MCH EPI Conference

EFFECTIVE PARTNERSHIPS AND TOOLS FOR PUBLIC HEALTH PROMOTION: WORKING TO INCREASE AWARENESS OF PRAMS AND IMPROVE PROGRAM SUSTAINABILITY

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BARBARA FROHNERT: So today I'll be talking about a collaboration that I did with Minnesota diabetes program at the Minnesota Department of Health and I'd like to describe the collaboration process, the results of the project and the benefits to each partner.

I think specifically for new programs, maybe ones that don't have so much analytic capacity on staff, that this is an interesting way to maximize the PRAMS data and get it into the right hands.

Minnesota is a 2001 grantee. Our data collection began in mid-2002. Data analysis really began in earnest, the 2003 data, which was our first full year in mid-2005. We have fairly limited resources on the Minnesota PRAMS project. We don't have a dedicated analyst.

We just have a data manager who's been with us from the beginning, and myself, the project coordinator.

And I do most of the analysis in addition to my other things that I have to do every day. But mostly what we've done is pretty simple descriptive analysis. And while there was initially some interest in sharing analysis data sets, we hadn't yet ever followed through on that.

It was a little early. We didn't have a whole lot of data to share yet. But this was kind of the trial run for that process.

Our collaboration is fairly simple. It was within the Department of Health, two divisions, the Community and Family Health Division and Health Promotion and Chronic Disease Division. We had three partners in the Minnesota Diabetes Program. They actually initiated this process. They had a senior epidemiologist, junior research scientist, and a senior research scientist and myself in the Minnesota PRAMS project.

And I think what really made this relevant for this discussion is that we were fairly well matched in terms of what our strengths and weaknesses were. What my weaknesses

were their strengths, and what their weaknesses would be were my strengths. So what initially was a simple data request, they wanted a cut of the PRAMS data, became a real partnership.

And Minnesota PRAMS really had the most knowledge of the methodology and the data set. And we knew how to analyze it according in the correct way. We had more experience with analyzing complex samples survey data using SAS in the Sudan. They had a very experienced team of analysts.

They had extensive knowledge of diabetes. They are the subject matter expert for this subset of our data. They had just come off doing some interesting research looking at birth certificate data, diabetes on birth certificates.

And so they were kind of moving beyond that. They felt that birth certificates were inadequate, and they had known that there was information on PRAMS. So they came to us.

One of the great things about their program is that they've been around for a very long time. They're a very well-established program and they have a broad partnership. The

Minnesota Diabetes Steering Committee was established in 1981. And it really has a broad representation of different public and community partners that are interested in diabetes. And it really has statewide reach.

Let's postpone that. All right. (Laughter).

And their goal is to exert influence and advocate for collaborative action and policy change to benefit diabetes control and prevention in Minnesota. That does call in -- they're the communication tool for this specific topic in-state. And it's not just the Department of Health. It's a pretty big group and it's been around a long time. So we want our data to get into these people's hands, and we'd like to have it be done in the right way.

So this was our first attempt to share PRAMS data with external researchers. I know the Department of Health is not really external, but kind of is external.

The diabetes program contacted Minnesota PRAMS to obtain the data set. They wanted to do a secondary data analysis. Through that we formalized our process for data

requests. And that was something that, as a new program, we had written it down, but we hadn't done it. And so we really had to come up with a more efficient way of doing it.

The diabetes program piloted this process for us, and we had their request reviewed and approved by the Minnesota PRAMS internal steering team and I prepared the analysis data set for them which was more complicated than I expected it to be. I helped them identify the variables they would want and maybe some they didn't know they want or need.

Through this process we identified the ones that we weren't really so keen on sharing, because of confidentiality reasons. So we kind of had this set of variables that we're just, you know, you need to have a special reason to get these variables.

And then there was just the logistics of preparing the subset for them, the formats, files and a secure transfer to their server.

When we started exploring the data, we both sat down together. We worked together with coding, interpretation when our variables didn't quite synch up. PRAMS is self-reported diabetes from the survey was -- we looked at both phase four and phase five versions of

the survey, because the diabetes question did change quite a bit between the two surveys. And we also use a pre-existing diabetes question. And I think there's a couple other states that use them.

And so we had to develop this matrix to figure out how to code people as prediabetes or gestational diabetes. Without their subject matter expertise I don't know I would have made the right call. So that was really crucial.

I think probably all of you that do analyze the data realize it's really broad and you can't be expected to -- I don't expect myself to know everything about every topic. And so I really do like to find the right people who can help make the right decisions.

Otherwise, it's a little overwhelming. The diabetes from the birth certificate, we don't use the 2003 standard. So there was issues there. We found out that our diabetes variable could have been improved, because we actually do collect pre-existing and gestational diabetes separately. And so that led to us changing how we code that variable in the future. And we did a special request to match/merge the data so we could get that variable split out for them.

And then they also wanted to try applying risk factors that they look at the general population to the PRAMS sample to see if they could estimate mothers who are at risk of diabetes mellitus. And that was kind of an interesting attempt and it didn't really go anywhere.

But one of your risk factors is being over 40, your sample size gets pretty low in this particular population. We found that the diabetes data from PRAMS survey was very useful for gestational diabetes surveying. But it does likely overestimate what they were expecting was about 5 percent in Minnesota. In 2004/2005 it was around 7 percent, but we think it probably has to do with the broad high blood sugar diabetes question wording. We found it was less useful for pre-existing diabetes surveillance, even with our standard question, which is even more specific to pre-existing diabetes.

We found that the core question missed about 33 percent of pre-existing diabetes cases that were identified by the other question and that 13 percent of the PDM cases had kind of ambiguous response in the core question.

And the detailed results are going to be presented in a poster at the MCH conference later this week; so if you want more, I'll give it to you.

The best help to us was how to influence the phase six diabetes questions. When they really got their hands into what does this mean, they were very opinionated about, no, scrap the high blood sugar. Be specific. Don't write it this way, write it that way.

And I don't know how happy everybody was with how much feedback they gave on the phase six survey, but we went on a little longer than maybe we should have. But we really feel confident that the new core questions that are very specific to Type I and Type II pre-existing diabetes and gestational diabetes will provide more valid and reliable information. So we're excited about phase six, and so is the diabetes program.

And we actually added a post partum diabetes high blood sugar screening question to our survey, because we felt that with what they had shared with us about why this is such a big issue, that about 70 percent of women who have gestational diabetes could go on to develop full on Type II diabetes.

But this is a bigger issue that I would have ever realized and it slowly eked up in our priority list. We know there's a need for true gold standard for diabetes data source and

that's what we should be using to explore the validity of the PRAMS data and birth certificate data.

So our partnership got a little bit bigger, because with the results, I'm here presenting this, and we have the poster that's going to be at the MCH conference later this week.

And also, when I go around and do local presentations, I talk about diabetes more, because I feel like it's a bigger issue than I had realized. So I kind of plant the seed.

And for their part, they presented the results of our work at the Diabetes Translation Conference in April, I think, of this year. So that gets PRAMS away from just PRAMS Maternal Child Health and into the chronic disease spectrum, which is very important.

And they also presented at the Diabetes Surveillance and Data Review Work Group, so that's the Minnesota target audience.

And the benefits of the collaboration. This was our first opportunity to look at the quality of PRAMS data by comparing it with another data source. We feel like we've improved the variable from the birth certificates and future data sets.

That we developed and refined the process for data sharing. We have a strong working relationship with the subject matter experts. I guess I knew that phrase more than I thought I did for input and development of the phase six questionnaire and we have an automatic market once when we get our first data set for 2009.

And we really feel we'll be able to market the MCH perspective and our population of interests to the diabetes program partners. And that is probably the biggest impact that we will have. The diabetes program had collaborative learning of PRAMS data analysis methods. They didn't have to start at square one. They lobbied for improved survey questions. And they got some. They got their postpartum blood sugar screening. And they were able to integrate PRAMS data into the Minnesota diabetes plan which is setting up their goals for 2015 and to use it to evaluate their progress towards those goals.

And the big thing that they offered us is to market their diabetes issues to the MCH audience. So overall, phase six questions, we feel like they will have improved quality and validity.

We expanded the state capacity for PRAMS analysis by adding our diabetes partners. And there's expanded opportunities for data to action through the Minnesota diabetes plan.