National Quality Forum

Moderator: Perinatal and Reproductive Health
November 8, 2018
3:00 p.m. ET

OPERATOR: This is Conference # 8298488.

Operator: Welcome, everyone. The webcast is about to begin. Please note today's call is being recorded. Please standby.

Suzanne Theberge: Good afternoon, everyone. Welcome to the Perinatal and Women's Health Committee Meeting. We are very excited to have you with us today.

Before we begin, I am just going to go over the usual NQF housekeeping items. Just a reminder that if you are dialing in via webinar, you can audio stream only.

But if you wish to have an open line to speak or to ask questions during the public comment period, please do dial in on the phone line and turn your computer speakers off, and then, of course, we ask that you mute yourself when you're not speaking to reduce feedback.

We have three exciting presentations today. And the – so I'd like to briefly go over the agenda. We'll do a roll call and introductions and then we're going to have Kimberly Gregory to present on patient-reported labor and delivery measures that she's been working on.

We have Saraswathi Vedam presenting on the MADM and MORi tools for measuring women's respectful care. And then, we have Carol Sakala presenting the results of the recent Listening to Mothers California survey.

After each presentation, we'll have a few minutes to have an open discussion for the – any committee members to ask questions or respond to the presentations. And then, we'll close out with a public and – NQF member and public comment period in which anyone can ask questions. We will also be taking questions via the chat box throughout the webinar, so please feel free to submit a question there.

All right. So next, I'd just like to quickly introduce the project team. This is Suzanne Theberge. I'm the senior project manager on the team.

And I'm joined today by Robyn Nishimi. You all know Robyn, our senior consultant. And we also have a new project analyst on our team, Navya Kumar.

And I would quickly like to do a committee roll call so we know which committee members we have on the phone with us today. We know there were a few folks who were unable to join us last minute.

And it sounds like somebody has their computer speakers on. We're getting some feedback (at this time). Everyone, can – great. Thanks. I think we fixed it.

All right. So I know that (Tim) and Carol are here as we were just speaking on the pre-meeting subconference. So, Matt Austin? I think Matt said he was going to be joining a bit late due to a conflict. Jennifer Bailit?

Jennifer Bailit: Here.

Suzanne Theberge: Thank you. Amy Bell?

Amy Bell: I'm here. Thank you.

Suzanne Theberge: Thank you. Tracy Flanagan? Ashley Hirai?

Ashley Hirai: I'm here. Thanks.

Suzanne Theberge: Thank you. I know (Julia) was unable to join us today. Diana Jolles?

Diana Jolles: I'm here.

Suzanne Theberge: Thank you. Deborah Kilday?

Deborah Kilday: Good afternoon.

Suzanne Theberge: Thank you. Sarah McNeil? Jennifer Moore? Kristi Nelson?

Kristi Nelson: I'm here.

Suzanne Theberge: Thank you. Juliet Nevins? I think she was going to join a bit later as well. Sheila Owens-Collins?

Sheila Owens-Collins: Present.

Suzanne Theberge: Thank you. Cynthia also couldn't make it today. Diana Ramos? Naomi Schapiro? Naomi Schapiro? Karen Shea?

Karen Shea: I'm here. Good afternoon.

Suzanne Theberge: Thank you. Mimi Spalding? Mimi, was that you? Thanks. All right. Sindhu Srinivas? Rajan Wadhawan?

Rajan Wadhawan: Yes. I'm here.

Suzanne Theberge: Thank you. And Carolyn Westhoff? All right. Anybody else or has anybody joined? Great.

And I also just wanted to mention that – because we are hearing about some patient experience and patient-reported outcome measures, today, we did invite the patient experience and function committee. And I do see some of those on the folks on the webinar listening in, so hello, patient experience and function committee. Thank you for joining us.

All right. So I think we'd like to go ahead and get started. I'd like to turn it over to Kim for our first presentation. Kim?

Kimberly Gregory: Great. You're going to have me this control.

Suzanne Theberge: All right. We should be transferring the leadership of the slides over to Kim now so that – yes, Kim, you should have control now.

Kimberly Gregory: Great. So I want to thank everyone for the opportunity to present our work funded by PCORI to develop – it should actually be Childbirth-Specific Patient-Reported Outcome Measures. And I want to acknowledge the research – (academic) research team, the maternal quality indicated workgroup. I believe Dr. Lisa Korst, the (inaudible) (investigators are) on the call with us, as well as the Project Director (Samuel Sahid).

And I really want to acknowledge the Childbirth Partnership, which is a community collaborative that has worked with us for the last three years actually helping pick out the items that went in the survey and helping to – with all of the focus group work and has been a cheerleader all along the way. So this project was funded by PCORI and we've received some supplemental funding by the Cohen Family Foundation.

And our overarching hypothesis was that women's predisposing condition that included the personal characteristics, experience and clinical risk generate value and preferences for the services they desire in childbirth. And that, after giving birth, women assess whether these values and preferences were fulfilled and, collectively, this led to their patient-reported experiences and outcomes and whether or not they were satisfied with the birth in the hospital. So that's our conceptual framework.

And in order to get there from here, we read – did an extensive literature search ultimately identify 19 domains and 58 subdomains using PROMIS methodology resulting in a 160 childbirth PROs and patient characteristic items that were entered into a 30-minute online survey. Sorry, I didn't know how this – (right here). OK.

So this is an example of a domain which was support and the subdomains were labor social support, partner support and provider support. And an example of a survey item for partner support is that "It is very important to me that my partner is at my side during labor".

We developed a two-part survey that was administered nationally. Phase one was during the antepartum period where we asked women, “What do you want?” We wanted to understand who wants what where “who” is the predisposing condition such as demographics, clinical status, relevant personality traits, beliefs and experiences and what is the patient-reported outcome.

And the, phase two was to link this with the postpartum data where we determine if women got what they wanted, if there were any gaps with what they wanted versus what they got; and collectively use this information to predict hospital and birth satisfaction.

So the Nielsen Company administered the survey to its online panels, and then, to be included in the study, you had to be at least 18 years old, 20 weeks pregnant and a U.S. resident. The survey was available on both English and Spanish and we’ve got over 2,700 responses in what was weighted to be a nationally-representative sample.

As you can see, people anticipated delivering at home or in freestanding birth centers. Most women expected to deliver in a hospital with – in a vaginal delivery. And that’s the blue represented by the 73 percent. And so, the rest of this presentation is going to focus on that patient population, the number of – I mean, the women who plan to deliver in a hospital and plan a vaginal birth.

So these are examples of the values and preferences used in the Childbirth Experience Survey which we have nicknamed CBEX. And we hypothesized that there are both the universal PROs which are things that everybody should want and patient-specific PROs in the different domains based on patient characteristics.

So an example of a universal PRO would be pain control, feeling safe, being treated with courtesy. But obviously, you would expect that different women would want different management things – management techniques and labor. So, for example, they may want to eat or drink in labor, but it may not be especially important to them. They want to have a massage or access to a pool or tub, but that may not be essential for everyone.

So we took all this information and, for the women who plan to deliver in a hospital, we identified that there were 39 patient-reported outcomes that were – that were important to them across the 19 domains. The PROs vary by patient characteristics, as well as their values and preferences.

We confirm that there are two types of patient-reported outcomes, the universal PROs and the specific PROs. So, for example, PROs that vary by patient characteristics. In this example, we found that race was very important with regard to patients who felt it was important that we respect their spiritual and cultural needs. For example, this was – this is off. Sorry about that.

Seventy-seven percent of black women felt that it was very important that their spiritual and cultural needs be respected; whereas this is important for only 61 percent of the Hispanic female – I'm sorry, that's Asian, the third one down. So it varies by race and ethnicity.

Women who are having their first baby were more likely to want to avoid interventions to receive information regarding baby care or feeding, to receive practical support regarding feeding, to want to breastfeed and to have a female provider available. And they also wanted to make sure that there were multiple pain management options available.

We found that there were additional patient characteristics that were important, but that providers would not necessarily have this information in advance. So feeling confident in the birth process was an important patient characteristic for 25 of the 39 PROs. It was – for some women, it was important that they believe that they could cope well with pain. It – whether or not they had negative memories about the previous birth experience, a history of abuse or discrimination and self-rating of mental health as poor or fair were all important patient characteristics related to many of the patient-reported outcome measures.

We developed models for each of the PRO for women anticipating vaginal birth. The models were – included age, education, parity, prior cesarean, pregnancy and medical complications, race/ethnicity, gestational age at delivery, region and multiple gestations. And we included important patient characteristics that were identified in the (binary) analysis such as discrimination, abuse, social support and provider preference. And we used the model to isolate the most important associated characteristics and to quantify their relative importance.

So, for example, for the model “Want skin to skin”, these were the patient characteristics that were important, along with their adjusted odds ratio. And the way that this could be interpreted using the last row is that women who planned to have a support person were more – were 2.3 times more likely than women who did not plan to have a support to want the baby placed skin to skin, and overall, 72 percent of the respondents and one as a – as an important patient-reported outcome.

We were then fortunate enough to get some supplemental funding from PCORI and the Cohen Family Foundation to deliver the survey postpartum and go back and ask them that they actually get what they wanted. We were also able to ask questions that we couldn’t initially answer in the antepartum period, specifically, “Was your pain managed the way you wanted it to?” We were also able to add the HCAHP question about hospital satisfaction. By doing both the antepartum and the postpartum survey, we were able to identify gaps in terms of whether women got what they wanted and use the gap to predict hospital satisfaction.

So we’ve got 800 postpartum responses and 500 of these women anticipated a vaginal birth in a hospital. And of those 500 women, 11 percent actually had a cesarean.

So we’ve focused on the gaps and you can imagine that there are four possible gaps, one is they didn’t – they didn’t want it – they didn’t want the service and they didn’t get it, they didn’t want the service, but they got it anyway, they wanted the service and didn’t get it, or they wanted the service and they got it.

We hypothesized that it is important when there is a difference between what was preferred and expected and what actually happened during delivery. I’m not going to go over all the examples, but I will go over two to give you an idea of how this works.

So, for the example of the gap measure "you wanted, but you didn't get the service" and an example of that was that you wanted to be reassured by your provider, by – if you wanted it and you didn't get it, you were less likely to be satisfied with the hospital at 29.6 percent compared to those women who wanted it and got it who rated their hospital satisfaction at 63.4 percent.

So examples of these universal PROs where you wanted them – well, I'm sorry – an example of the PROs where you wanted it and didn't get is pain treatment with specifically using narcotics or finding out information about where the newborn should sleep. So if you wanted this service, but you did not get this service, you were least – you were the least satisfied. And for this PROs, it helps to know in advance if a patient wants these options.

So using another example where you didn't want it, but you got the service anyway. And this is kind of interesting because we used the example of partner in the room. There are some women where it is important to them that they not have their partner in the room. So if they didn't want it and they got it anyway, they will less likely be satisfied at 28 percent.

Other examples of these are breastfeeding encouragement. If you decided you didn't want to breastfeed, but you got a lot of breastfeeding encouragement, you were less satisfied with the hospital. So for these PROs, it helps to know in advance if a patient does not want these options.

We developed logistic regression models to predict hospital satisfaction and wanted to identify what were the strongest predictors amongst the predisposing conditions, the values and preferences, the gap variables and the clinical complications. And again, we adjusted these for multiple pre-existing conditions.

And these are the patient characteristics associated with hospital satisfaction that we measured during the antepartum period. And those variables in red were associated with being less satisfied. So if the maternal mental health was reported as poor or fair, if there was a history of discrimination, if they had negative memory from a previous childbirth, if most days were reported as stressful or if they were very worried about the birth; then, these women with these characteristics were more likely to be less satisfied with the hospital experience.

Similarly, patient characteristics that we were able to identify in the postpartum survey was if they felt that they lost control during the labor or felt pressured by providers, family or friends to have a cesarean; these women were less likely to be satisfied with their hospital experience.

And with regard to the gap measures, if you wanted and got a massage, if you wanted and got no support, and if you wanted and got a tubal sterilization, you were more likely to be very satisfied. However, in red, if you wanted narcotics, but you didn’t get them; if you did not want your partner in the room, but you got it; and if you did not want breastfeeding, but you got too much breastfeeding encouragement, then you were less likely to be satisfied with your hospital experience. And again, what’s important to realize is that these are all things that a hospital can do something about.

And our final model for hospital satisfaction, where on a scale of 0 to 10, you scored 9 or 10 out of 10, these are the patient characteristics and their adjusted odds ratio that were associated with hospital satisfaction. Coping well with labor pain, continuous monitoring surprisingly, had adequate space or food support for your person, had debriefing about what happened during the birth process, had practical support for newborn feeding, you were told about your labor progress, you wanted and got a massage and wanting the partner in the room – and again, these were all adjusted for the variables that fit here.

Lessons learned. Irrespective of what women say they want or do not want antepartum, there are certain service expectations which we call the universal PROs that are associated with increased patient satisfaction. Feeling safe, having a baby placed skin to skin, being in control or having control and having adequate space or food for your support person are all things that are important to provide regardless of whether a person says that it’s important to them.

Based on patient characteristics, there are specific preferences that matter and can be known in advance that could improve patient satisfaction with their birth and hospital experience. And that there are also services that patients may be expecting that hospitals cannot provide and this would be an opportunity for expectation management and education. A specific example is vaginal birth after cesarean. If your hospital doesn't provide it, that patient is going to be very unsatisfied. And so, that might be prudent to actually refer that patient somewhere else.

We've been fortunate to receive a second round of funding in the PCORI Dissemination and Implementation portfolio. And then – and this ongoing grant which we've shortened the CBEX so that it's about 10 minutes. It now has a mobile version as well as the web version. And our goal is to collect information, both antepartum and postpartum on 3,000 women across 10 diverse hospitals in California.

And our primary outcome is actually to achieve the 3,000 completed surveys, but these are additional measures of success. And, most importantly, what we want to do is to – is to identify if there are meaningful comparisons across hospitals.

And then, we want to be able to define improvement strategies. So, for example, it makes sense to provide universal PROs to all women and that would be a first step. But the follow-up steps would be to ask about preferences directly, perhaps integrate it into the EMR, and then use this information to identify vulnerable patients based on their antepartum survey and develop training or education programs for staff to help women get what they want.

Academically, we want to continue along the NQF/PROMIS pathway for performance measurement development for the childbirth PROs. We've currently completed step one of – one through five and the PROMIS pathway, which is the complete childbirth-specific set of PRO domains and the preliminary item bank. And we're currently working on steps six and seven of the NQF pathway which is evaluating the PRO measure and the target population and comparing aggregate data across hospitals.

So this is the algorithm for the NQF pathway. And so, our first project was in the light blue and our second project is taking care of the yellow and the dark yellow, six – yes, six and seven of the NQF pathway.

So again, I'd like to acknowledge the research team which is listed there and express my ongoing gratitude to the past, present and future member of the Childbirth PRO Partnership. And I guess I can take a few questions now.

Suzanne Theberge: Great. Thank you so much. Yes. We have some time if any of our committee members have questions. And we can also take some questions from the audience members, non-committee members via chat, but I'll open it up to the committee first.

Jennifer Bailit: Kim, this is Jennifer Bailit. First of all, this is great work; really interesting stuff; and well done.

Do you envision these being sort of standalone quality measures or are these sort of adjunct quality measures to other kinds of sort of more traditional outcomes, hemorrhage, you know, and (the adjunct). I mean, it's measuring different things, right? It's actually trying to – you know, the difference between patient-reported experiences and patient-reported outcomes. But we're definitely trying to capture both the experience and outcome of the hospital birthing experience. So it would be separate from the actual clinical outcome.

Kimberly Gregory: And would you envision these being sort of incorporated into patient satisfaction survey work that's otherwise being done?

Jennifer Bailit: Yes.

Kimberly Gregory: OK.

Jennifer Bailit: Because you know, right now, there is nothing that is childbirth specific on the HCAHPS survey.

Tracy Flanagan: Hi. This is Tracy Flanagan. Hi, Kim.

Kimberly Gregory: Hi.

Tracy Flanagan: Hi. Great work. I was a little bit late to the call, so I heard the latter half of it. But I – as you know in separate conversations, I think this is great work. And I actually have a separate question.

You know, one of the things we do at Kaiser Permanente is we actually pull out our maternity-related HCAHPS and still struggle with satisfaction for all the reasons you've probably outlined. How would it – how would it marry up with the hospital recommendations for HCAHP and some of the current requirements expectations of a hospital especially the maturity line? How do you envision that happening?

Kimberly Gregory: Well, I mean, this could be like a hypothetical example. One of the things that sort of stood out for us and our childbirth partnership is the breastfeeding issue, right. So it seems as though there that a patient profile primarily educated, affluent who is very literate, who had made a decision that they don't want to breastfeed and if you harass – they actually feel like they're being harassed. And so …

Tracy Flanagan: Right. We know this.

Kimberly Gregory: …if you harass them, you're not going to help your hospital satisfaction scores. So perhaps, you know, with some training by staff, we can identify their people who say they don't want to breastfeed who actually benefit for more information as compared to people who've made an informed choice and, in their informed choice, we would be respectful of that. And so, we should not continue to provide additional information to that.

Tracy Flanagan: Yes.

Kimberly Gregory: That to me would be an easy win for everybody.

Tracy Flanagan: So, yes, I totally agree. And, you know, in our HCAHP question, we very often hear exactly what you just described, the comments – the comments section. I'm still thinking at a large system level about how it would actually – how you could streamline this and make this actually part of just what you do as a – as a system. And I still have a – I'm having a hard time going from study phase to actually all system not because it's not valuable but just to make it easy.

Kimberly Gregory: Yes.

Tracy Flanagan: Can you lay that out a little bit?

Kimberly Gregory: Well, actually probably when I finish phase two of the study, because we're actually doing it in 10 hospitals now, I'll probably be able to answer it more honestly. But I can say, theoretically, I think that what we will probably find is that there are – that there are some clustering in patient types in different hospitals so that it won't be a one-size-fits-all. It'll be hospital specific about what the recommendations would be.

Lisa, do you want to add anything to that? OK. I'm not sure if she's on. So, anyway, any other questions? Great.

Suzanne Theberge: We do have some comment that…

Kimberly Gregory: I'm sorry?

Suzanne Theberge: Via the chat box from committee member Diana Jolles. It first says, very exciting; congratulations. But then, she said there are (assistant) business needs which help providers work to confirm that decisions are fully informed versus based on a knowledge deficit.

Kimberly Gregory: So she is sharing that there is – that there is ways to tell that is what she is saying. Is that correct?

Suzanne Theberge: Yes. Just passing along this comment from her.

Kimberly Gregory: Well, thank you for that.

Female: (Inaudible) on your comment, yes.

Kimberly Gregory: All right. We'll follow up on that. Thank you. So I'm going to turn this back or can someone take the lead for me to pass on to our next presenter?

Saraswathi Vedam: Yes. This is Sarawathi Vedam. Can you hear me?

Kimberly Gregory: Yes.

Saraswathi Vedam: I have a question for Kim. Thank you for that presentation. I find it extremely exciting. As you'll see in a moment, I don't have the slides about pressure and – or what people's preferences were, but we study that also in Canada and across (community color) and with people who chose community birth and it lines up beautifully to what you have found.

In our study which I will talk about is we also connected pressure to, you know, personal characteristics and what – to – or to outcomes or interventions, so we'll talk about that. But I would love offline to talk about how data informs each other. You know, it's kind of two sides of a coin and very exciting to see what you've done and also how it can translate into, you know, what happens at the hospital.

I'm reminded of the Penny Simkin's work in 2002, which she did a systematic review around experience and found that patient – similarly found that people expect that – what predicted their satisfaction was more whether the reality met their expectations and whether or not they had a C section or had this or had that and has similar findings. So thank you for that.

My question is about satisfaction. When we've done the review of the literature on patient satisfaction, there seems to be a lot of debate about whether that's a good metric that, in fact, patients – many people, particularly in maternity care, are – overall will say they're satisfied because they went home with a baby and, you know, don't always – or unable to identify how it could have been or are reluctant to discuss their – they often blame – you know, especially when they will say, "Well, that's because labor is hard," or, "I was – my body didn't work," and not link it to the care that they got. I'm just wondering how you negotiated with that.

Kimberly Gregory: You know, I guess my first response is that – one, is it is – it is a measure that is being reported whether we like it or not. So trying to at least have it be meaningful based on things specifically related to childbirth I think will make it more valid.

Saraswathi Vedam: Absolutely. No, I'm not saying it's not valuable. I'm just wondering how you respond to that.

Kimberly Gregory: And I almost don't tell people I'm an OBGYN at a cocktail party because they might have to hear about their birth experience and what went wrong it. So I think that every woman actually – not every – but I'm amazed that the women who do remember their birth experience irrespective of how long ago it was.

Saraswathi Vedam: Yes. They say even people with Alzheimer's can tell you their birth experience.

(Inaudible)

Kimberly Gregory: But I actually…

Saraswathi Vedam: I believe in studying these things. I'm just grappling with this – the concept of satisfaction versus an experience, yes.

Kimberly Gregory: Well, I think – yes. I think it's a good point and it's certainly something maybe we can still continue to struggle with together offline.

Saraswathi Vedam: Yes. That's great. Thank you.

Kimberly Gregory: OK, Suzanne. Thank you.

Suzanne Theberge: Great. Thank you so much, Kim. We are now going to turn it over to our next presenter. And Saras you should have the slides and be able to move those forward now.

Saraswathi Vedam: Thank you.

Suzanne Theberge: And both Kim and Carol, as the co-chairs of our committee need no introduction to our committee, but if you could just spend a moment letting everybody know who you are since I don't think folks have heard from – many folks (might have) heard from you before, that would be great. Thank you.

Saraswathi Vedam: My name is Saraswathi Vedam and I'm a professor of midwifery at University of British Columbia. I run a lab called the Birthplace Lab and we focus on person-centered – person-centered care and that includes measurement, as well as evaluations of essential maternity care and how people define what quality and safety means to them, and so, that's taken us in a number of directions including transdisciplinary work on working with inter-professional groups around teaching them how person-centered decision-making happens. But that's sort of the lab that I come from.

And what I'm going to talk to you about today is I'm going to tell you a story of how a participatory research project led to the development and validation of three new quality measures and how these measurements allowed us to examine and describe quality in pregnancy and birth care from the – from the servicer's perspective, as well as the differential treatment by race, place of birth and model of care that emerged.

I really enjoyed hearing Kim's – you know, the process that she went through and the – you know, the detail process and theoretical underpinning or not. And we also did that. I'm not going to talk a lot about the methods, some – we have published some of them. But our methods are slightly different.

First, I'll mention, on the first slide you'll see that we work with a number of different councils and taskforces that are community based around North America and this particular talk – I'm on – I'm speaking on behalf of these different taskforces and steering councils. And we were supported in this work by the New Hampshire Charitable Foundation as well as a Canadian Tri-Council Fund or the Michael Smith Health Professional Investigator Award and Vancouver Foundation and then a Groundswell Fund which supports community engagement in this kind of work.

I think everybody on this call is very familiar with what patient-centered outcomes research is, of course, the PCORI guidelines. And the way our team and our teams define it is that we are engaged service users in every step of the way that they're involved in deciding what to study, how to study it, who to study, how to collect the data. They're involved right through to the analysis and interpretation data and also right now in the – in the (knowledge and lesion phases). And I'm going to talk to a little bit about how we did that and what that means to us. And then, the rest of my talk will really show you some of the results of implementing these measures.

So the first study that – I'm going to focus on two North American studies. One was changing childbirth in B.C., which would capture data on 3,400 pregnancies across diverse populations. And it led to some scale development.

The community in B.C. was a – we did a community consultation with 1,300 women who first identified a long list of things that they wanted us to study about maternity care in B.C. We had originally reached out to the community members because midwifery was a relatively recently implemented model of care in British Columbia and we thought we would just be studying people who had care by midwives.

But when we engaged the communities, as midwives themselves, they were very clear that they wanted to – a larger maternity care experience survey. They wanted their sisters and neighbors and they wanted us to study about studying the characteristics of the preferences of women who lived on the street and women who were formally incarcerated and immigrant – (recently as) immigrant and refugees – as well as current and potential maternity clients who do not see midwives because they felt that they were not well understood.

And so, we convened a – these steering council that represented those different portfolios through NGOs and through hospital partners and they then self-organized into four working groups, these four working groups that we thought that we will – we convened them and then taught them – said, you know, "We can study – you have to first decide what you want to study and then how we want to study it." And so, they were working actually as separate working groups.

Interestingly, they all independently came up with the same domains that they wanted us to study in B.C. and those were access to care, preferences for care, experiences with maternity care. And almost everybody was very certain that we needed to tell the story about decision-making. Place of birth emerged here as well as knowledge of midwifery.

And so, we – once I was worried, anxious because we had – at that time point we had really just the first funding portfolio which was the Vancouver Foundation. It was a two-year fund. It was not a very large funding portfolio. The first year was supposed to be convening the team and doing a participatory process and the second year was supposed to be dissemination which is, you know, clearly not realistic in the way participatory research goes.

But we followed the process and they – communities decided that they wanted to do both a survey and focus groups and initially they started to develop individual surveys and we went out into the – so the researchers and the team, the partners, we went – our job was to go to literature – do the literature review, find validated items that might measure those domains.

We did (so) and let me tell you about that in a moment. I will also tell you that what happened along the way, we had an opportunity to do a similar study across communities of color and across communities who planned home and birth center birth in the U.S.

The changing childbirth in B.C. study had been, by that time, launched and we had collected some data and we had the survey instrument and one led to the other, and so, that we use the same method – similar methods in the U.S. then to convene – and convene teams and community members from the different – from African-American, Latina, indigenous communities and Asian communities, as well as all types of women, all races who have chosen home and birth center birth.

And we have a number of community partners. They also convened community members. And, interestingly, when they came up with their domains that they wanted to study, without prompting, they also wanted to talk about access to care or preferences to care experiences, maternity care. But, in the U.S., they wanted to add the domains with respect to autonomy, racism, mistreatment, non-consented care and predictors of resilience.

We – they were able to review the survey instrument that we had – that we had developed in B.C. And they saw that we had – by that time, we had already developed these two quality measures I'm going to talk to you about on respect and autonomy and done the psychometric analysis. So they felt those were very relevant. But for these new domains around racism, mistreatment and non-consented care, we had to go back out to the literature and find either – find validated items or, when they didn't work, we – the patients actually designed that they went to an iterative process of addressing items.

We talk to them about how you can't all ask all negative. You have to have – ask positive. You have to show you can't lead people into, you know – or you cannot influence how they are going to (answer).

There's a lot of B.C. We had – when they wanted to do focus groups we trained 33 community facilitators to collect – to run these focus groups. They were – they ran 20 focus groups all over B.C. and they themselves got the qualitative information to supplement our survey.

So both the – both settings, the Canadian and community partners, we did literature review. We reviewed previously-validated survey items and then the steering committee and the clients drafted new questions. And then, we went through a formal content validation process where we found community members who would look at a draft survey and rate each question for relevant clarity and importance. And then, there were these ongoing community consultations throughout the data collection (status) even we're doing all the draft and distribution plans.

They even – you know, when they beta tested it they would tell us that we were missing certain things. When we send it out to community members, they would say things like, "Well, you can't just ask us about whether or not we consult with our parents. What about our aunties?" And that one came from the indigenous communities. We had many items that came out that we couldn't find anywhere in the literature that they designed and (talked to us that) I'll tell you a little bit about that.

So one of the – when we – when – one of the first things we did was we had to grapple with whether or not we were – wanted to measure, whether they wanted to measure shared decision-making versus women-led decision-making. We found this validated tool, the 9-item shared decision-making questionnaire.

The community members reviewed it and said some of the questions spoke to them, but they felt there was no opportunity in this list for them to say, "I made the decision. My decision was respected and I had enough time to consider my options." And so, we actually took this questionnaire which was built for shared decision-making around cancer and turned it into a person-centered or a person-led decision-making tool which I will show you in a moment. So that's the (divisional) thing.

We looked and took some items from listening to mothers. Some of these items were wonderful items, but they weren't – the response options weren't in a (light grid) format or maybe there were some portions of the cultural – or maybe it asked about non-consented care, but not what happened. And so, our community members said, "You need to ask happened and who stood up for us," or, you know, how did we negotiate that.

So that's the Giving Voice to Mothers study. You can see that the image that we had to choose also wasn't a fully pregnant woman because they said that we need – we need to capture data from people who also had losses and they may also want to – they wanted something that – an image that did not locate itself on – in a particular race or (racial) of pregnancy and it was translated into Spanish as well.

The psychometrics and the development of the actual tools are published in a couple of papers and the ones that I'm going to talk to you about today. And they've also been tested around the special care and cash payments in Hungary and now in many other settings. And actually, in about nine countries now they're being tested in those research and as quality measures. And we have an (air) grant now to pilot them in hospitals across the United States.

So just to show you a little bit about the application, however, our – in B.C., which is a very large province; it's, you know, as tall as going from the top of the United States to Mexico. That's how tall British Columbia is and this is, in fact, where the population is. We ended up – we – the (surveyors) decided to distribute and collect through social media and live links and e-Listservs and through the networking sampling and I was anxious about not knowing the denominator. But just like what Kim said, we got – it's overwhelming – we had 1,300 completed responses in 24 hours and we eventually got about 4,000, of which, 3,400 pregnancies were good and complete.

And so, we had – in that – in Canada, they wanted to be able to capture information about – up to three pregnancies and up to three providers. In the U.S., we limited it to the one pregnancy in the last five years. We did get a geographically associated (outcome and vastly represented half).

(Last) you can see in the U.S. which is much, you know, broader we – we're (going to do) just New York where they had a data collection system in place, but the community member said, "No. It's too urgent. We need to be able to send it everywhere." And we did end up getting responses from all 50 states.

It was – we had a – it was representative as far as the rates break down, maybe not totally with the socio-economic (background) and that was expected because we were, as I said, intentionally trying to oversample community (verse), which is not a well-funded option.

So we did – we did regression descriptive analysis and as well as mixed effects analysis to figure out what the connections were to this. So – and, as I said, we did the scale development. Sorry, this slide didn't translate so well, but we did end up with having seven items in a 14-hour item scale. One of them is the Mothers Autonomy in Decision Making Scale, which is here, which shows you that – my doctor and midwife asked me how involved I wanted to be decision-making, they told me the different options, they explained the different advantages and disadvantages, they helped me understand the information, I was given enough time to consider my options, I was able to choose what I considered to be the best option and my – this is my choice, it was respected. And then, you can see the score gives them a level of autonomy.

There's a similar – I just lost my ability to advance. (Inaudible), can you – I've been – I'm no – OK, there we go.

OK. So then, you can see here that – you can see here that when we analyze by provider type, this is the level of autonomy depending on provider type. And we did, as I said, have a fairly even – it's interesting, in the U.S., we had an even number of people respondents who had community birth and then even in the hospital, so it was 50-50 even though that we know – we know that that's not representative of what's happening in the U.S. But we were able to look also across different provider types.

This is autonomy in decision-making by actual birthplace and care provider, so hospital with a doctor, hospital with a midwife, freestanding birth center and home. And we did the (patient consent) as you can see (written out) by stars here. We could look at also – look at it by race and the sense of autonomy. And, in this case, there was significantly less autonomy experienced by respondents who were black and Latina.

And that held true even when we analyzed it by their socio-economic status. You can see that orange is the – is women who self-identified as black. We had a very detailed method for people to self-identify their race and – or their many different races and that's for another talk. But you can see here that no matter how wealthy these women were, the black women had the lowest levels of autonomy.

We, interestingly, just did not hold up if – as well if you knew that – you know, when you looked at Medicaid status and things like that. But when you – this was I think labor and delivery and with the way the – when we worked with the communities to interpret the data, they said, "Well, when you have a hospital gown on, people don't know you're a lawyer or doctor and you're treated on what people expect to."

And that was also about how we had to do our cohorts as far as – initially we did people who just self-identified as black or just self-identified as Latina.

But then, we had this huge multiracial category. And they said, “No, it’s – when you analyze it, how we identify ourselves is different than how people perceive us, so you need to analyze it by how people perceive us.” And so, it was black and, you know, nothing – black and anything else, indigenous but not black and anything else. We then analyzed it by the communities that experience the worst outcomes (and we did).

So the lowest autonomy scores were among the communities of color in the whole – in our whole dataset. When you look at respect and these are – this was other scale – I felt comfortable asking questions, I felt pushed into options, during my pregnancy I felt I was treated poorly by my doctor or midwife because of and then the list of options including a difference of opinion with their caregivers and how did it affect their behavior.

I held back my questions because I felt my doctor or midwife is rushed, or I wanted care that was different from what my doctor or midwife recommended.

And again, they end up with a score, a respect score, and these are very similar findings. Slightly higher respect scores overall, but differences by provider, differences by place of birth and the lowest respect scores experienced by persons of color.

So then, the – finally the – our constituents really especially in the U.S. really wanted to talk more about what – they didn’t call it mistreatment. They called it abuse and disrespect and they wrote and they came up with these seven items which, interestingly, line beautifully up to WHO typology for mistreatment which is why we are calling it mistreatment.

But these were much more in-your-face disrespect and abuse, privacy, being shouted or scolded, being – having providers withheld treatment or force you to accept treatment, providers threatened you in any other way, they ignored you, refused your request for help, failed to respond or you experienced physical abuse such as aggressive physical contact.

And we – for this analysis, we did also use some innovative patient-centered items that capture social determinants of health. I'm sorry this is small. But we didn't just look at income.

We looked at whether or not their lights were turned off, whether or not they had a hard – inability to find food or pay their bills at the end of the month. So that is what we are talking about when – in the next slide when you look at (LOSCF). And then, we also had a composite income for outcomes – pregnancy risk status and history of social risk.

So you can see mistreatment by sociodemographics. Overall, the level – the baseline level of experiencing one of these aspects of mistreatment was 17 percent in our whole population. And, mind you, this is a population that has – typically are more satisfied; experience, you know, greater that they choose it because they have more control or they feel like their – we have, you know, a large proportion who are experiencing community birth.

And – but it is, of course, different by place of birth as well. But you can see here if you have low SES, elevated pregnancy risks, social risks, it increases with any of those things at their level of mistreatment.

When you stratify it by mode of birth, unplanned cesareans, quite high levels of experiencing this as being shouted at, scolded, having treatment withheld, instrumental birth, so (operated) (inaudible). And this one is the one that was quite, you know, I think disturbing is the level of any mistreatment based on if they had a difference of opinion about what they want and they felt that was the right care for themselves and their baby.

And we actually – we're intending to do qualitative analysis, but we did have some open comment about (boxes). And around the non-consented care and around this item, we got over 11,000 (right) in narrative responses which we have also analyzed now. Mistreatment by race and actual place of birth, you can see again communities of color experience more mistreatment in our dataset and it's much less when they are in community settings.

So that lines up with the WHO typology. And we – you know, why is it important to study these things and why do these (quality measures) asking these questions in these ways matter. I think it's pretty well established that delayed response to clinical (consent) actually can lead to extremely adverse outcomes and that's been studied in California and documented widely now.

And it also lines up with the WHO new standards for improving quality of care in health facilities for maternal and newborn care where you can see experience of care is – this was the first time considered as important so that experience of care doesn't just – it's not about whether they – if it is health and outcome and, of course, it's associated with depression and PTSD satisfaction, but that the WHO said that experience of care itself should be considered quality and outcome in itself, so.

And the last two slides are just to show that most of our funding and attention has been in first-line management of complications. But, fortunately now, we are looking at more of – broadly at what quality means and quality as defined by its service user where things like respect and experience of care, health services are equally important to look at so that everyone can end up having children (who look as happy as them).

So that's what we do at the Birthplace Lab. Thank you.

Suzanne Theberge: Thank you so much. I'd like to open it up now for questions and comments from the committee.

Kimberly Gregory: This is Kim. It's amazing work. I can – I guess I can say not – as a black woman, not surprising to some extent. And so, what I want to know is how can we use this information to make it better or difference?

Saraswathi Vedam: Yes. That's a great question. And I – indeed, our communities of color said, "Well, you know, when we started with these – so we had a gap in funding." And in the – in the – in the interim, I said, "Well, you know, we can look at preferences, we can look at place of birth. There (are some other things). What do you want us to look at first?"

And they said they wanted us to look at this decision-making. And so, for example, they said 95 percent of women in Canada and 91 percent of white people in U.S. said their preference was to lead decisions. But then, when you look at who was making the decisions around, say, fee section, it was overwhelming that the provider.

So where to go from there is that they said, “Well, what about teaching health professional – you know, having a way to teach people about how to engage in” – you know, many of them were seeing physicians like their physicians. It wasn’t about, you know, score satisfaction, but they felt really disenfranchised around that decision-making moment and so – and there was a big difference among people who were cared for where they had more time.

And, you know, I don’t think it’s about doctors and midwives. I think it’s about the model of care that allows more time to engage in those kinds of conversations. So the community members themselves have come up with a lot of ideas and where in the knowledge translation phase where they are helping us interpret and (decide).

But they have talked about both having themselves, that is the service users, understand what their rights are and also having mechanisms. And we have created, of course, which I can show you that model – but we have created a model for person-centered decision-making which is a step-by-step process that we teach now across the profession and so it comes out to a five-module – five-module online set of modules that we have piloted in our university across the profession.

So now, it’s being also applied in the U.S. with a collaboration between ACM and ACOG. They’ve taken our course.

So what to do? I think it’s how you – how you respond to those. I think that those ideas also come from the community. I think that it – around non-consented care, do we have a lot of data about – very upsetting data about, you know, they did it anyway; they referred me to child protective services; no one stood up for me.

You know, they – how many out of 1,100 responses, I think we have 250 that talk about being threatened that their baby would die and for very odd reasons that, you know, aren’t necessarily hard to understand this.

So talking – I think what the service users want is how do we talk with each other when we make choices and where it's an acceptable risk to us. Or can you tell us what those absolute risks are and not just relative us? And, you know, is it – is it later we found out or we want to be involved and we want to be able to direct our own care.

So we are working with the communities now around that to figure out. You know, I think it's a – it's, of course, a multi-pronged. You know, you have to – a systems – you have to have things that have to change in the system that things that are public information and there are domains that are health and special education.

But that's a long answer, but I think it's a complex realm. But absolutely, it's not enough just to say, you know, there's disparities or, you know, now we can prove it that it's actually race. It's a society – a society with race and not something else.

It – the question is what do we do about it. (Is it implicit bias) training? Is it respectful maternity care as a standard? Is it understanding what our human rights are? I think it's all of those things.

We're actually planning an implementation summit around these domains that we have collectively developed, these – all these tools in April. And I think, Kim, you're going to get an invitation, so you can come give us your own ideas.

Kimberly Gregory: It's very elegant. Thank you for sharing.

Suzanne Theberge: Any other questions from the committee. OK. Well, hearing none, again, thank you so much for that presentation and for joining us today. And we will look forward to hopefully receiving some measures on this in the near future.

Saraswathi Vedam: I guess I should have said that we are in conversation and submitting these measures through the NQF process and, you know, really look forward to mentorship from any of you on the call around that. But that's certainly the communities desire is that these are widely implemented.

We are testing them right now in five sites across the U.S. in a – with young, black and Latina women in Florida in a tertiary care center in – at Dartmouth – in home at the birth centers in Oregon, in a transfer from home to hospital quality assessment program in Washington State, and in a clinic that (serves substance) using women in New Mexico.

So we have a lot of different places of these autonomy and we expect quality measures are going to be piloted as far as what's the right time, is it prenatal, is it postpartum, is it – you know, when will people fill this out? How can it be used to inform what needs to be done at the institutional level? So thanks for the opportunity.

Suzanne Theberge: Thank you. And, OK, I think we can now go to our third presentation, Carol Sakala. And it looks like you have – now have control of the slide deck, so I think we're set to go.

Carol Sakala: Great. I do. Thank you, Suzanne. And I'd like to begin by expressing my great appreciation to Kim and Saras for helping us to fill in crucial measure gaps in maternal and newborn care that we keep identifying and including in our committee report. So this is a very exciting update on that work.

And I appreciate this opportunity to share with the committee selected results from two major projects that came to fruition this year at the National Partnership for Women and Families. We released both a new population-based survey of childbearing women and a consensus blueprint for system-level maternity care transformation.

And the national partnership is a nonprofit, D.C.-based organization that works to enable families to have dignity and be able to thrive and prosper. And we do this primarily by working in three interrelated areas – promoting access to quality affordable care, reproductive health and rights, and fair and family-friendly workplaces. So today, I would like to help you become aware of the new resources, share just a small portion of the selected results that are possibly most relevant to our committee work and encourage you to further explore these extensive materials that are now available.

Our national Listening to Mothers surveys have been carried out since 2002. They've provided a new understanding of the views, experiences and outcomes of childbearing women that have not previously been available at the national level. And Listening to Mothers in California is our first state-level survey.

Over 2,500 women completed the surveys last year in English or in Spanish on any device or with a trained interviewer and we had the opportunity with this survey to break a lot of new ground. So we were thrilled to be able to include for the first time a survey in Spanish to adjust our questionnaire and technology to be able to enable people to participate on any device.

We also – because it's a state-level survey – were able to sample and wait with 2016 birth certificate files. We did oversample to increase our ability to understand the experiences of several priority populations. The proportion of black women in California is smaller than the national proportion and in many other states and we wanted to be sure to try to understand their experiences very well. And also, our funders had certain priorities leading us to oversample on midwifery-attended births and oversample women with VBACs that are a fairly small portion of the total population.

We also were able to link to an abstract from additional data from the Medi-Cal claims database. And we have an extensive set of reporting materials available at both of the webpages shown here at – the national partnership web site includes a digital report that makes this material available and this material is also available on a conventional webpage at the California health care patient web site.

And, of course, we are extremely grateful for the amazing support of the funders of our work. And also, I'm really grateful for our partners on this work. So we had our traditional national Listening to Mothers team that has participated from the start including (Jean Declercq) at Boston University. But we also collaborated with the people at UCSF who do the MIHA survey which is the PRAMS variant that is carried out in California and with the survey research firm that they use called Quantum Market Research. So that was a wonderful partnership that we had with them.

And I also want to note that a couple of our standing committee members from California served on our project advisory council, Tracy Flanagan and Diana Ramos. Very grateful for the input that we had from that group.

So California's maternal demographics do differ in key ways from the national profile of childbearing women. And it's extremely valuable for stakeholders in the state to have current information, including some questions that have – were specifically tailored to specific policy matters and initiatives going on in that context for their population overall and to break down by subgroups.

However, I think it's important for all of us to understand that the results are generally quite consistent with what we have learned from the national surveys and with 12 percent of the nation's birth – that's one in every 8 in California – we feel that the results are a value to all responsibility for maternal and infant health.

We also would welcome the opportunity to do other state-level surveys or this would be very suitable for system-level surveys as well. And I think it's important to note that we are seeking support to do that next national survey.

So jumping into some of our results and here it's very selective compared to everything that is available. We were pleased to find that about four in eight women thought quality information about perspective maternity care providers and perspective hospitals for giving birth and nearly all of them – and it was shown here in orange – said that that information had informed their choice of care.

Similarly, one in three reported seeking information about hospital cesarean rights and are – all of our – as Saras has mentioned previously, all of our participants gave birth in hospitals in California. Only 1 percent of women are not in hospitals. So we would not be able to meaningfully describe that population with our sampling methodology.

A troubling result, however, was the flip side of that that just one in three correctly understood that the quality of care does vary from hospital maternity unit to hospital maternity unit and across obstetricians and about equal numbers told us that they either did not know or that the quality did not vary.

We asked about interest in four types of high-value care – should our respondents give birth in the future. So these were first-time moms and experienced moms and all had this experience at least once. And in all cases, their interest greatly exceeded the actual youth in their 2016 birth.

So overall, 9 percent shown here in orange, had a midwife as a birth attendant. And we also looked at who the prenatal care providers were as well. However, 17 percent, so they would definitely want and 37 percent would consider a midwife in the future. And we think these figures are especially striking because most women would definitely not want a midwife and those data are not shown in this slide, mistakenly believe that midwifery care was a lesser quality than medical care which systematic reviews do not bear out.

The women's preferences, I think it's quite interesting, a more closely match actual use of midwives in nearly all high-income countries. And I want to call your attention to the responses of black women who, in each of these future birth questions, most frequently preferred this care option and Medi-Cal beneficiaries who expressed strong interest in all four. And, in our survey, both of these populations frequently experience disadvantage and troubling disparities as we find across our country and we could do full presentations on the breakdown set we have by payer, by race and ethnicity and by some other dimensions.

Whereas, we estimated that just 9 percent of our respondents had a birth doula. Again, most said they would either definitely want or would consider a doula for a future birth. And here it's important to note that the relevant Cochrane review identified very impressive benefits for women who received this type of care versus usual care. And I would refer you specifically to the subgroup analysis that looks at types of labor support providers.

So our survey, as I mentioned, was limited to hospital birth, but we know from birth certificates that 0.3 percent of California women gave birth in a birth center in 2016. By contrast, 4 in 10 respondents expressed interest in a future birth center birth. And we asked these questions clarifying that it was with hospital care if needed or was previously with doctors' care if needed. And this – they said that 11 percent, so they would definitely want this; and 29 percent said they would consider it.

And lastly, according to birth centers, 0.7 percent of women in California had home birth in 2016. By contrast, one in five had an interest in the future. So 6 percent of our respondents said they would definitely want this and 11 percent would consider it.

The bar on the right shows responses to our questions – how much do you agree or disagree with the statement that birth is a process that should not be interfered with unless medically necessarily. And three in four agreed and half of all California women strongly agree it was a statement, while just 8 percent disagreed. The remaining bars show results of the same question from our national surveys.

Well, national and California methodologies and populations do differ in important respects. Women's views on this matter appear to have shifted dramatically over a 15-year period. So when we first asked this in 2002, there were a fairly similar number, so the agrees and disagrees and the disagrees – I have just been disappearing over the course of this survey.

A major takeaway from this survey is the contrast between women's care preferences and their actual experience of care arrangements and procedure-intensive style of care that nearly all in U.S. hospitals are receiving. And despite preferences, they did get high level – high level of reservations – this – interventions.

This slide is a proxy for two entire chapters in our full report. So I encourage you to take a look at much other data that is available at this time. Forty percent experienced labor induction and, conservatively, more than a third of those lack an evidence-based indication.

And I know, for those of you who understand what comes out of birth certificate data, well, feel that this is a very high number. But validation studies, quite a few of them have identified – have shown that induction is undercounted in birth certificates and we feel that our results are closer to the actual rate. So that's another use for this type of survey besides previously unknown questions if some questions might be difficult to collect through other sources.

Just 3 percent had intermittent auscultation with no EFM, three quarters had epidurals, nearly half experienced synthetic oxytocin to induce and/or stimulate labor. And we didn't – we've never asked about third stage use of synthetic oxytocin because we're not clear that women would be able to answer that one with accuracy.

Three in 10 had a cesarean and fully 85 percent with a past cesarean had a repeat cesarean. And finally, just 5 percent met the ACOG reVITALize definition of physiologic childbirth which has been endorsed by a numerous other national clinical professional organization as well.

So we also have a chapter on respectful and disrespectful care and a handful of the items in that chapter are covered on this slide. Most women reported receiving respectful care and we found some striking disparities.

So describing experiences during the hospital stay, 11 percent of black women versus 1 percent of white women felt that they had been treated unfairly due to their race or ethnicity. And 13 percent of women who spoke in Asian language at home and 10 percent who spoke Spanish at home versus 2 percent who spoke English reported being treated unfairly due to the language they spoke. And finally, 9 percent with Medi-Cal versus 1 percent with private insurance felt that they had been treated unfairly due to the type of insurance they had.

And we did have major open-ended questions – what was the best part of your care when you were in the hospital for giving birth, what was the worst part and anything else you'd like to tell us. Those results are being analyzed and they bring these types of numbers to life in very important ways. And we also include in our full survey report a selection of those illustrative quotes as well.

We again asked, as in our national surveys, whether women have experienced pressure from a health professional to have several pretty consequential interventions and from 11 percent to 14 percent reported pressure for labor induction, epidural, analgesia that's among those who labored and cesarean birth. And one in four with a previous cesarean reported such pressure. It was very notable that those who experienced pressure for labor induction and cesarean were far more likely to have these procedures than those who did not.

So this slide gives selected results from our postpartum chapter. Nine percent did not have a postpartum visit. And again, our committee is very familiar with respect relevant HEDIS measure on this. And I think it's important to note that HEDIS comes out with a much higher number estimates of those who don't get a postpartum visit.

But I think that is because it does not capture the care in the first three weeks after birth which I think they're now trying to rectify. And also, it is not modeled by global billing codes that cannot capture many postpartum visits.

So I feel that our number here is closer to reality. And nonetheless, I don't want to downplay. I think we increasingly understand that the postpartum period has not gotten enough attention and there are definitely major concerns with 9 percent having no postpartum visit.

So another one for a subgroup is more than one in six women with Medi-Cal reported never having sources of both practical and emotional support since giving birth. That's a very concerning state of affairs for this population that has a lot of needs at this time.

Most women with a pay job had not been able to stay home with their babies as long as they liked. Most who breastfed at one week and were not breastfeeding when they participated had not breastfed as long as they liked. And I should have said that the women participated from two months to 11 months postpartum.

So some of these questions, we had to look at a selection of our participants who – for whom it made sense to do the analysis. Just 28 percent who participated, six months or more months after birth, met the consensus recommendation for exclusive breastmilk feeding to six months or more months.

And finally, here we see selected results from our maternal mental health chapter. We included the PHQ-4 screener from that PROMIS set of – family of tools that Kim referred to earlier with subscales to screen for depression and for anxiety. And we asked about both during your recent pregnancy and during the last two weeks which were in the postpartum period when the women participated.

And whereas postpartum depression is most salient for many, we found that anxiety symptoms were more frequent during both time periods and both conditions appeared to be experienced more frequently during pregnancy than after birth.

So when combining the two subscales, the PHQ-4, the developers consider this to be a measure of psychological distress and 14 percent of the women fell in the moderate or severe range of psychological distress prenatally versus 7 percent in the period before completing the survey. And of great concern, the great majority who screened positive for these conditions have not received treatment or counseling for mental health issues.

So, in addition to the full survey report, the cover of which is shown on the left, we have a really rich array of resources that described our survey and the survey results. And we invite you to learn more about what we have been able to learn and what is very current information about this population at a population level. And I have the list of the national partnership URL here, but I also mentioned earlier that these resources are also available on the California health care foundation web site.

So I want to quickly touch on a major consensus report that we also released this year. And this came from 17 national multi-stakeholder and multi-disciplinary leaders including past presidents of ACOG, ACNM and A1, as well as experts in payment reform, performance measurement, quality improvement, consumer advocates, clinical and policy researchers. And, once again, on our standing committee, Amy Bell was one of the participants in this project and we were very happy to work with Amy.

Whereas the survey results identified challenges or, as I like to say, many opportunities for improvement, this document points to systemic solutions. And it built on a previous in-depth report showing benefits of experiencing healthy perinatal physiologic processes and I will share a link to that report at the end.

The new report aims to balance the maternity focus – maternity care focus on high-risk and complicated situations with care that minimizes both overuse and underuse. And it was very germane to the second to last slide that Saras showed where there's a – in the upper right-hand corner is a lot of our focus which we need to continue and strengthen, but also to not forget about the other more preventive and upstream parts that we could strengthen.

So virtually, all childbearing women and newborns can benefit from care that helps them experience these innate processes and the co-authors identified four different groups.

First of all, we – the amazing journalist who have helped to bring the maternal health care crisis to light this year have shown again and again how much we're relying on rescue. And we feel that this particular approach can help reduce the need for rescue by implementing a preventive perinatal safety model that changes care upstream and reduces the need for rescue.

Secondly, the persistent disparities that we have experienced probably for as long as we've been documenting this and also came to light very well in the past year from the reports of journalists, we feel can be impacted. We can improve health equity by ensuring that this kind of attentive, respectful care is consistently received.

And again, (earlier slide) focused on not paying attention and delays in acting and also not providing good care. So that's another group that can be affected. And then, most women and newborns are healthy and can remain so by avoiding unneeded interventions and complications.

And finally, this report emphasizes that those who do receive higher acuity care, and perhaps especially those who do receive higher acuity care, can also benefit from experiencing these healthy processes whenever possible. So an example would be after a cesarean, ensuring that skin-to-skin care is available and appropriate breastfeeding support is available.

So our blueprint arrays 22 high-level recommendations each with action steps and extensive documentation. And that would be helping to clarify why we made the recommendation and how people can learn more and actually go begin implementation.

And the first strategy emphasizes two types of payment reform that really open up possibilities for care transformation, as well as making good use of high-value forms of care and quality improvement in order to succeed with the greater accountability that comes from ultimate payment models.

The other strategies – and I should say that all of these are closely related to the National Quality Strategy – are performance measurement, consumer engagement, inter-professional education and team-based care workforce composition and distribution and also filling research gaps.

So I’d just like to end with two slides that identify elements of special relevance to our standing committee and this is just highly selected pieces from this whole document.

One recommendation focuses on filling measure gaps and specifically calls out those that would address over and under use, those that would measure woman-reported experiences and outcomes of care, and also those that would help us all to row together by aligning – we have now a number of important facility-level measures, but it would be important to align as well with appropriate clinician and health plan level measures.

The blueprint encourages, as I mentioned, two types of payment reform – episode payment and maternity care homes – and recommends a selection of game-changing performance measures for accountability and transformation. And what we’re seeing in a lot of the alternative payment models that are being put out there is people put in measures that are good measures that they want to see changes and improvement such as chlamydia screening or HIV screening. But those are not measures that will really be transformational for maternity care, so that's a strong recommendation.

And finally, we recommend building out QI resources and initiatives to add upstream preventive attention in addition to the more common focus on rescue. So that would include things like simulations or quality and safety course where you might begin the course talking about how to promote these innate processes and help to keep people on a healthy pathway, and then, if that is not successful, how to care for them with more crisis type of situation.

And lastly, focusing on women, we need user-friendly evidence-based portals similar to hospital and physician compare with maternity performance reporting. And here I've been very impressed with the work of Judith Hibbard who leads – who gives us a lot of guidance for how we can report information that can be very meaningful to a broad range of service users.

We also identified the importance of care navigators who can help many women identify and interpret performance results that are relevant to them, as well as serving many of their functions. And finally, we need to collect and make available to service providers and women themselves results of woman-reported measures of the experience and outcomes of care.

So this slide shows the covers and web locations of the new – excuse me – blueprint and also the previous report that provided the impetus for the blueprint. Hormonal Physiology of Childbearing on the right synthesized over 1,100 citations.

So that was really a labor of love and it's organized in a very intuitive way and it also comes with a lot of related documents like a consumer booklet and infographics and fact sheets and so forth to make this very sophisticated scientific information accessible to various audiences.

So I encourage you to delve into these documents. And I would love to hear from you about these work at any time and welcome any discussion at this point. Thank you.

Suzanne Theberge: Thank you, Carol. Let's open it up to the committee for any questions or comments.

Female: Great work, Carol. I can hear the labor of love in your voice.

Carol Sakala: Thank you. And I feel very privileged to be able to do this work.

Female: Do you find, when you compared this one to the last one and you said you were priming a third one, like, what are the trends you're starting to see?

Carol Sakala: Right. Well, that one question showed very strong trend information. And we also have some new information that we didn't have before. For example, this is the first time we looked at anxiety and the first time we asked about mental health during pregnancy.

So some of it is new, but I have to say that the general feeling of gaps between what women want and what they're getting and the patterns of care that they receive, the experiences and the postpartum period, the question of respectful care, these are things that we've documented fairly well in the past and we – it's really important they have new and timely information. But also, I think it's time to get to work on addressing some of these in a more systematic way – systemic way.

Tracy Flanagan: Carol, Tracy Flanagan, just want to make a comment. First of all, great work. Second of all, I have to say that I read through this report – most recent report about a month ago and one of the things that was particularly striking to me was the information on alternative birth centers.

We know that many countries have a much different model of childbirth than we do in the United States and there's very little published on what women want in the concept of a birth center, some people call it freestanding birth center or an alternative birth center. There has been recent data on, quote "safety or quality-related birth centers", but not in – from a – from a patient's perspective like what is important about a birth center. And so, I found that very – working at a large health care system that is looking very intensely at some maternity experience, I found that very helpful but not enough. So that's my one comment.

Carol Sakala: Right. So I could say, Tracy, that the Strong Start Program that came out of the Center for Medicare and Medicaid Innovation that was one of the earliest projects that came out of that ACA-created center has got a lot of information on those center experience. And some of those – there've been a number of articles published, but also there's more to come on that. So I think that's an exciting source of data.

And then, I think it's really important that everybody realizes that we have large datasets where we could ask a lot of questions that are organized by the American Association of Birth Centers and also (Manustat) project that is organizing this Midwifery Alliance of North America where a lot of the midwife members there and certainly CPMs nationally are trained to attend birth and what (sheriffs call as) community facilities and community sites at home and in birth centers. So there's information there.

And then, the national birth center study, there was one published in about 1989, I think that was the first big article there in the New England Journal of Medicine, but one was published more recently, a little less detail. I'm still hoping they'll pursue that dataset, but actually the databases now are more extensive and up to date than that dataset. So that's a possible source.

But those are very instructive as well in terms of women's experiences and the figure that leaps out at me all the time is that 6 percent – and this was just a few years ago – of women in the national birth center study who began labor – laboring in birth centers, had a cesarean at a time. When that rate for those women are definitely selected, but often experience pretty significant social risks, would have had over 20 percent cesarean rates.

So I think that's one of the reasons for the autonomy, the choice, the respect, the more homelike environment – those are some of the reasons, I think, why women are very interested in that type of care. And as we look for high-value of care, it's a model that as well can save us a lot of money and I think make, you know, a lot of women happy. And it will be great if systems like Kaiser Permanenter were able to build out birth center facilities for their members.

Tracy Flanagan: Thanks for your comment.

Suzanne Theberge: Do we have any other questions or comments from the committee? OK. I'd like to open the lines for public comment.

And thank you again to all of our presenters for these excellent presentations. We really appreciate your time today. And thank you so much. So, operator, can you open the lines, please?

Operator: Certainly. At this time, if you would like to make a public comment, please press star one on your telephone keypad. Again, that is star one to make a public comment.

Suzanne Theberge: And just a reminder, we can also take questions via the chat box.

Operator: And at this time, there are no public comments.

Suzanne Theberge: All right. Thank you. Well, I will turn it over to Navya to just go over the project next steps and some upcoming dates.

Navya Kumar: Thank you, Suzanne. So for our fall cycle of 2018, we still have one more meeting for a topical discussion. Our second committee meeting will be held on March 15, 2019 from 1:00 p.m. to 3:00 p.m. Eastern Standard Time. And we are, at this time, expecting measures for the spring cycle of 2019. So for developers, the intent to submit deadline will be January 5.

The measure submission deadline will be April 9. The first Committee Orientation Webinar will be held on May 13 from 3:00 p.m. to 5:00 p.m. Eastern Standard Time. And the first Measure Evaluation Webinar will be June 21 from 1:00 p.m. to 3:00 p.m.

The second Measure Evaluation Webinar will be June 24 from 3:00 p.m. to 5:00 p.m. And the Post-Evaluation Webinar will be June 28 from 1:00 p.m.

to 3:00 p.m. ET. And the Post-Comment Webinar will be held on September 20 from 12:00 p.m. to 2:00 p.m. Eastern Standard Time.

And for – to contact us with any questions, comments, concerns our e-mail address is perinatal@qualityforum.com and our phone number is 202-783-1300. And you can always view our project page on the NQF web site. And for the committee members, you have the SharePoint page open to you.

Suzanne Theberge: All right. Thank you, Navya. And I'll just add we'll be in touch next week with the meeting summary and some more information about the March call. Again, since we didn't have any measures, we're just – we'll be doing these webinars. But we are really hopeful that we'll have some measures for you to evaluate next year and we'll know in January after the intent to submit deadline passes, so we should be able to let you know in early January about that.

So, again, thank you so much, everyone, for joining us today. We hope that our committee members and the other folks listening along today enjoyed the call as much as I know the NQF staff did. So, again, thanks so much for your time, everybody and we'll be in touch soon. So, I think, with, that we can adjourn and have a good evening.

Female: Thank you.

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