS deaths on the death certificates. A lot of time was spent doing a survey of local obstetricians to see what guidance they were offering their prenatal care patience and sometimes surveys can be done by stakeholders groups. It's better to use data that you have, if you have data. But they found that most doctors didn't discuss safe sleep with expectant parents and most were not aware of smoking cessation services and so there didn't really work too hard at counseling their patients on smoking, either. Next slide. Guided by PPOR findings, urban stakeholders decided to use another

source of information that they could have. They worked closely with their counties community action team which modified their usual process and had their case review teams review only SUIDs or sleep-related deaths for six months. They found that the mothers of most of these babies had both physical and mental health problems, including extremely stressful lives and a lack of social support. Next page, next slide. Now we're on to quick side trip number two. This brings us to another side trip to talk about what steamer is and why so many cities use PPOR and FIMR together. FIMR is fetal infant mortality reviews. The case review team on FIMR projects look at important maternal view looking for patterns and try to improve health in social systems instead of assigning blame. The case review team makes recommendations to the community action team. Next slide. There are many examples of how PPOR data and FIMR information complimented each other. In one case, FIMR found that mothers of premature babies had not known how to recognize signs of early labor. They were concerned about this and since PPOR data indicated that prematurity was important in that city, it accounted for 80% of their excess mortality, an education campaign seemed justified. In another case FIMR team found that immigrant mothers were not seeking or receiving prenatal care at all and they considered a major prenatal care media campaign but PPOR data found that 99.5% of mothers were receiving prenatal care and most receiving it in the first trimester so it was decided not to do a population-based prenatal care campaign but instead to let -- to inform a group that was working with immigrants of this problem and they were eager to address the lack of prenatal care problem in their particular population. Next slide. What does the Fetal Infant Mortality Review bring to the table? We highly recommend that communities use FIMR if they can. FIMR gives us answers sometimes when we don't know what the question is yet. FIMR can identify cause and effect relationships which surveillance data and observational studies cannot do. FIMR works in small or large populations and PPOR only works in large places with many deaths. FIMR helps to paint the faces behind the numbers. We should not underestimate the power of authority. Next slide. But every information first has limitations. FIMR's limitation is it only looks at babies that died. The population of babies that died have more risk factors, probably, than the general population of mothers. The Urban County team found that almost every death case had maternal physical and mental health issues, which was concerning but it didn't tell Urban County stakeholders anything about how common the problems he were in the general population of mothers. If possible, concerns raised by FIMR should be confirm uses sources of population-based data like birth certificates, etc. It may not be possible. Next slide. Step three. Now that Urban County knew about some of the risk factors for its sleep related death, it was time for estimating the potential impact of the risk factors and the impact of changing them if we could. A population at -- it is how much -- for

this we need good data on how common the risk factor is and also on how much it increases the chance of death. PRAMS can give an estimate of how common tummy sleeping is but even though we know that safe sleep practices reduce deaths, even the national experts are having difficulty figuring out how much SUID rates would decrease if all babies slept on their backs but they're working on it. Estimating impact is a good idea but the limitations of the data need to be kept in mind. Non-statistical considerations may be more important. Which factors are modify able and do effect evidence-based intervention exist and do we have the capacity to use them at this time? The stakeholders weighed the evidence. The data committee kept investigating. I'm sure you are all thinking of questions and potential data issues now even as I'm speaking and I hope you'll type them into the moderator. Questions are entertaining to us and help us do the job better. Next slide. Urban County stakeholders put all this information together and finally decided on three initial action steps. They changed their back to sleep message of the 1990s to a more comprehensive safe sleep message. The safest place is a baby to sleep in its back in a smoke free room without a blanket near you. They worked with physicians on safe sleep messaging and informed them about smoking cessation services for pregnant women and began to meet with a group of healthcare providers working on maternal mental health issues already and the process continued. Next slide. It was time to celebrate again. Urban County had accomplished a lot. Their time investment had been focused; they had found some answers and some action steps that had a good chance to have impact. And best of all, community stakeholders were convinced they were on the right track. They were energized and ready to continue. This is partly because they knew where the data had come from. They understood it. Next slide. This is another success in outcomes. After a decade of this work, the overall fetal and infant mortality rate in Urban County had decreased and looking at the boxes, this decrease was mostly because the green box rates had gone down. It is impossible to prove that this was because of PPOR. Because we only have observational data. We can't prove cause and effect but the community stakeholders group is not planning to stop doing PPOR any time soon. They're seeing it as a good vehicle that helps them stay on track with preventing mortality in that community. Next slide and I'm turning it back over to Laurin.

LAURIN KASEHAGEN: Thank you, Carol. Now that you know what PPOR is in terms of how fetal and infant deaths are counted, and the way in which Urban County use their data. What about readiness and monitoring an evaluation and sustaining stakeholder involvement? Next slide. First stage is before you begin to collect and analyze the data we encourage you to go through some processes to assure community and analytic readiness. Next slide. This is a map created by NACCHO that talks about and identifies who are potential stakeholders in a community may be. It's worthwhile to look in your own

community who are the likely suspects in terms of partnerships and the unlikely subjects and see the champions inside on outside the systems in your community. You need to be ready and to have committed leadership. This is a big effort and it will not be effective unless it is sustained over a long period of time. You'll have to have committed leadership and it is good to have all your ducks in a row before involving new partners. Readiness insures initial success which will assure long term success. Next slide. So CityMatCH has some tools for assessing and evaluating readiness and to help you explore whether our community is ready to take on infant mortality. You can access these tools through the CityMatCH website and use them to determine readiness at both individual and community level. On this slide you can see a stick figure on the left. That was developed by -- on the right-hand side of the slide you can see the beginning of a questionnaire or survey and collaboration factors. There is another tool called the partnership assessment. All these tools are free and readily available for you to use and we can help guide your use if necessary. Next slide. Can everyone use perinatal periods of risk approach and what do you need to know before you start using it? Next slide. So our first rule is that you need at least 60 deaths in your study population, your reference population and any subgroups you want to study. Rates based on fewer than 60 deaths can have large fluctuations from year to year simply due to randomness with no real underlying systems change. It is unwise to make policy decisions based on random changes. So therefore, by studying 60 deaths it allows us to differentiate between real underlying changes and differences and those due to random fluctuations. What if your community doesn't have 60 deaths in a year or what if you don't have 60 deaths in a period of three to five years? Are there alternatives? Yes. You can try combine similar health service systems areas or you can consider not doing PPOR at all and just convening a special FIMR panel. Next stage. Next slide. You'll also need to have a clearly defined steady population. The geographic boundaries must be clear. Anything from a neighborhood, a Healthy Start site service area, counties or municipal limits so long as it's a well-defined population and the residents share some sort of healthcare system. Next slide. You will also need to have three vital records data files. The first is the fetal death. Second the infant death filed late to the birth records and then the live birth file. This is the raw data about each individual baby, not summary tables. Sometimes we find that confidentiality can be an issue. So data is usually de-identified and by law individual test data can be used for Public Health Service but it may take some time and negotiating. We request and recommend that you think about developing close relationships with the holders of that data, the vital records registrar. Once you get the data files you'll also need someone like a data analyst and epidemiologist who knows what to do with the files. PPOR is more than just about data and we meant it. It is an effective community tool for decreasing infant mortality. Its

purpose is to help communities use their own local data to help prevent infant mortality and shape interventions that are responsive and appropriate for their own community. It provides guidance for starting an infant mortality prevention record and the whole health cycle. If you already have a community Maternal and Child Health project that's John going PPOR can be a valuable tool to get information and mobilize your work community members to action. Next slide. PPOR is designed to be integrated with John going community planning cycle or project, not meant to be a specific program or community-wide project standing by itself or to supplement or bump over another program that's already in your community. Next slide. We recommend that PPOR be used with existing efforts like a FIMR, like a Healthy Start community project. My community health assessment. If you don't have any of those, PPOR can start a project moving with the framework. As a reminder PPOR has two stages and within the stage -- within stage two there are two phases. There is the calculation, pairing the mortality rates with the reference population and identifying the periods of risk that contribute the most to the preventable deaths. Next slide. The second phase in stage two helps you identify the most important probable causes of local excess of mortality, examine the risk factors of those causes by clearing your steady and reference populations and by talking about your risk factors. Stage three is about developing action. The community stakeholders here decide for their own how best to address the specific areas found to be contributing most to preventable deaths. Anywhere from assessing their relevant community assets or find and defining evidence-based programs for adapting or designing new interventions and for determining appropriate policy changes. Next slide. In stage four the community implements their new program or their revised or strengthened programs. This is based on their findings from the three previous stages of PPOR. Stakeholder knowledge and assets within the community. Next slide. Stages five and six close that loop of the program planning or community planning cycle and it involves evaluating, monitoring and assuring the sustainable community involved work. CityMatCH has a treasure chest of tools that you can use to explore and see what works best for you and can be adapted for your community needs. Next slide. So why use PPOR? First, we want to help you improve your community's birth outcomes. Next slide. And we want to make sure that your community strollers are filled with healthy, thriving infants. Next slide. PPOR is not just a pretty face, it really is a means of helping communities understand their infant mortality problem and to help them work together with their own data and look for solutions. Next slide. CityMatCH has been working with PPOR users a long time and we've learned a lot from them all so we have tools for making the whole process work better. We have a learning network group that meets most months to hear from experts on particular topics and each other. We share ideas and connect you with each other and with other

resources. We also have data analysis advice and instructions both on our website and by phone and email and we offer a limited number of workshops on side -- we'd like to thank you for your time today. The last two slides show our contact information and the logos of many communities who have been using PPOR in the past and now currently. And we would be happy to entertain any questions that you may have now.

JOHANNIE ESCARNE: Thank you, Lauren. Okay. We've now entered the question and answer portion of our webcast. I have a couple of questions in the queue. This would be a good time to type in your question. What would you recommend for rural areas with high IM rates but low total number of births for PPOR?

CAROL GILBERT: That would be one of those cases where probably you would need to use some other method. If you don't have at least 60 deaths it's not going to -- PPOR really cannot help you.

JOHANNIE ESCARNE: Thank you, Carol. Next question, can you address whether you can use PPOR on a state level? Statewide level? Do you want to take that one, Lauren?

LAURIN KASEHAGEN: Sure. We have several partners with whom we've collaborated and provided technical assistance to who do use PPOR on a statewide level. Most often PPOR is used at the community level because it's viewed as a community tool and a community mobilizing tool. In the case of Louisiana, they calculate their rates both statewide and then by their health regions and they have nine different health regions. And then all of those rates are compared to their statewide rates. And they use this for public -- for planning. So for planning what kind of services and for identifying where needs exist in those ranges.

CAROL GILBERT: Another role that states have played is by helping provide some infrastructure, some analysis support because it really isn't necessary for every city in a state to do the same analysis in the same State of preparation steps. They took a long time. If a stay can provide that for all their cities at once it can be very helpful.

JOHANNIE ESCARNE: Thank you, ladies. As I give the audience a couple more moments to type in some questions, do you guys have any other comments or any other examples you would like to share?

CAROL GILBERT: We might just add that even though we need 60 deaths for a PPOR, for phase two analysis we've run into the need for more deaths even than that. If you think about dividing up the cause -- the deaths in the infant health period with different causes of death, you usually cities who

want to do phase two analysis have to start out with more deaths than 60 or else add years or add -- add years to their data because we really do need -- PPOR is not magical. We can't make our confidence intervals magically small. We have to work with the law of numbers like everyone else.

JOHANNIE ESCARNE: Thank you, Carol.

>> Our cities have been a little bit creative. So they've started by combining several years at once. They may be three years worth of data. They still didn't have a tough number of deaths for PPOR. They then went to five years and we've even had cities look at longer periods of time. There is a risk that you'll into fire or

>> Changes in healthcare systems or other system level change that would make it difficult to interpret the data. We caution about the number of years you can find. Another thing that is consider might considering doing is looking at if there are contiguous areas that they could combine. Maybe it's two neighborhoods. So long as they're similar in their system.

>> We do have a lot of Healthy Start areas that use PPOR and often they will use their whole counties when they're doing PPOR but many know that their Healthy Start mortality rates can drive the county rates. When the health -- they'll see the county PPOR rates go down.

>> I think the other thing that we might want to mention is that the reference population. You need to have a reference population that really is representative of what it is that you hope for the population at greatest risk to achieve and that there are sufficient number of women in that population to provide a good statistical evidence. You wouldn't want to pick a very, very small population that has a very, very small number because it will make it very hard for you when you try to compare that with your population data.

JOHANNIE ESCARNE: Thank you. Are you finding a predominant group across all participants, either maternal health, versus newborn, versus infant? For example, in lane county, Oregon, infant and maternal health were common.

CAROL GILBERT: It’s very common the blue box and green box be the predominant periods of risk. Sometimes it's the pink box. I don't believe I've seen a city that had high excess mortality in the infant health, the yellow box. Newborn care, sorry. The yellow box is usually very good in cities because of good access to neonatal intensive care probably.

JOHANNIE ESCARNE: Thank you, Carol. I'm going to see if anyone else. Sometimes we have the last-minute typers coming in. I think I have given most of your comments. Anything else you would like to add in case there is someone out there typing away?

>> We just encourage you to go ahead and call us if you are thinking about using PPOR and you have further questions. We do give some workshops and we have more materials, this is just the broad introduction and we have specific materials if you're thinking of taking the plunge and doing this. We don't mind taking calls at all. In fact, we enjoy it.

JOHANNIE ESCARNE: Thank you. It was a lot of information but a lot of great information. So I hope that our participants took it all in. We haven't gotten any other questions right now. I guess it was such a great presentation that everything was answered along the way. So then I will just close out the presentation. On behalf of the Division of Healthy Start and perinatal services I want to thank our presenters and the audience. And thank our contractor the Center for the advancement of distance education at the University of Illinois Chicago School of Public Health for making this technology work. Today's webcast will be archived and available in a few days on the website mchcom.com. We encourage you to let your colleagues know about this website. Thank you and we looked to your participation in future webcasts.