Media File Name: FIMR and PPOR.mp3

Media File ID: 2376142

Media Duration: 1:21:40

Order Number:

Date Ordered: 2015-09-16

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Naomi: Hello, everyone. And welcome to FIMR & PPOR: Amazing Data Processes to Help Healthy Start Sites Improve Population Health webinar. My name is Naomi Clemmons and I'm the Technical Assistance Coordinator for the Healthy Start EPIC Center. I will be moderating today's webinar. We have approximately 90 minutes set aside for our conversation and presentation. This webinar is being recorded. The recording, along with the transcript and slides, will be posted at the EPIC Center website following the webinar.

Before I introduce our guest speakers for today, I want to let you know that we want your participation during this activity. So at any point, if you have questions or comments, please chat them in at the bottom left-hand corner of your screen. We will only be taking questions via chat. These questions will be posed to the presenters after the last presentation. If we don't get to them by the end of the webinar, all of the questions, we will include them in a Frequently Asked Questions document that will be posted with the webinar materials on the EPIC website. One quick reminder I want to make is that you'll be asked to complete an evaluation survey at the end of the webinar. We really appreciate your feedback, so please take a moment to complete it.

Before I introduce our speakers, I want to say a few words about FIMR and PPOR. FIMR and PPOR really are amazing data processes that will help your programs improve your population health. First, I believe that these two processes and maternal mortality review are important continuous quality improvement efforts for Level 2 and 3 Healthy Start programs. The data obtained can inform systems gaps and support improvement efforts. The National Fetal and Infant Mortality Review is funded to support your FIMR efforts with training and technical assistance. This presentation is intended to provide an overview of these processes, and more specific information is available and will certainly be shared.

So now, I'd like to introduce our speakers for today. With us is Allison Miles, a Health Data Analyst at CityMatCH, the National Organization of Urban Maternal and Child Health Leaders. At CityMatCH, Allison works with vital records data using the Perinatal Periods of Risk approach. She assists with

PRAMS analysis for the state of Nebraska and supports all data-related activities.

Also with us is Dr. Jodi Shaefer. She is the Director of the National Fetal and Infant Mortality Review Program at the American College of Obstetricians and Gynecologists. Dr. Shaefer's involvement with FIMR started in the early '90s through the Association of SIDS and Infant Mortality Programs. As a national FIMR consultant, she has provided educational programs on the FIMR process and bereavement support. Her multiple national FIMR publications include cross cultural expressions of grief and loss, annotated bibliography on bereavement, and home visiting. She brings skills and service delivery, education, and research, including an extensive local, state, national, and international experience in program implementation and evaluation.

Lastly, I'd like to give a warm welcome to our Healthy Start mentees Carol Isaac, who coordinates the Fetal Infant Mortality Review for the Douglas County Health Department located in Omaha, Nebraska. Carol also coordinates the Baby Blossoms Collaborative, a 35-agency collaborative which develops the county, the community action plan, and identifies emerging MCH issues. In addition, Carol is the CAN Coordinator for Omaha Healthy Start. She has worked in the area of public health for over 30 years.

Now, I'd like to hand it over to Allison Miles of CityMatCH.

Allison: Great. Thank you, Naomi. As Naomi mentioned, my name is Allison Miles, and I'm the Health Data Analyst at CityMatCH. And today, I'm not going to explain necessarily how to do Perinatal Periods of Risk analysis. Rather, we'll discuss what PPOR can do for your community. Okay. Let me just make sure this is advancing. There we go.

Okay. So today, we are going to discuss how communities should makes decisions and prioritize. We can say that these four sources of knowledge to be

complementary. Population-based data used in the Perinatal Period of Risk approach, in-depth case reviews that are used in FIMR, research, such as clinical trials and epidemiological analysis, and stakeholder knowledge of their communities. Together, these four sources of knowledge create the four legs to support a table of good decision-making. And none of these four legs can stand on their own. Sorry, it looks like they're dancing.

All right. So population-based data, like birth and death certificates, census data, and representative sample surveys, such as the behavioral risk factors surveying system, and the PRAMS, the Pregnancy Risk Assessment Monitoring System, helps us to understand how common the problem is, and how different characteristics like demographics and health behaviors interact. However, these data sources only measure things we know to be important. Often, these things aren't even measured accurately or may not measure what we think they measure. For example, what does marital status on the birth certificate really mean about a woman's support system? Also, small areas have small numbers of people. And consequently, estimates are not always precise and reliable. It also takes a long time to collect and process these big data sources, so the data is rarely timely. And usually, you'll see a two- or three-year lag time with these big data sources. And finally, correlations in observational population-based data do not necessarily mean causation, so we have to be careful when we're talking about causation and interpreting population-based data.

So FIMR or case review data here...so Fetal and Infant Mortality Review, which Jodi is going to discuss with us in a few minutes, provides in-depth case review information to help communities learn as much as possible about select cases. Case reviews help stakeholders identify systems, problems, contributing to fetal and infant deaths in the community. If the community reviewed every fetal and infant death case or a random sample of those deaths, then FIMR could be considered population data about the population of death. Not the population of births, but just the population of death. So it's important to remember that FIMR is not representative of the population.

So typically, case reviews only investigate a small number of cases. And I guess that these cases are not usually a random sample or census of the deaths, especially maternal interviewed information, which is only available if the mother consents. And case review information is not representative of the population, and thus should not be interpreted as representative of the population.

So you might think that scientific research should be our gold standard. Just go with what science says. But you'll notice if you read scientific publications, they all have a limitations section. And after a close review, you'll probably notice more limitations than the authors actually ever say. And in reality, it takes a long time for scientific information to provide clear and robust answers. In the interim, we may not have the luxury of sitting and waiting for science to make a conclusion before we take action.

So local stakeholder knowledge and experience. Even stakeholders with intimate knowledge of their community have limitations. One strong voice may carry a lot of weight, but everyone bases their opinions on personal experiences. Likely, not all points of view are represented at the table. It's problematic when everyone has a different opinion and when everyone agrees. So by now, you can see how all four legs of the table are needed for good decision-making. So they're all integral parts of the decision-making process.

So now, I'm going to talk a little bit more about population data and the Perinatal Period of Risk approach or PPOR. So why should we used population-based data? So the large circle you see here on this slide represents the entire population of births, while the small circles only represent a portion of births. For example, Medicaid databases only include births covered under Medicaid, and stakeholder groups often include people who work for agencies that serve the community like those included on the slide. So it's important to remember that the population you come in contact with is not likely representative of everyone. So the population in the Home Visiting Program does not represent your entire population in the community. All right.

But most importantly, everyone receives a birth or a fetal death record. So vital records provide a complete picture of the population. So like it says in bold here on the slide, vital records data includes all babies. So the PPOR approach is an organized way to use population-based data available to the community. The basic method utilizes vital records data, including birth certificate, infant death certificate, and fetal death certificate. Other data sources, like PRAMS, can be incorporated in Phase 2. So Level 2 and 3 Healthy Start sites are required to address population health and the PPOR approach can help guide interventions and monitor success. And you'll see more of that as we discussed PPOR.

So what do you need to conduct a PPOR analysis? Can your community conduct a PPOR analysis? Now, it's important to remember that not all communities can. Even though vital records data are collected in every state for public health purposes, many local health departments have trouble gaining access to the necessary data files. Also, you need a data analyst and appropriate statistical software to analyze these large and often complicated data files.

Because PPOR dissects fetal and infant mortality into four subsets, communities need at least 60 fetal and infant deaths in a 5-year period to conduct a PPOR analysis. With fewer than 60 deaths, rates will have very large confidence intervals and be pretty much useless for decision-making purposes. If your community is too small to conduct a PPOR analysis, you still [inaudible 00:12:05] with them on key population health indicators, such as infant mortality rates, prematurity rates, teen pregnancy rates, and social determinants of health like poverty and insurance coverage.

So why do we include fetal death in PPOR? Well, both FIMR and PPOR include fetal deaths. But why do we need to add this layer of complexity? First off, fetal deaths are a tragic loss for their families and communities, and fetal deaths are much more common than you may think. In fact, fetal deaths are about as common as infant death. Like infant death, fetal deaths are an indicator of a community's health. And PPOR is about using all of the available

information we have to address infant mortality, and fetal deaths are a key piece. Okay.

So what information is available on vital records data? So birth data files contain a lot more information than what parents see on that paper birth certificate that you receive in the mail. So birth certificates include [inaudible 00:13:10] information such as age, educational attainment of the mother and father, county where the baby was born, and much more. Medical history information that is relevant to pregnancy, so like a mother's weight during pregnancy, pregnancy diabetes, hypertension. The birth record also includes whether or not the mother used a WIC during pregnancy, how the delivery was paid for, gestational age, and birth weight of the baby. And if the baby died, the record includes age of death and underlying causes of death.

So PPOR is all about data to action. So vital records data contains so much information, it's often overwhelming. So PPOR is intended to guide communities through the data analysis process by utilizing a series of simple, organized steps to progressively narrow the focus until the community [inaudible 00:14:09] a short list of potential actions that are likely to produce measurable impact. At that point, the community makes decisions based on the other three legs of the table, the resources in their community, and political will.

So the six stages of PPOR approach, including getting ready, conducting the analysis, using the analytical results to develop action plans for targeted intervention, implementing those actions, monitoring and evaluating the actions, and then sustaining efforts by public [inaudible 00:14:44], and leveraging your successes. Step five, monitor and evaluate, often includes repeating the PPOR analysis at a later time to see improvements in infant mortality.

So now, I want to go over with you...I have talked about how PPOR deaths are grouped into four subsets. So these are the PPOR boxes. So although PPOR analysis takes a lot of work, it's really pretty simple for even a lay audience to

understand. So first, fetal and infant deaths are stored into four periods of risk, as you can see here on the slide. So you've got the blue box, maternal health and prematurity; the pink box, maternal care; the yellow box, newborn care; and the green box, infant health.

And so I stored it into these four crates of risk based on their birth weight and age of death. And the periods of risk are named based on the general categories action needed to prevent a death in that period. So specifically, a fetal or infant death who weighed between 500 and 1600 grams at delivery, or technically 1499 grams at delivery, is stored into the blue box or the maternal health and prematurity period of risk. A fetal death who weighs 1500 grams or more is stored in the pink box...isn't weighing more than 1500 gram at birth who died before the first month of life are sorted into the yellow box. And infants who are weighing more than 1500 grams who survived the first month of life but died before their first birthday are sorted into the green infant health box.

So that was a lot of information. But essentially, babies are sorted based on their birth weight and age of death into the four boxes. And after each baby is sorted into the correct box, the mortality rate is calculated for each period of risk.

So like I said before, each period of risk is associated with its own set of risk and prevention factors. So the first stage of PPOR analysis is to determine which period of risk contributes the most to preventable death in the community. We will talk more about preventable in a minute. Each period of risk is associated with a different set of potential preventive measures. Narrowing down to one or two periods of risk helps a community focus on a smaller, more manageable set of solutions. However, there are still numerous actions for each period. The second phase of this analysis will allow us to narrow the list even further, and eventually, the community will have a short list of specific actions that will produce measurable impact. All right.

So now, we will talk more about preventable deaths. Most often, we cannot tell directly from the cause of death whether or not it could have been prevented. How then do we decide which period has the greatest number of preventable deaths? We need to know what mortality rate we expect to see in each period of risk. We answer this by identifying a reference group or a real population of mothers with optimal birth outcomes to determine the expected mortality rate in each period of risk. Our underlying assumption is if a group of adult, college-educated, white women can have low fetal and infant mortality rates, other groups should be able to achieve the same low rate. Any deaths in excess of the reference group rate are assumed to be preventable.

The healthier population provides a realistic benchmark for our community. Each community can choose its own reference group. The reference group could be a group of different ethnic women. It can be the women within their city, in their state, or in their region. But it's a lot easier statistically if the reference group and the study group do not contain the same [inaudible 00:18:58]. We want to make sure those groups are independent of one another. Okay.

So this is an example of how the Phase 1 PPOR analysis looks. So the top row, the non-Hispanic, Black row is the study group for the community with the high infant mortality rate. And in that case, specifically black women in Irving County. The second row is the mortality rates for the reference population, which you can see are much lower for all four periods of risk.

So the math to find our X's mortality is just simple subtraction. So as you can see, the study group mortality rate in the blue box is 5.7, and the reference group mortality rate in the blue box is 1.8. So we subtract 1.8 from 5.7 to get 3.9. And I forgot to mention this earlier, but the rates are per thousand live births. So if our X's mortality rate is 3.9, then there are almost 4 X's or preventable deaths per 1000 live births in the blue box. So here we can see that the blue box, those weighing less than 3.3 pounds at birth, contributes the most to the community's preventable deaths overall. So 3.9 is about 46% of the 8.5, so almost half of the excess deaths. The green box babies who weighed more

than 3.3 pounds survive their first month but die before their first birthday contribute 2 excess deaths per 1000, or almost 1/4 of the excess mortality in Irving County. So this community can choose to do more analysis with an either or both the blue and green box. So simple subtraction to find our excess mortality.

That was Phase 1, the basic PPOR map with our four boxes. So during Phase 2, the community starts by exploring the causes of excess mortality. The community should focus on the causes that account for the greatest amount of excess mortality. So in the case of Irving County, we're going to want to focus on the blue or green box. Then they would use any available data sources, like PRAMS, to examine known risk factors for those causes. For example, if injuries were a major cause of mortality in the green box, the community need to further explore infant [inaudible 00:21:38] practices, say sidewalks and child abuse. Risk factors found to be common in the community are further examined. If possible, to estimate the potential impact of reducing those risks.

Phase 2 differs according to the community's data sources and data quality. Precise estimates are not always necessary because the community is prioritizing about known risk factors, not engaging in scientific research. However, poor data quality can result in large biases that made it through the community, so it's important to consider the data quality in all stages of your PPOR analysis. Okay.

So we're going to talk a little bit more about Irving County and use this example. So for example, Irving County's greatest excess mortality occurs in the blue box. Remember 46% of the excess mortality is in the blue box. So the tiniest babies are contributing the most to the excess mortality. In this case, Phase 2 begins with a Kitagawa analysis, which is just some algebra essentially that determines whether the excess mortality results from too many babies being too small or the birth rate distribution essentially. Or is the excess mortality due to babies who are born too small are not surviving as well as the reference group's babies when they are born too small? And this is called birth rate-specific mortality.

So a Kitagawa analysis is going to help us identify whether we have a birth rate distribution or a birth rate-specific mortality problem. So if birth rate-specific mortality accounts for the majority of the excess mortality in the blue box, then that community may have inequitable access to healthcare for infants. But if the birth rate distribution accounts for majority of the excess mortality in the blue box, then that community is stated to determine which of the known causes of preterm births are having the greatest impact on their community.

So you can see here on this diagram some of the known and measurable causes of prematurity include maternal infection, access to preconception care, maternal stress. Some others may be maternal weight gain, short inter-pregnancy intervals, previous preterm birth, social determinants of health, environmental factors, and much more. So the list is really long. With the numerous risk factors and very different solutions for each of those risk factors, the community shall use data to identify the most prevalent and important factors rather than just selecting interventions at random. So we're trying to target the risk factor that's causing a lot of those excess mortality that we're seeing.

So this next slide we'll skip over quickly, but it's just essentially showing you Phase 1, we identify the maternal health and prematurity gaps. Phase 2, through the Kitagawa analysis, we found that the birth distribution is contributing 91% of the excess mortality in the blue box is caused by having too many very low birth weights for the babies born in Irving County. So we know we have a birth weight distribution problem in Irving County. So on Phase 2, we can explore some of those risk factors for the birth weight distribution problem like close pregnancy spacing, high maternal stress and so forth.

So on this next slide, Phase 2, kind of step two, this is just comparing risk factors for very low birth weight births between Irving County mothers and the reference groups. There's a lot more detail to this, and I apologize for the really

brief overview. But most importantly here in step three, we are going to be able to estimate the potential impact of certain risk factors.

So this table shows some key risk factors for prematurity in Irving County. So being unmarried, which we're going to assume means less financial and social support, is more prevalent in the Irving County study population than the reference group. The unadjusted Population Attributable Risk is 24%. So PAR, or Population Attributable Risk, answers the question if the risk in our communities high-risk groups -- so in this case, unmarried women -- could be reduced to the risk in the low-risk groups -- in this case, married mothers -- by how much would our community's very low birth weight births decrease? So this is telling us that if the risk in unmarried mothers could be reduced to the same risk in our low-risk group, married mothers, we would expect to see a 24% reduction in very low weight births in Irving County.

Now, it's important to remember that this doesn't guarantee that if we could force every woman to marry, which we can't, the Irving's very low birth weight rate would decrease by 24%, because there's these other compounding factors. So even though some unmarried women get married, they'll still have other health problems and things that will not disappear after marriage, which would impact [inaudible 00:27:00] to produce very low birth weight birth. So this is just to help us prioritize the different risk factors and see where we have the greatest potential for impact. So what this does show though is evidence that social determinants of health are impacting infant mortality in urban Irving County.

So just to quickly sum up our Phase 2 analysis strategy. We eliminate risk and preventive factors that are unlikely contributors to the health disparity. And we identify and isolate a few measurable factors that are likely contributors to infant mortality in the community. And that's where we want to target and focus on intervention. So PPOR helps unify stakeholders around the problem and then focus on a particular targeted action plan. Okay.

So the four legs of the table work together. So at this point in this PPOR process, we would consult with the other three legs of the table. So what have we learned from FIMR case reviews? What do we know from the scientific literature? What do we know about our community? Does marital status really represent father involvement? Or are extended families more important in this community? How does it feel to be an unmarried, pregnant woman in Irving County? Are prenatal services accessible and friendly? Are there unmeasurable factors that should be considered? So the stakeholders may want to consider every best practices to improve social and economic support and to decrease stress amongst their unmarried mothers. So after this, the PPOR analysis phase, you would continue on with the six stages of PPOR and implement your evidence-based actions and monitor and evaluate their success and work on sustainability.

So hopefully, after this you can understand what PPOR can do for your community and how it can help you address population rate-based health and infant mortality in your community. So now I will turn the time over to Jodi to discuss Fetal Infant Mortality Review.

Jodi: Well, hello. I am delighted to be talking to you about Fetal and Infant Mortality Review. It has a long history of working with Healthy Start. The original Healthy Start programs actually had FIMR programs with them, and so many of you are familiar with this process. And in a minute, we're going to ask you some questions about it.

So the purpose of what I'm going to be talking about is honestly a commercial to help you think about using FIMR within your programs. If you're all the already using it, that's amazing, and the NFIMR program would like to help you. It is an amazing action-oriented community process. And one thing to think about, too, is that PPOR, I think, you need an epidemiologist. You need a number of people that help you with that process. And FIMR, you can still get wonderful information from FIMR, and many FIMR programs do not use PPORs. So ideally, you have multiple ways you are looking at data, but you're

really not limited to having all four legs of the table in terms of what you're doing.

What I'm going to be talking about is FIMR processes and principles. What happens with the Case Review Teams and Community Action Teams? Think about some members of your community that could be involved in FIMR, and then what you need to know in terms of actually doing a FIMR in your community. And what we're trying to do is really drill down to what is the cause of death. And if you could just fill out this little survey for a few minutes, that would be wonderful. It should have popped up. I hope that whether your Healthy Start program is associated with the FIMR or not. Oh, excellent. That's good. Almost half of you are. And we'll keep getting that information. So if it's still on your screen...so many of you are familiar with it.

So I'm really going to give you an overview about what are some important things to know about in terms of the FIMR process. Okay. First of all, the key components start with case selection. And for some communities, that can be decided by ZIP code. It can be cause of death. It can be one type of death, prematurity. Some cases started with ZIP codes and then went to looking at PPOR as part of their way to define what cases they should really be looking at. Because this is an opportunity to drill down and understand what are the factors surrounding this cause of death. And so cases are selected. Records are abstracted that includes medical records, social services, home visiting records, police reports potentially. And then the other component of it, it is so essential is the maternal interview.

The maternal interview is really one of the reasons that I ever got interested in FIMR in the first place because we ask consumers what their perspective is. Over all, the FIMR process is looking for gaps in the system, ways we can improve the system so that it's de-identified. And we're interested in finding out from mothers and fathers what do they see that could have made a difference in terms of their situation. So FIMR is different in that it's de-identified and that we have that consumer input, which is frankly the only way we're going to understand what the source of many of the infant mortality issues are. We've

been counting infant mortality forever, and we really need to take a look at what families are telling us in terms of their situation and how it can be improved. And that kind of information is what we're looking for.

And so the case is summarized, and we find out that some of the information may be inaccurate. One statement I was looking in talked about how birth and death certificates were not totally accurate. And that was a huge issue because it was related to funding for their program. And so we find out what the mother says and then look at what the records actually say to tell us what are the issues with this case. So the information goes to the case review chain, and they look at it, discuss it, and then decide what are the recommendations. How could the deaths have been prevented? Or what contributed to the death?

So they make recommendations. And then that goes to the Community Action Team, who are the movers and shakers in the community that can actually make the change happen. And so the Community Action Team then looks at the recommendation. They prioritize and then they decide what they want to do relative to those recommendations and what they can fix. You want people at the table that can fix it. And we're going to talk a little bit more about that so that we can fix the system and improve health in general. And we used to continue with quality improvement circle here. We start with data gathering, do a case review, community action. We see changes. And then we go back and start over.

And I'll give you an example. One state actually had issues with the fetal mortality. They had a huge campaign that the Community Action Team started that was for the community in general, for providers, for families, and for pregnant women. But they found that some of their literature could be improved a little bit. The only reason they knew that was because they continued to do maternal interviewing. So they learned that, so they could revise it and make it better the next time. So it's really about having that circle, and you keep moving through the circle to make sure that you are delivering the best care that you can.

So as a resource to you as a Healthy Start program, we have things on the website. In fact, we've actually got a special place for Healthy Start. You can search for topics now. We have a Listserv I hope you'll join, and you can join up right from our website. We've got webinars and requests for information. We are funded by the Maternal Child Health Bureau, and so we want you to use the services. And we are charged with helping Healthy Start programs. So we are there to provide technical assistance as you need it.

Now, on our website, we have a four-minute video that gives you the FIMR process. And that's Janet Smylie from Alabama there on our website. And so this is a nice overview of the FIMR process. It's only about four minutes. We were going to show it, but there were some technical issues. You can go into the website and take a look at it. Here are some pictures from it. And the idea is to give the viewer an overview of the FIMR process. And so I would encourage you to use this video with new Case Review Team members. If you want to understand more about the process, go ahead and take a look at it. It will give you some information about some of the things that have happened throughout the country. And so this is just a nice overview, new Community Action Team members. This is a good orientation piece for the community to understand what the FIMR process is about.

And again, the key piece of this is the maternal interview, which is a standardized home interview with a mother who's had a loss and she tells her story about what had happened. And usually, to successfully have mothers participate, one approach is to encourage them that we are interested in what happened, and we're trying to find ways to prevent it from happening to other women. And so that it is what the FIMR process is all about. And frankly, we need the mother's story.

One of the things we learned with a program we did on life course or what local programs did, they found that fathers were very supportive to mothers. And so we've rediscovered fathers again. So when you think about maternal interviews,

think about family, potentially including the father and other family members that really give such a devastating experience that we want to hear what system issues the families have identified.

So the other thing we found out, and Allison talked about this before, is that most of the related to the deaths that would be their contributing or causing are really social determinants of health. We're finding that in the Case Review Team, it's important to look at what is going on in the family situation. And we're going to talk more about how we bring the right people to the table so that we can get solutions and make a difference in the community. So life course concepts are critical to this whole process. So FIMR really has two key components to it. We talked about case identification and then the data abstraction. It's all de-identified so that you never know who the family is or who the providers are. And this has been reviewed in the Case Review Team, and then that goes to the Community Action Team.

So let's talk a little bit about the Case Review Team. That is a multidisciplinary group. The meetings may be one to two hours. It could be three to five cases. And the idea is really to discuss the issues and then make some recommendations. So after listening to these de-identified cases, what does the group see as important to solving this particular case? And then you group that and look at trends over time.

So this is an example of some of the Case Review Team members that are involved. And it really depends on what are the issues in your community. One example we've had, and this is one of the meetings that I sat in on. The mother had a fight with her boyfriend. He left in the morning. She started noticing decreased movements. She called her mother for a ride, but it took a couple of hours before her mother got there. And tragically, the baby died in utero. And so transportation issues was an important piece for this family. And so we would want to have someone from transportation at the table. And as it turns out, there could have been away for her to have other transportation to the hospital, but she either wasn't empowered to do that or didn't realize that it was available.

Now, since many of you are connected to FIMR teams, could you type in down in the little chat box a recommendation or two that you've had from your Case Review Team, the kind of things that people have recommended? If you all could just type in a couple of those as you think about how your FIMR team worked. Yes, I would like it to be more interactive. I don't see anything yet. Go ahead. Just type in a recommendation because I'll show you some of the ones we've had. I think you just have to type in down in that bottom box and then you can just send it to everybody if you want.

Oh, good. Ask a question a different way. If you had been to a Case Review Team, give me...here we go. "Change in bus routes to include neighborhoods with greatest needs." These are recommendations from a Case Review Team. "Education prior to discharge." "Case manager at hospital for postpartum women." "Fetal kick count training to providers, and now common in Delaware." So Delaware actually was my example earlier about looking at fetal kick count and making that more of a standard service.

So those are some examples of what Case Review Teams recommended. So nationally, the major one that has been recommended by Case Review Teams is bereavement support for family. That's one of the things that we'll have started with. And what we're see more of now is mental health and substance abuse. And then of course we have prenatal access to care and being able to get to care. So the Case Review Team takes a look at the case and then they make some recommendations. The idea is really to take action. It's not to just ruminate over what it is we have to do. And I was impressed. I found a Bruce Lee quote about that.

So the next phase of the system is the Community Action Team. And this is the group that needs to come up with creative solutions, and they are the people that need to be at the table for making change. For example, in one city, the Community Action Team is in the mayor's office. Politicians can be very helpful with moving action along.

I think we have a survey question here. Do we? Yes. And this works for Healthy Start. "Is your Community Action Network linked to your Community Action Team?" So if you could just take a minute and tell me if it is. If you don't have a FIMR, then probably not. But it could be. Because the Community Action Network is very similar to the Community Action Team. And you're going to hear more about that from Carol Isaac because they used their whole system to make it work in Omaha, in Douglas County. Good. Excellent. So the Community Action Team really depends on the community that are the movers and shakers that can make a difference. And so they develop strategies for implementation. So in Delaware, it was the Community Action Team that put together the plan to really get a kick count program in all levels of the group.

Okay. Again, what I'd like you to think about, and you can put this in the little text box over here --because honestly, I'd like to look at these things later -- is could you think about two members in your community, not people, but the organization that you think would be appropriate to put on your Community Action Team or your Community Action Network? And so I'm just hoping for more information. So if you could just type in a couple of those, that would be wonderful.

"The early intervention people." Yeah, because it really depends on the type of problems you've got. There's going to be a core group that are involved, and then you bring in other people depending on what the problems are. Teresa has County Commissioner. I love that. I love politicians. It can help you. "Comprehensive perinatal service." "Provider's ambulance." So that you really have to think outside the box about who can make it work for you. Who are the mental health professionals that you want at the table to either make the services available or help you legislate for getting the services available? "So mother and father," that's another one. Parents can be our biggest assets. And so thank you, Sarah, that is excellent.

Okay. So in setting up a FIMR...and again, I just try to give you a broad brush of FIMR and how it works. So first, you have your target population. Make sure you're coordinated with other death reviews. And then there are always legal and institutional issues around getting medical records, but we have a lot of that verbiage that can help you with it. How are you going to collect your data? You want to make sure you formalize policies and procedures. And the key thing is really community support and training. And we have a lot of resources that can help you with that.

And so for Healthy Start, if you go to the FIMR website, just search Healthy Start. We have a one-page handout that many of you I hope have had that talk about it. And then we have a guide for communities. And some tell me that that really does everything. I think we've got one more survey question, but it's really kind of a joke. But please fill it out. So if you want more information about FIMR, this is where you can go. Ah, excellent. Okay.

And finally, I would like to say thank you. Working with families who have a death is really hard, and I know that. And wanting to prevent the death, you are to be commended for that. It makes a difference. What you're doing makes a difference, and it's appreciated. Infant mortality is a most sensitive matter, and we need to change our numbers. We need to take care of our families. Thank you for all you do.

And finally, this is just contact information. This will be on the slide. And I come from Baltimore. And we've got great some sports teams and crafts. So now, Carol Isaac is going to tell you about how they've actually put all these together up in Omaha. Amazing work that they're doing. Carol.

Carol: Thank you, Jodi. I appreciate that. I'd like to take a few minutes to pull some of this information together and discuss FIMR and PPOR from a local perspective. As background, Douglas County is the largest county in Nebraska with a population of a little over half a million. The largest city, Omaha, is also found in Douglas County. And here's a watercolor for skyline, so I hope that

you'll come and visit us. Countywide, our health disparity rate between Caucasian and African-American women has consistently dropped over the last five years. That's something that we're just very pleased about. It's dropped from a three-fold disparity to less than a two-fold disparity. In fact, our current rate is 1 to 1.5. However, infant mortality rates remain high in our Omaha Healthy Start target area.

Just a few numbers here. As far as population diversity in our state, we are overwhelmingly White, non-Hispanic, with Black non-Hispanics making up a small percentage of the overall population, and Hispanics are at 9.2%. We do have a number of [inaudible 00:51:05] in Nebraska. But countywide, our Hispanic and Black non-Hispanic percentages are close, between 11% and 12%, with White non-Hispanics over 70% of the population. In our Omaha Healthy Start target area, White non-Hispanics and black non-Hispanics make up the majority of our population at 40.1% and 46.2% respectively.

Our next slide focuses on birth and death over a three-year period. In our Omaha Healthy Start target area, the infant mortality rate is 9.5, compared to 5.5 in Douglas County. The teen birthrate is at 13.1% in the target area, while that's 6.2 countywide. And lastly, the percentage of low birth weight infants in the target area is 12.1%, compared with 7.5% in Douglas County. So that's a short overview of what we look like in this area.

As far as our history, in the late 1990s or early 2000, Douglas County realized that we had a high infant mortality rate. In fact, we were the seventh highest in the nation. And the primary organizations who partnered to address this issue were Omaha Healthy Start, CityMatCH, who brought their PPOR model to the table, and then Douglas County health Department, who formed the Baby Blossoms Collaborative, at that time, about a 40-agency collaborative dedicated to decreasing the infant mortality rate in our county. Now, the healthy department did adapt the FIMR model in 2006. And at that time, BBC became the Community Action Team or CAT in the FIMR cycle, as Jodi was talking. I think habits die hard though. In our community, to this day, when we say BBC,

usually people will think of the collaborative. And when we say FIMR, they think of Case Review Team. So we are still educating about that.

When we talk about integrating FIMR with PPOR, I can't emphasize really how important it is to determine where your excess deaths are coming from. We have talked to a lot of FIMR programs across the country who are reviewing a lot of cases and developing a lot of recommendations, but they're really not sure what to focus on or how to prioritize the resources because they're skipping this step. When you determine where your excess deaths are coming from, you can focus your resources and you have a much bigger impact. So that's one nugget of wisdom that I will give you.

I also wanted to mention that since we started out with BBC or Baby Blossoms Collaborative prior to FIMR and the only information we had was population-based data, we've always had a strong population-based focus. Then you do have a comparison point with your case-based data, and it does give you a bigger picture. You don't want to stay down in the [inaudible 00:54:17] because it's not good to stay down there too long. And then back to the boxes that Allison was talking about. Our highest rates have typically been in the blue box and then also in the green box.

So as far as just examples of integration, let me just give a few. The first one is case review, and qualitative information can find underlying reasons for disparities. PPOR, in the case that among African-American mothers, 50% of excess mortality is on the infant health period of risk, which is the green box, and [inaudible 00:55:00] mortality rate is higher among African-American infants than other groups. The stakeholder group then uses case reviews, where they focus on the qualitative data, much of it is probably environmental, and community meetings to learn about infant sleep practices in the African-American community. This may then move into some messaging that's developed for a targeted or community-wide campaign. And this is a fairly old example from our community. Many of these issues come up again, and I will discuss this again later in the program as the emerging issue that we're dealing with.

So another example is population-based data can confirm case review findings. In this example, mothers in death review cases said they didn't know how to recognize signs of early labor. And we have run into this a lot. The community considered an educational campaign, PPOR data indicated that there were a high number of variable birth weight births that accounted for 80% of our local excess mortality. PRAMS data indicated that only 60% of high-risk moms reported that their prenatal care provider talked about the signs of early labor. So this example shows population-based data confirming case review data. And that certainly does happen. It happened to us a fair amount recently. In fact, when we noticed the downward trend in our health disparity, it was mirroring our population-based data.

My last example, population-based data can test stakeholder assumptions. Some infant death led stakeholders to believe that many mothers were not seeking or receiving prenatal care. The community was considering a broad prenatal care media campaign. However, vital records data indicated that 99.5% of mothers were receiving prenatal care. Further analysis of vital records data show that only certain high-risk groups were not receiving prenatal care, and so our efforts were targeted toward those groups.

So I wanted to talk just a minute about how Omaha Healthy Start has participated long term in our FIMR cycle. And Jodi talked about the FIMR process. And the FIMR cycle has been around a long time. I'm perhaps using an old picture here, but we've used it for a long time. And I think [inaudible 00:57:36] FIMR process fairly well.

So with Omaha Healthy Start, there are staff review cases for CRT or Case Review Team, and they see firsthand the contributing factors that are driving some of these deaths. And for our CRT, we actually look at right around 171 potential contributing factors. So there are a fair number of them. They're also able to bring in the social component or perspective. The Omaha Healthy Start staff, which sometimes gets overlooked by the medical professionals around the

table...and truly, our richest discussions take place when we have almost an even mix of our medical folks along with our community experts. I wish more people could be there to see this and hear this, because it's just really pretty neat to see. So the OHS perspective helps craft the CRT recommendations which drive the community action plan.

Now, Omaha Healthy Start has always had staff participation on BBC. Even prior to the FIMR model, and eventually, again, BBC became our Community Action Team. So they've really played an important part in developing the community action plan, which we develop every two years or revive every two years, where we identify goals, objectives and action steps which then set our plan into motion. And then of course, the goal of the plan is system change, which hopefully impacts the overall the overall infant mortality rate and decreases the health disparities.

Now, with the addition of CAN, or the Community Action Network, to Omaha Healthy Start, the larger community has become involved, and our local Healthy Start has really leverage their story even further. The Omaha Healthy Start CAN is made up of members from their general council. This is a group who is knowledgeable about program operations and issues. They're a participant subcommittee and the number's from BBC. One focus of this group is collective impact. And I between if you're with Omaha Healthy Start, this is a term that you're becoming familiar with. Simply put, collective impact is bringing partners together to work at solving complex social and health problems that really don't have a single design source or solution. Those are the problems that bubble to the surface that you may have tried to problem solve within your program, but you haven't been able to. They're significant and they're just not going away. I facilitate the OHS CAN, and we're just getting started with this process. But we're learning more about it at each meeting, and we're often learning how to work out together to achieve collective impact.

And I wanted to end by sharing two examples of linkages between FIMR and CAN. And the other speakers have talked about counting kicks. And how these got involved is Count the Kicks for us is a grassroots campaign out of Iowa that

is focused on counting fetal kick movements. And they just have a really cool app you can put on your phone, and there's a lot more to it. But at the heart of it, its strength lies in empowering women and providing more accurate information for physicians. At our collaborative, our CAT, not only do we develop the community plan, but we have quarterly meetings where we invite keynotes to help all of our BBC participants connect the dots in our community, where they learn about new services, what the hospitals are doing from a community perspective. We also look at emerging issues nationally, and we try and identify if they are a local issue.

This program, Count the Kicks from Iowa really turned out to be an emerging program. So we developed a community that looked at it, and most of that committee of interest ended up being home visitation agencies, including Omaha Healthy Start. Omaha Healthy Start incorporated this program into their Home Visitation Program. So this was a FIMR linkage, the Community Action Team linkage. That program has really taken on a life of its own. It's also moved out into the physician communities through our new Nebraska Perinatal QI Collaborative. And so we talked with a physician who is a part of the collaborative, who is well known, one of those guys who has his ear to the pavement. So other physicians go to him if they hear about something and they say, "Hey, what is this?" And he'll say, "Oh, this is what it is."

So this Count the Kicks from a grassroots perspective has just developed a life of its own, and we couldn't stop it if we wanted to. But OHS took advantage of it by incorporating it not only into home visitation, but another potential linkage is Omaha Healthy Start works closely with the local federally qualified health center that has a medical clinic. One of the clinic nurses [inaudible 01:03:07] from CAN, and so we have a CAN linkage also. So it just goes to show how these things, just these partnership just develop a life of their own and they move across the community.

Another example is the SUID, Sudden Unexpected or Unexplained Infant Death, community campaign. If you're like us, we've seen a rise in our SUID/SID deaths recently. I know there's been a national increase. We've had a

local increase. And that's become one of our emerging issues. A BBC hot topic is what we call it. We have an OHS staff member on this committee who has made home visits for many years in the OHS target area. She was able to confirm case review findings and plans to assist us with our messaging. Things like with a number of our deaths, it's not the mother or the father or a grandparent who's there, but it's somebody else, not even a family member, who finds the child. Or that many of these kids are in adult beds. There is a lot of, I know, softer bedding in the bed. She was able to just report back what she's finding, what she's seeing, really, over the years. So that's a link with FIMR.

Now, another potential link is we have a child care provider who sits on CAN who has raised generations of families in the target area. She knows other matriarchs in the area who do the same type of work [inaudible 01:04:43] generations. Now hopefully, these women will help us to determine how to get this message out, our SUIDs campaign message out into the target area. So once again, you have a FIMR linkage and a CAN linkage.

So anyhow, I guess that's the end of my presentation. I hope that some of these examples were helpful. And I will turn it back over to Naomi.

Naomi: Great. Thank you, Carol. And thank you, Allison and Jodi, for three excellent presentations. We do have a couple of questions. A questions for you, Carol. Many of the examples you have given have involved successful partnerships. Do you have any advice for the rest of us on how to develop those successful partnerships?

Carol: That is a good question, Naomi. First of all, you need to have a meaningful cause. If you want to rally partners, you need to have a cause that resonates with them, and infant mortality really does. I would be surprised if anybody in their community would not find people who have an interest in that topic area because in so many of our communities, we have a significant infant mortality rate. So first of all, it's a meaningful cause.

And second, what we found is early on, we started out with three main partners. And these are some things that come to mind. I think I have mentioned Omaha Healthy Start back in the late '90s, Douglas County Health Departments, and then CityMatCH. These were key partners. And I bet you can identify two or three key partners in your community, too. Well, partners invite partners. Many times, they are the best people to know who to invite. And Jodi gave some good examples, and I think tried to prod us into examples of people who might be good partners to sit on CRT and CAT. And in their manuals, they have some great examples. In fact, when I looked at those at one point, when I first started close to five years ago, they almost near to what we have sitting on CRT and CAT. So if you're looking to recruit, that's a place to go. And also they mention some partners that may be don't...they aren't traditional partners and don't necessarily come to mind initially.

But maybe even a bigger question is how do you keep your partners engaged? Because many times I haven't had a problem pulling in partners, but over time, it's keeping them engaged. And I guess this is just some simple things come to mind. One of them is you have to make sure they have meaningful work. You also have to respect their time. And then even though infant mortality is a huge issue and should be able to see a decrease in your rates where your health disparity is very meaningful, eventually you need to think through what other benefits can we give this group? How else can they benefit?

So just some examples. With our CRT, I'm a nurse, and I am not in love with meetings, especially meetings that go on forever. So our CRT is a fine-tuned machine. We have physicians from all the health systems. We have people who are just very prominent in our community that we cannot waste their time. So we have just a very exact, a very workable process that we put in place. So people know the meeting will start at 8:30. It will end at 10:30. And then in the middle of that, we will do very meaningful work that makes a difference.

On CAT, what we call our Baby Blossoms Collaborative, that has waxed and waned through the years. And as I was talking to my supervisor about how to get more people involved, we have gone back to a quarterly meeting where we get keynotes. Right now, we're working through some of the CEOs of our hospitals. We have two medical schools, five or six nursing schools in Omaha. Some huge hospital systems that are doing community work that people want to know about and want to know how to partner. So we're getting many of those executive directors and maternal child health to come and tell us what their initiatives are and how we can partner with them. So that has drawn people back in.

And I mentioned that we've also identified emerging issues at a national level. Then we asked our BBC partners who's interested. We developed committees and our first question is, "Is this a local issue? If it is, then how are we going to pursue it?" If it's not, we put some simple surveillance on it usually and just monitor it. And of course, the community plan is in there. And typically, we will call people. And if they can't come at that time when we're developing our plan, we ask who else we can send? So we have a good number and a mix of people around the table. A long answer. I hope that was helpful.

Naomi: That was incredibly helpful, thank you. And Allison, I have a couple of questions for you. Access to vital records is highly restricted in our state. Do you have any advice on accessing these data?

Allison: I'm looking at Carol. This is a problem that we so often run into. All right. Carol, I'll let you answer this. You will be better at it. Carol's had a lot more experience in this department than I have.

Carol: I'm the old lady of the department. So sometimes it helps to show your vital records department that other states do distribute that. Show them what they've done with data in other places. One resource for this is the [inaudible 01:11:03] around that it really is a good way to compare. Sometimes it's just a matter of developing relationships, too, really calling them up, getting

somebody at the seat on your side, maybe someone from Maternal and Child Health, a Title V, on your side to help you approach the state vital records people. You can get vital records from the federal government. It's just too late to use it if you need it from your state or your county. But it's usually just a matter of filing a form that you won't share information and you won't have the data be identifiable. It can usually be done. Sometimes it takes a while, but it can usually be done.

Carol: This is Carol Isaac. Can I maybe chime in there, too?

Naomi: Oh, absolutely.

Carol: I just wanted to mention that we have a close relationship with our Nebraska Maternal and Child Death Review Team, and they have helped us out in that area. We house vital statistics at our health department. But they were aware, actually of...it's not a legal document, but a statistical form that the hospitals put out which they were able to get for us, which we use extensively and gives us some additional data. But they also help us out with just other reports and different things we need. So I'm not sure what the relationship is with that entity, but it might be worth cultivating.

Naomi: Okay. And Allison and Carol, I have another question for you. How often do you perform PPOR analysis? We need five years' worth of data in order to get vital results. We completed one for 2007 to 2011, so I was planning to do another analysis for 2012 to 2016 so there was not overlap between the two study periods to see if things have changed. What is the typical approach? And if you need me to reread that, I'm happy to.

Carol: So usually people do it when there's a need when there's an interest. And there's no rule that you have to have non-overlapping. A rolling average is acceptable for PPOR. You can watch it change. But yes, having five years means that you'd only change it a little bit every time. They actually do this in

Douglas County. We redo the analysis every year because it's gotten to be sort of routine, it's pretty easy to do, says I who don't do it. But it can be done as often as every year or as seldom as when is the next time people are interested in worrying about how to allocate resources.

Naomi: Thank you. And Jodi, I have a question for you. How can I learn what other FIMR programs have done to improve safe sleep? Do you have to have two teams? Does anyone have one team?

Jodi: Okay. The first is how to find out what other programs are doing. If you go NFIMR.org and look across the top bar, you'll see programs. And if you click on that and then click on state, you can see what different states are doing in terms of safe sleep. So that's one way to find out what other states are doing around their efforts with that. A couple of states, there are many states that have pretty exciting programs with what they're doing. So that's one place, as well as the new nap centers that talks about safe sleep that's out of Georgetown. And that's just a national program that is looking at safe sleep. So that's what you can do with that.

As far as some FIMR programs has combined case review with Community Action Team, we have shown an evidence-based...FIMR's an evidence-based project. And that was evaluated at Johns Hopkins a few years ago and said that it is an evidence-based approach to improve perinatal systems of care. When there is only one tier, when there's a combined case review and Community Action Team, it's not as effective. But what some programs do is that they may do case review for a few months and then aggregate that information, and then return the team into community action and add some other people to it. And so that's not the best way, but that's okay. I think the important piece is to use the process in terms of getting the de-identified information and looking at recommendations.

Naomi: Okay. And I have another question. If it take a few CRT meetings to develop a complete recommendation to give to the CAT, what are your

recommendations for giving the CAT meaningful work while waiting for CRT recommendations, especially if the recommendations will not be published until the -- I'm sorry, it' getting cut off -- year of the CRT meetings. If you give a few recommendations to the CAT earlier on, how do you ensure that they are informed by enough data if only a few cases have been reviewed?

Allison: I think that that can be a challenging piece and I'm going to ask Carol to answer this, too. Usually Community Action Teams may meet once or twice a year, so they aggregate the information from the year. There is a humble county out in California, aggregated a number of years' worth of data. But in the meantime, they were still making some programmatic changes, particularly around safe sleep and some other topics. So that I think Community Action Teams are not going to meet every month the way Case Review Teams meet, and some of that does depend on volume. And I think it is important to look at the population-specific data to make sure everybody's on the same page in terms of what you should be doing to take action in your community. How has Omaha done that, Carol?

Carol: About four or five years ago, we developed what we call adapt analysis process in CRT where we constantly have our recommendations before us. And so as we complete, say, three or four cases out of CRT meeting, we will come up with our top five contributing factors and then compare them with our recommendations because we have recommendations in certain categories. We have a preconception health recommendation to prenatal care recommendation, from infant health, safe sleep, and then other, which usually applies to just records issues and things that we're having.

But each of those top five contributing factors should sit within...you should be able to place them or match them with a recommendation. If it's covered by the recommendation, the recommendation stands. If it's not, you can revise the recommendation. Or if there's no recommendation that addresses that particular top-five issue, then you can develop a new recommendation. So in each CRT, we are evaluating and sometimes revising. We really don't revise as often as you think partly because our recommendations are fairly global. So those

recommendations then are taken every two years to CAT, where they're accepted by CAT. And then we go through this community action plan development where CAT will meet maybe two meetings in a row. And those might be two months in a row or we might skip a month. And then our plan is put into play for a two-year period.

For our CAT, we have developed enough and we have enough people that we typically meet quarterly. And one time during that year, we had a real focus on population-based data. And then we report out on that. We compare it with our case data. We look for themes, that type of thing with CAT. So is that what you were looking for, Jodi?

Allison: Yeah. The Community Action Team really does need work to do in terms of implementing recommendations, so you build it around what needs to happen. And the timeline can vary depending on the volume and the type of recommendation.

Naomi: Okay. Well, I want to say thank you again to Allison, Jodi, and Carol for three great presentations. And before we end, I want to ask that everyone, please mark your calendars for an upcoming webinar this month on September 24 at 1:30. There will be a special initiative webinar called Healthy Start 101 for Frontline Staff. You can get the registration information for the webinar from the latest EPIC Center alert, or visit the grantee forum on the EPIC center website. Keep in mind that the website contains all recorded webinar information, transcripts, slide presentations from webinars that have taken place. And a final reminder, please complete the evaluation survey. You will receive a link as soon as we close the webinar.

This concludes our webinar, and thank you very much for your participation. Have a great day.