

# **Mothers' experiences and ideas for improving perinatal care in Maine:**

**Results from focus groups and key informant interviews of pregnant and postpartum mothers representing populations experiencing disparities in health care across Maine**

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## Background

Maternal mortality rates are unacceptably high and rising in the United States. While thankfully still rare (Maine had 15 pregnancy-associated deaths between 2009 and 2018), it is estimated that 50-100 women experience severe maternal morbidity to every maternal death in the United States.<sup>1</sup>

It is widely recognized that pregnancy and childbirth pose significant risks to mothers' health, however serious pregnancy-related medical complications can affect mothers for up to a year after childbirth. Postpartum complications are increasing due to rising trends in maternal age and prevalence of chronic conditions, but in Maine and nationally, perinatal risks are also not distributed evenly across the population. Residing in a rural area, being a part of an immigrant or refugee community, and having limited access to health care are known contributors to poor birth and maternal outcomes.

Perinatal Quality Collaborative for Maine (PQC4ME) includes a mix of over 65 clinicians, public health researchers, advocates, and representatives from community-based organizations guiding the statewide implementation of evidence informed practices to improve outcomes for infants, mothers, and families. Although the Collaborative began in 2018, in 2022, PQC4ME was awarded a competitive cooperative agreement of \$275 thousand per year for 5 years by the Federal CDC (US CDC–RFA–DP22-2207). During the first year of federal funding, PQC4ME's strategies were to:

- Establish PQC4ME as Maine's center of excellence for perinatal quality improvement initiatives by enhancing its capacity to make measurable improvements in perinatal care and outcomes statewide.
- Advance health equity in the diagnosis and management of maternal hypertension by engaging populations experiencing health inequities in evaluating tools and resources used in birthing facility patient and family education.
- Expand implementation of the AIM Severe Hypertension in Pregnancy Bundle to all of Maine's birthing hospitals.

Seeking to advance health equity in the diagnosis and management of maternal hypertension, PQC4ME partnered with the Maine Medical Association Center for Quality Improvement (MMA CQI) and four public health, primary care, and community-based organizations serving vulnerable populations throughout Maine. Through focus groups and interviews, we asked patients for feedback on birthing-facility patient education materials and processes, as well as how they navigated Maine's systems of care during and following their pregnancy. Our project included the following goals:

1. Provide recommendations to improve awareness of maternal hypertension and other post-birth maternal warning signs.

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3880915/>

2. Identify potential perinatal care systems in need of further exploration and/or improvement by capturing diverse patient and family experiences during and after pregnancy.
3. Partner with public health, primary care, and community-based organizations to develop processes to capture patient and family feedback.
4. Encourage greater collaboration between community organizations, patients, and birthing centers to support improved birth outcomes.

## Project partners

Our four public health, primary care and community-based organization partners were:

- Maine Center for Disease Control and Prevention, Public Health Nursing Program
- Nasson Health Center and Greater Portland Community Health Center (affiliated with Maine Primary Care Association, an organization that represents and supports 19 community health centers across the state in urban and rural locations)
- In Her Presence (a nonprofit community-based organization led by and serving immigrant women across generations and communities)

These partners were chosen because they are closely connected to families living in rural areas who participate in prenatal and postnatal home visits (Public Health Nursing), their clients receive primary care in rural and urban areas with geographically isolated and/or diverse populations (Nasson Health Center and Greater Portland Community Health Center), and they support immigrant women and families (In Her Presence).

## Methods

### Coordination with public health, primary care and community-based organization partners

Beginning in October 2022, we held several preliminary planning meetings with each partner organization to discuss the importance of the project, confirm their interest in participating, capacity to recruit parents in various stages of pregnancy, and experience in conducting focus groups and interviews. Our overall approach centered on establishing equitable relationships with project partners, leveraging their deep experience and trusted relationships with patients, clients, and communities, and balancing their contributions with project consultant expertise in evaluation methods.

Each community partner agreed to recruit participants who were either pregnant or had recently given birth. In collaboration with project consultants, each partner organization developed their own plans for outreach, logistics, and implementation:

- Public Health Nurses preferred to involve the evaluation consultant in doing remote interviews, using computer and/or phone apps to assure that the interview could be completed during the limited time of a typical home visit.
- Nason Health Center's focus group was conducted at their facility by their clinic staff, with assistance from the evaluation consultant who participated virtually. Snacks were provided.
- Greater Portland Health Center's focus group was conducted by two native language speakers (French and Spanish). Childcare and food were provided.
- Two In Her Presence focus groups were facilitated by native language speakers (French and Spanish) and provided participants with healthy snacks, fruit, and water.

Appendix A includes photos from some of the focus groups. All interviews and focus groups ranged between 30 and 90 minutes. Consent forms were provided and written or oral consent (Appendix B) was collected in advance of each interview or focus group.

The project budget allocated a small grant to each health center and In Her Presence (as a state agency, Public Health Nursing was ineligible to accept external funding) to cover the costs of paying facilitators, providing snacks and beverages, childcare, and stipends/gift cards for participants.

Recruitment of participants and scheduling groups and interviews was done over a three-month period (January through March), with each of the partners needing to integrate project activities within their busy schedules and provision of ongoing services. All focus groups and interviews were completed by mid-May. Follow-up conversations with each community partner were scheduled for July and August.

### **Development of facilitation guide**

The CQI team asked all of Maine's birthing hospitals which post-birth education materials they provide to patients. Twelve facilities provided a total of 38 samples of patient education materials. The most common educational handout was ["Save Your Life: Post-Birth Warning Signs" \(AWHONN poster\)](#) from AWHONN. Others included:

- EMR owned educational handouts,
- photocopies from books, and
- hospital-developed materials.

A total of 25 different educational materials were provided. Considering its high frequency of use, and available translations, we selected the AWHONN poster (Appendix C) for our qualitative assessment of post-birth education tools and processes. The AWHONN poster is part of a toolkit developed to assist birthing facilities in providing post birth warning signs education. The full set of resources was developed based on AWHONN's work with over 20 hospitals and user feedback. The AWHONN poster has been translated into 23 languages, several of which were used during focus groups.

The facilitation guide was divided into two sections. (Appendix D) Section 1 included questions to identify potential cultural, language, or literacy barriers associated with the AWHONN poster. Section 2 included questions to identify potential perinatal care systems in need of further exploration and/or improvement. The facilitation guide was developed by the CQI team and incorporated feedback from our public health, primary care, and community-based organization partners.

## Participant details

A total of 40 respondents participated in either a focus group or interview:

- In Her Presence conducted 2 focus groups with 10 and 12 women, comprised primarily of Black Africans in an urban area.
- Nason Health Center conducted 1 focus group with 3 women, comprised of white individuals in a suburban area.
- Greater Portland Health Center conducted 1 focus group with 9 women, comprised of Black Africans in an urban area.
- Maine CDC Public Health Nursing conducted 6 key informant interviews, comprised of white women in rural areas.

## Data analysis

All interviews and the Nason Health Center focus group were audio recorded and transcribed using MS Teams and MS Word. Facilitators attending the Greater Portland Community Health Center and In Her Presence focus groups translated and provided a mix of quotes and themes from each session. Interviews and focus group responses and notes were coded in NVivo 20 for thematic analysis. Analysis occurred concurrently with data collection.

## Results and Discussion

### 1. Ideas to improve awareness of maternal hypertension and other post-birth maternal warning signs.

To develop recommendations designed to improve awareness of maternal hypertension and other post-birth warning signs, we asked whether the AWHONN “Save Your Life: Get Care for These Post Birth Warning Signs” poster was appropriate and accessible to Maine parents representing diverse geographic, cultural, and socioeconomic characteristics.

#### 1.a. Main messages from the AWHONN poster

During each focus group or interview, we gave mothers time to review the AWHONN poster and then asked each of them to describe the main messages from the poster. Themes and representative quotes are included below:



### **Recognizing danger signs:**

- “The main point would be obviously looking for any of these post birth signs that could be potentially dangerous.”
- “Detecting the alarms signs after childbirth.”

### **Importance of calling for help:**

- “You have to call when you have any of those symptoms.”
- “React before it’s too late.”

### **Knowing who to call for help:**

- “The top section will say call 911 and then has the specific points of where you should call, like emergency services versus just calling your healthcare provider.”
- “If a woman has these signs, she should call 911.”

## **1.b. Positive feedback on the AWHONN poster**

We also asked mothers what they liked and didn’t like about the AWHONN poster. This section includes themes and representative quotes that highlight positive feedback:

**Useful information:** Mothers consistently reported feeling that the information presented was very relevant and useful to them or other pregnant parents:

- “I would pass it around if I had someone who was about to have a baby or just had one.”
- “Seeing myself as someone in need of such knowledge.”
- “Knowing these conditions can happen, it is good to know.”
- “It definitely gives me the impression that a lot of women aren't getting the help they need...I wonder how many people have, like, not been OK, before this poster happened.”
- “I think it’s short, simple and everything you need to hear.”

**Well organized:** Many mothers felt the poster was well organized:

- “It was organized so that I could be able to do what I needed to do if I was experiencing any of those symptoms.”
- “Easy to read.”
- “I think it’s short, simple and everything you need to hear.”

**Bold colors:** Several mothers felt the large, bold, red colors were a strong addition to the poster:

- “Save your life definitely jumps out to me.”
- “I like that it's kind of just plain and simple at the top. Big bold letters.”
- “The colors are helpful.”

**Helpful explanations of concepts:** Mothers felt the additional detail at the bottom of the poster was helpful:

- “I like that there's a little like glossary at the bottom there... I'm thinking about blood clots... having good judgment for how much is too much is useful information.”
- “It goes into detail a little bit more at the bottom... I'm not a big reader so I like bullet statements and then if I wanna know more about it, there's a little blurb about it at the bottom.”

**Guidance on what to say to EMS:** Mothers appreciated the guidance on what to say when calling EMS:

- “So I like the reminder of you had a baby and this is a medical event that you might be having complications from.”
- “I do like that there's a little box here that says, “I had my baby on this day and I'm having these symptoms.” I think that's a handy little script to give because I imagine when you're calling 911 all in a flutter having the words to is helpful.”

**Knowing when and who to call:** Several mothers appreciated the distinction between calling 911 versus your provider:

- “I was home by myself for the first three months. It is definitely better for me to know who to call... like I don't wanna take away from someone else having emergency situation if mine wasn't [one].”
- “I like that there's a breakdown ...OK, that's something that's concerning, but it's not necessarily a 911 call, but these things are 911 calls... That's helpful information.”
- “I also really like that it includes what's really dangerous, where you possibly have like hundreds of things going on.”
- “I also just realized it says post birth... It's nice to use the acronym...so you'll remember.”

**Paper format:** While some mothers suggested alternative formats for the poster, others appreciated having it as a paper form:

- “I think having things in writing is super handy, especially for your first time around.”
- “You get so much information at birth and you know you're never sleeping and you have a lot to be focusing on outside of whether or not you're having some sort of symptoms that are concerning. Having it in writing is handy.”

**Translated forms are very helpful:** Several focus groups were conducted in non-English languages and used the translated versions of the poster. Mothers were grateful these versions were available and emphasized the additional clarity the translation provided: “It looks clean in French but confused in English.”

### 1.c. Ideas for improving content of AWHONN poster

While many mothers provided positive feedback on the AWHONN poster, others identified opportunities for improvement. Themes and representative quotes are provided below:

**Emphasize trust your instincts:** Several respondents felt encouraging new mothers to trust their instincts was very important, and suggested highlighting that section more:

- “There are some [parts] that maybe should be bigger. Like trust your instincts is a good encouragement for mothers, because... they think they're doing a terrible job when they're doing great...trust your instincts is very encouraging to save your life.”
- “I like the trust your instincts because the mother's instincts are always right, and I feel like that should be made more prominent and not just like a little blurb on the bottom.”

**Provide clarification on using 911:** Some women expressed fears around the financial costs of using 911. Another respondent felt the poster may discourage mothers from calling 911 when needed:

“It makes it almost, in my opinion, feel like 911 is a last resort resource that you shouldn't use unless something really serious is going wrong. Whereas I feel like you should feel comfortable with calling 911 even if you're not necessarily in a dire situation ... If you feel like it's serious enough, don't hesitate to call 911 and get immediate medical attention.”

Another respondent suggested adding in a suicide hotline number in addition to 911.

### 1.d. Ideas for improving accessibility of AWHONN poster

Several mothers suggested providing the poster in alternative forms including:

**A size that fits into their diaper bag:** One respondent suggested a smaller size:

“Especially for new moms that have so much on their plate, are getting so much paperwork. They give us the COVID vaccine cards... and I was always bringing that card because you could stick it in your diaper bag... I always obviously knew where my diaper bag was in the first few days... It's in a place that I can pull it out and be like, OK, this is who I can call or this is what my options are.”

**Fridge magnets:** Other mothers like the idea of magnets on their fridge to make this information useful to the rest of their family, in addition to themselves: “I definitely think that if this had been given to me I would have posted it on my fridge.”

**Online:** Many mothers suggested putting this information online:

- “Sometimes people just get annoyed by printed things.”

- “Having it online, whether it’s its own separate platform or if there’s like a pregnancy or postpartum section of any website. That would definitely be helpful, especially where a lot of people are mainly digital now. I mean, I know I lose paperwork all the time.”

Some mothers were also concerned about accessibility related to literacy barriers:

**Video:** One respondent suggested turning this information into a video:

“I think they should do a video...that you have to watch... Some people have a hard time reading... a video would be better than to hand someone a piece of paper because you don’t know if they’re going to read the piece of paper. But you know they’re going to watch the video.”

**Additional visuals:** Mothers noted potential accessibility challenges among individuals unable to read and suggested adding in some visuals:

- “Add pictures for the moms who can’t read.”
- “Pulling that in pictures too, it’s easier to understand.”
- “Add some pictures of pregnant women because some are more visual.”

**Reduce quantity and enlarge existing text:** Several mothers were concerned about the small size of some of the fonts or thought there was too much information presented:

- “The two columns in the bottom of the page: small writing - people are more likely to read big writing.”
- “The presentation should be more concise such as bullet points.”
- “Too much information given at once.”

### **1.e. Ideas to increase awareness of AWHONN poster**

Many pregnant or post-partum respondents recalled seeing the poster and highlighted the positive effect it had on their post-partum experiences:

- “[One of the nurses} went over this [AWHONN Post Birth Warning Signs poster] with me... and I think that’s the only reason I knew any of [the symptoms to look out for]. I wouldn’t have an idea about those ... I would have like, gone on to look it up and gotten like a million different scary things. Yeah, so I think it’s really good that someone did this with me.”
- “The nurse who I loved by then came and sat on the bed with me and was like, “let’s go through this AWHONN Post Birth Warning Signs poster] and really was like “make sure you got this” and then put in my folder.”

However, other respondents didn’t remember ever seeing this poster before:

- “I don’t remember seeing this in the hospital.”
- “I wonder if it’s in the millions of paperwork that you’ll never look at.”

And expressed frustration that they hadn’t seen it:

- “This information is very helpful that could have saved some lives.”
- “Wish I saw this during my postpartum as I felt most of those symptoms.”
- “I’m looking at it now and I think it should be shoved in their face.”
- “With the postpartum preeclampsia, I couldn’t breathe and I had edema in my lungs... but no one had ever said at any point that I wouldn’t be able to breathe, as a postpartum complication. And right here it says obstructed breathing or shortness of breath. So I feel like that would have definitely helped me put two and two together a little sooner.”

Recommendations for increasing accessibility and representative quotes are included below:

***Use the AWHONN poster to begin discussion of postnatal complications earlier in the pregnancy:*** Mothers suggested this poster could be provided during prenatal visits in addition to being given following labor:

- “I think it’s definitely a helpful tool that should be given at the start of pregnancy.”
- “If I hadn’t spent some time in the hospital beforehand [because I was induced], I feel like I probably would have missed some of the recommendations... a lot of the information you got was before you delivered and you didn’t hear that same information again afterwards.”
- “This should be shared at the clinic’s reception as well.”
- “Should pass it to the patient after a [prenatal] medical visit.”

***Ensure providers take time to review and discuss the AWHONN poster:*** Several respondents noted that being given the poster without a provider reviewing it with them was insufficient:

- “[Medical providers should] explicitly review the information with them and stress the importance of looking for these symptoms.”
- “I think a nurse at discharge briefly went over it with me, but we didn’t spend a whole lot of time.”
- “Honestly, I probably [would not have filled out the bottom section by myself] with everything that was going on.”

***Post the AWHONN poster in more community locations:*** Mothers had several suggestions of locations to share the poster outside of birthing centers and prenatal visits:

- “I wonder if [mental health provider] has these and is giving them out to patients. That would be very helpful.”

- “Maybe her and the guy are having trouble and she ends up at that shelter for a period of time, and that’s the perfect window to get this poster in their hands where she’ll pay attention to it.”
- “Not everyone is going to the OBGYN. Maybe they go to a free clinic or urgent care for some of these things.”
- “Place the posters at the entrance to the hospital to attract people’s attention.”
- “Post at public locations where immigrants go. Supermarkets, community centers, churches.”

## **2. Perinatal care systems in need of further exploration and/or improvement.**

To identify systems in need of further study and/or improvement, we asked pregnant parents and families to share their positive and negative experiences with Maine’s perinatal care systems families had during and after birth. The following provides a list of potential perinatal care systems in need of further study and/or improvement.

### **2.a. Blood pressure monitoring systems**

Blood pressure disorders in pregnancy have doubled in prevalence in the past three decades, affecting one in 10 pregnancies. Several respondents had issues with hypertension during or following their pregnancy, illustrated by the following quotes:

- “For the 1st 29 weeks of my pregnancy, my blood pressure was near perfect every single time. So it was really strange to go in and go from having ...120 over 70 to 163 over 100. A very dramatic change very quickly.”
- “A lot of my pregnancy was based around my blood pressure. So yes, they definitely talked to me about that. I stopped taking my [blood pressure] medicine when I got pregnant and didn't have that blood pressure at all for months... but then it went back up... they had me take a baby aspirin every day ...and that's all I did.”

However, based on feedback from our respondents,

#### ***Providers are not consistently educating pregnant patients on hypertension:***

- “I think my PCP might have talked about it? But [my OB did] not that I remember.”
- “Never [discussed blood pressure] and did not ask about it due to the language barrier.”

During pregnancy, several respondents were asked to measure their blood pressure at home, which for some, was the first time they’d ever done this. Unfortunately,

#### ***Mothers have issues with inaccurate readings from blood pressure cuffs purchased for home monitoring:***

- “My blood pressure spiked at home. I was tracking with a home cuff. And so they were like, “come in and have a baby.” And it was just like the random lady on call. I feel like it

was very rushed... there weren't in between steps between "my home cuff gave me this reading" and "come be induced". And then when I got to the hospital, I think I had a couple more normal-ish readings [but] we were already there at that point. So my husband and I decided ...we might as well just stick around and be induced today, cause like we've gotten this far and the kids are with grandparents or whatever."

- "What bugs me is like ...do people actually own blood pressure cuffs? Like I didn't. I went and bought one after I had a high reading at my appointment and they were like, "go get a cuff and track at home." And so, I went to Walgreens and bought one. I don't know if it was accurate, even that first time when I was like, "it's been high at home." I wish they had said "come in and we'll check it for you with, like, somebody who knows what they're doing"... At my next appointment, I brought my cuff in and measured it against the cuff they had at the hospital. And it was inaccurate, like, considerably off. And it wasn't giving consistent readings either."

Perhaps in part due to known issues around the accuracy of home-blood pressure cuffs,

***Mothers are infrequently asked to check their blood pressure at home postpartum.*** Instead, many reported being asked to watch out for symptoms of high blood pressure, but

***Mothers are uncertain what high blood pressure feels like:***

- "I kept telling them, like, hey, I don't know what high blood pressure feels like, but my heart's racing all the time."
- "I almost wish that as part of your discharge from the hospital, someone gave you a blood pressure monitor or get it approved through insurance so you could pick it up at the pharmacy."

Some mothers were asked to return to see their provider a week following birth for blood pressure checks, but unfortunately,

***Postnatal blood pressure check provider visits can easily be missed:***

"I thought, "Wow, six weeks is a long time for the blood pressure check." And then looking back through some of my paperwork, it was like: "follow-up blood pressure check one week from today." And I never did it. They didn't schedule it for me. And I never called. And I was like, oh, cool, they did care."

However, there are postnatal blood pressure monitoring success stories, one of which highlights the important resource of Maine CDC's Public Health Nursing Home Visiting program:

***Public Health Nurses can help ensure postpartum blood pressure checks take place:***

“I was seen by the doctor for the first six weeks and [public health nurse] as well... I believe I went in once a week for blood pressure checks and then public health nurse] was here every week as well or every other week.”

**2.b. EMS integration into Maine’s Perinatal System of Care**

Given Maine’s rural nature and the recent closures of birthing units, EMS plays a crucial role in Maine’s perinatal system of care.

***EMS may be asked to provide transportation for laboring mothers to the hospital the mother chooses, even if that is not the closest geographically:***

“I feel like they would not have done what I asked him to do. They would have ended up sending me to [the nearest hospital] and I didn’t want to have her in [the nearest hospital].”

***EMS staff may benefit from education on post birth warning signs:***

“The 911 operators, the EMT’s... especially if their pronouns are he/him, I think there can be a little insensitivity to just like what you could be going through. When the EMT was taking me off the ambulance, he said, “You know, there has been a lot of RSV going around, so I wonder if it’s that.” Despite everything we had gone through, and even my O2 saturation being so low, he still was like “Oh it’s probably RSV” and I’m like, “No, I had a baby. And I’m clearly having a medical complication.”

**2.c. Prenatal patient education**

Many respondents felt that:

***Prenatal visits with their providers didn’t prepare mothers adequately for pregnancy, birth, and post-birth:***

- “I just assumed that I’d have a vaginal birth, but it turned into an emergency C-section and they never talked about C-section, and I never thought to do research on C-sections because I wasn’t planning on having one. I feel like at your prenatal appointments, you think that’s the place to talk about it, but they don’t do a whole lot of, like, “this is what you should expect. This is what could happen.””
- “You’re supposed to wait at home, but I didn’t know how long to wait. And then people have babies at home because they’re not completely informed. So they’re going too early or they’re going too late. It’s like you never find the right sweet spot.”



- “Nobody mentioned the [prenatal] class. I forget that they even had classes.”

***Mothers value birthing classes, which need to be culturally accessible:***

- “I went to a birthing class, and I'm like, “I wouldn't have been OK at all without it.””
- “Hospitals or Medical facilities should organize women orientation sessions to provide awareness around such topics by using foreign-trained.”
- “Train immigrant social workers to explain before and after birth.”
- “Incorporate women from their community who have already given birth in the US to help them understand what they can expect.”

**2.d. Postpartum education and supports for mothers**

Postnatally, several respondents shared positive experiences that highlighted the support and education they received from providers:

- “I actually thought that [hospital name] did an excellent job with this. I had follow-up calls every couple of days.”
- “They had us watch videos in the hospital, which covered this material.”
- “The midwife at the hospital... that was like, really the only thing that got me to the hospital. She said ‘if something's not right, call 911. Say you had a baby X amount of time ago... That's really important to stress to any sort of paramedic or something.’”

Respondents also shared that,

***Online portals are a valuable post-birth communication tool:***

“They have online things through the portal where they would go through and ask you questions of how you're feeling and if you answered a question that was concerning, a nurse will call you right away. So that was like super helpful. It was postpartum questions.”

And,

***Postpartum home care is helpful:***

- “I was lucky enough to have [name of Public Health Nurse] like as my right-hand man basically. So if I was having any symptoms, she either was the one that recognized it first or I was able to reach out to her...Emotionally I would have been worse off if I didn't have her.”
- “I suggest after giving birth, mothers can be assisted at home at least in the first 2 weeks.”

Unfortunately, new mothers also shared negative experiences post-birth. For example,

***New moms may be confused about what complications they should look out for:***

- “And then post birth...they were like, well, yeah, well you had changes to your breathing and you had a lot of the edema in my leg...that really, really confused me. They said, “oh yeah, edema in your legs is natural, you might expect some swelling.” But then my legs swelled up a lot after birth, and I'm just like, “Oh well, I think this is like a just a normal thing after birth.” And it was so significant that I should have reached out to someone, but I just thought it was something that was supposed to happen after you have a baby.”
- “I was like, “So what should I look out for? Is this significant enough of an event to maybe cause another stroke? And everyone's like, “No, you're probably fine.” There [were no] specific recommendations based on my experience during the pregnancy to look out for postpartum, it was just sort of the general rundown of like what could happen to a woman postpartum.”

***New moms felt their health was perceived as less important than their infant's health:***

- “Everything is centered around the newborn. Which I get it. They're everything. But I'm a person too. Please don't forget about me.”
- “There's so much going on, but ... looking for things that are wrong with yourself is just as important as all the things you are worried about with your baby because you're already worried. I don't think you need the reminder of if your baby's sick... But you don't think that about yourself as a new mom.”
- “The way that they present it [post-birth warning signs] is important. Instead of like being like, “you need to look out for this. Be scared for these.” It needs to be more like, “OK, honey, just make sure you're taking care of yourself. You are super important. You are still important.” ... just making sure that they don't feel bad for needing help because a lot of moms feel bad for being selfish. And you need to take care of their basic human needs.”
- “It was really only when I was being discharged that they kind of gave me the little like quick and dirty run down. And I don't know if it's just because you know, now you have another human to worry about. And so they're telling you about all these things with your baby... I didn't feel like they really focused on me and what could happen to me when I was being discharged. Like, my discharge was kind of just, like, an afterthought.”

***New moms want to be seen sooner than 6 weeks after birth:***

- “It almost felt like you had to watch out for yourself... They schedule a 6-week follow up or something... that's just forever... It's a long time to make sure nothing's wrong.”

***New moms sometimes cannot access the provider's afterhours line:***

“I tried to call their afterhours line, and no one picked up. And I tried like a few times and I was like, well, now I don't know who to call... my personal gynecologist before the pregnancy, I don't think knows yet that I had a baby. My care hadn't even been switched over because my six-week postpartum was supposed to be at maternal fetal medicine. So I literally was like, I don't really know who to call right now.”

***New moms receive different advice from different providers:***

“Have everybody on the same page instead of being like “Oh, this is the first time I'm seeing you” and then having to figure out from scratch again what needs to be done.”

***New moms have significant mental health challenges:***

- “I had some really, really good days and really, really bad days. So my fiancée ... was gone a lot of the winter time. So a lot of times I was completely by myself doing it. So lots of mixed emotions, definitely.”
- “I felt like I didn't have him. I just got a tumor out and like I didn't have my baby. So that was stuff that really affected me. And I feel like we need to talk about that more and get more therapy for women that go through traumatic birthing experiences.”
- “Labor gets so glamorized to especially a lot of young women. It's like, “oh, it's so beautiful. It's so perfect.” And it's not like that for everybody. And you don't think that going into it, you're like, “this is gonna be awesome. I'm going to meet my baby!” But I'm just, like, disappointed.”

And,

***New moms want more postpartum support:***

- “There is a lot of neglect after childbirth so there needs to be a lot of follow-up in women after childbirth.”
- “Women are very fragile beings after childbirth. It takes a lot of care. Women don't show what they are feeling, and you have to be vigilant. There are other women who hide their stress after childbirth.”
- “You need a lot of support after childbirth to stay healthy.”
- “I feel like something that maybe would be helpful would be doing more, more like support groups ... I was alone for the first probably 3 1/2 months... Maybe some more like support groups for even just postpartum in general. I wish I had been able to attend ... even just like a zoom support group, just people that are in the same boat as I was and could talk to them, whether it was just meeting once or as many times as we needed or. Something like that definitely would have benefited me, probably helped boost morale a little bit.”

- “MaineCare... should cover a therapy session... I think that should be in the folder they give the mothers... That could really help out a lot of moms and reduce the amount of unfortunate times where hurting a child is the result.”

## **2.e. Respectful care**

While mothers shared many positives experiences, others shared instances where they felt standards of respectful care were not met, resulting in psychological harm and disinterest in returning to that birthing center for future care.

“If I ever have a third, I'm not going back to the doctor. I'm gonna do homebirth, even if it kills me, because I just had such a bad experience and I don't wanna go back under any circumstance.”

### ***Mothers want to be more involved in decision-making during birth:***

- “I know that the system has to be standardized because they're responsible if someone sues them. But that's probably my biggest beef with the system that like, there's no individual decision making.”
- “Just yeah, the general sense of being kind of like another patient in a long line of patients, I think... It felt like, you know, you put this information in the box and the box pops out an answer and that's what we do for every patient that has this presentation. Maybe there's a reason to individualize the process and that didn't feel like it happened at all. Except for with my doctor.”
- “I think it seems like there is a huge discrepancy with the balance of power and being in a vulnerable place. We're already pregnant and feel even more vulnerable. But having someone who's constantly telling you instead of asking for permission or giving you options...”

### ***Mothers struggle with advocating for themselves:***

- “Building a consent form together might be a huge move.... I feel like they should have sat down with me and been like, “what do you want?” instead of being like “you do your own research, bring it in on a sheet of paper and we'll look at it when you tell us you did it, but we're not going to ask you about it.””
- “I always had to speak up and advocate for myself. It's really, really hard. I feel like you definitely always need at least one nurse that'll be there and advocate for you. Like a doula.”

### *Some mothers appreciate the support of doulas:*

- “I think some nurses are probably like, “yeah, bring your doula. That's amazing.” But some OB's are like, “OK, you can bring your, like, witchcraft friend in. But we're really educated.””
- “Birth for me was really communal and I feel like most people I know who are pregnant are talking about it [doulas] to other moms at least. And so I think that if [doulas were an] option, they probably be persuaded to have one too.”

### *Mothers want their support people to feel respected by their providers:*

“It's hard seeing your partner in so much pain and going through something so traumatic and sometimes life threatening. And they're just like ignoring them and not taking the time to say “You doing OK, Dad?””

### *Mothers sometimes feel judged or experience stigma:*

- “I did feel a little bit like me asking questions: ‘Is this the right decision for me to come in and have a baby?’ was treated like I was being cavalier with my baby's health.”
- “I was on Suboxone at the time, so I just kind of expect to be treated like a lower citizen, to be honest with you.”
- “I wasn't worried I would experience bias. I knew I would experience bias because I do every time I go to the doctor's or to a medical facility. Once they know you're on Suboxone that's pretty much it. It's not OK, but ... you get used to it. You know what I mean? So you just expect it because it's easier to expect the worst than to go in and think the best and then to be treated like ... you're less than human. It's kind of aggravating at times, especially when you hope that that they're gonna help you.”

## **Recommendations**

1. Given the variety of perinatal education materials given out in hospitals, PQC4ME should collaborate with providers to explore standardizing hypertension (both severe and chronic) education among all Maine hospitals (birthing and non-birthing) and other sources of care (health centers, primary care, specialty care, public health nursing/home visiting, etc...). This would support consistent messaging across providers and settings to reduce patient confusion, increase understanding, and support healthy behaviors.
2. The AWHONN Save Your Life poster is an excellent resource. PQC4ME should work with a broad variety of providers and community organizations to increase access to their materials, both prenatally and postnatally.
3. While an excellent resource, the AWHONN Save Your Life poster presented some accessibility issues for populations we sampled. PQC4ME should explore different

modes of education (video, social media, etc...) and develop processes for integrating these into perinatal care received by diverse providers.

4. The PQC4ME website and/or CQI's learning resources hub should be explored as a potential option to house videos and resources.
5. New parents need more postpartum support for both their physical and mental health. PQC4ME should explore incorporating mental health resources on its website and ensure referral tools are accessible for providers.
6. Maine CDC's Public Health Nursing and other home visiting programs also offer opportunities for increased postpartum support. PQC4ME can assist in raising awareness of these services as well as providing referral tools and resources of its website.
7. Emergency Departments and EMS are an important component of the perinatal care system. Increased collaboration between emergency services and PQC4ME will illuminate opportunities for system improvements and education.

## Limitations and future considerations

The sample in this study included participants' opinions and experiences that may not be generalizable to all birthing parents. Moreover, this study was based on the opinions and experiences of respondents, and they could have provided socially desirable responses and/or personal bias.

While we collected demographic details (race, language, rural/urban, etc...) from each participant, our sample size limited our ability to find meaningful differences. Greater subpopulation analyses should be a priority for future work.

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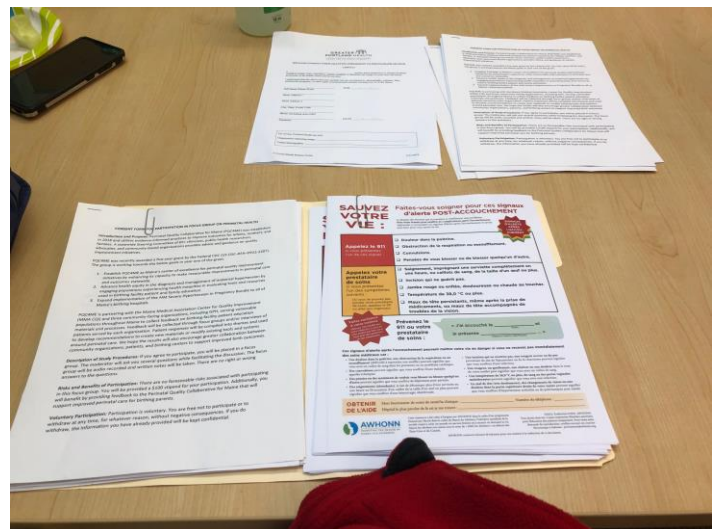
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These partners' willingness to take time out of their incredibly busy schedules to help us plan, recruit, and facilitate focus groups enabled the project to move forward.

Deborah Deatruck, Public Health Consultant to PQC4ME, assisted with outreach and coordination to community, primary care, and public health partners. Most importantly, we also thank the women who participated in the interviews and focus groups, for sharing their stories, and suggesting ways to improve care for all Maine mothers.

Appendix A. Photos from focus groups





## Appendix B. Consent Form

### **Perinatal Quality Collaborative for Maine Assessment of birthing-facility patient education tools and processes**

**Introduction and Purpose:** Perinatal Quality Collaborative for Maine (PQC4ME) was established in 2018 and utilizes evidence informed practices to improve outcomes for infants, mothers, and families. A statewide Steering Committee of 65+ clinicians, public health researchers, advocates, and community-based organizations provides advice and guidance on QI initiatives. PQC4ME was recently awarded a competitive cooperative agreement of \$275 thousand per year for 5 years by the Federal CDC (US CDC–RFA–DP22-2207). The project’s Year 1 goals are to:

1. Establish PQC4ME as Maine’s center of excellence for perinatal quality improvement initiatives by enhancing its capacity to make measurable improvements in perinatal care and outcomes statewide.
2. Advance health equity in the diagnosis and management of maternal hypertension by engaging populations experiencing health inequities in evaluating tools and resources used in birthing facility patient and family education.
3. Expand implementation of the AIM Severe Hypertension in Pregnancy Bundle to all of Maine’s birthing hospitals.

PQC4ME is partnering with the Maine Medical Association Center for Quality Improvement (MMA CQI) and three community-facing organizations serving vulnerable populations throughout Maine to collect feedback on birthing-facility patient education materials and processes. Feedback will be collected through focus groups and/or interviews of patients served by each organization. Patient responses will be compiled into themes and used to develop recommendations to create new materials or modify existing tools and systems around perinatal care. We hope the results will also encourage greater collaboration between community organizations, patients, and birthing centers to support improved birth outcomes.

**Description of Study Procedures:** If you agree to participate, you will be scheduled for an interview/focus group. The facilitator will ask you several questions while facilitating the discussion. The interview/focus group will be recorded, and written notes will be taken. There are no right or wrong answers to the questions.

**Risks and Benefits of Participation:** There are no foreseeable risks associated with participating in this interview. A [\$\$ stipend] will be provided for your participation. Additionally, you will benefit by providing feedback to the Perinatal Quality Collaborative for Maine that will support improved perinatal care for birthing parents.



**Voluntary Participation:** Participation is voluntary. You are free not to participate or to withdraw at any time, for whatever reason, without negative consequences. If you do withdraw, the information you have already provided will be kept confidential.

**Confidentiality of Records:** Your participation and responses will remain confidential. No names will be included in the final report, and any identifying information will also be removed. No one will be able to link your information with your name.

**Contact Person:** For more information please contact Liz Winterbauer, [liz.winterbauer@gmail.com](mailto:liz.winterbauer@gmail.com), 802-860-5070.

**Signature/Dates:** I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this interview, although I have been told that I may withdraw at any time without negative consequences. I have received (or will receive) a copy of this form for my records and future reference.

Print name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix C. Educational Handout

# SAVE YOUR LIFE:

## Get Care for These POST-BIRTH Warning Signs

Most women who give birth recover without problems. **But any woman can have complications after giving birth.** Learning to recognize these POST-BIRTH warning signs and knowing what to do can save your life.

**POST-  
BIRTH  
WARNING  
SIGNS**

<p><b>Call 911</b> if you have:</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Pain in chest</b></li> <li><input type="checkbox"/> <b>Obstructed breathing or shortness of breath</b></li> <li><input type="checkbox"/> <b>Seizures</b></li> <li><input type="checkbox"/> <b>Thoughts of hurting yourself or someone else</b></li> </ul>
<p><b>Call your healthcare provider</b> if you have:</p> <p>(If you can't reach your healthcare provider, call 911 or go to an emergency room)</p>	<ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Bleeding, soaking through one pad/hour, or blood clots, the size of an egg or bigger</b></li> <li><input type="checkbox"/> <b>Incision that is not healing</b></li> <li><input type="checkbox"/> <b>Red or swollen leg, that is painful or warm to touch</b></li> <li><input type="checkbox"/> <b>Temperature of 100.4°F or higher</b></li> <li><input type="checkbox"/> <b>Headache that does not get better, even after taking medicine, or bad headache with vision changes</b></li> </ul>

**Trust your instincts.**  
ALWAYS get medical care if you are not feeling well or have questions or concerns.

**Tell 911 or your healthcare provider:**

"I gave birth on \_\_\_\_\_ and  
(Date)  
I am having \_\_\_\_\_."  
(Specific warning signs)

**These post-birth warning signs can become life-threatening if you don't receive medical care right away because:**

- Pain in chest, obstructed breathing or shortness of breath (trouble catching your breath) may mean you have a blood clot in your lung or a heart problem
- Seizures may mean you have a condition called eclampsia
- Thoughts or feelings of wanting to hurt yourself or someone else may mean you have postpartum depression
- Bleeding (heavy), soaking more than one pad in an hour or passing an egg-sized clot or bigger may mean you have an obstetric hemorrhage
- Incision that is not healing, increased redness or any pus from episiotomy or C-section site may mean you have an infection
- Redness, swelling, warmth, or pain in the calf area of your leg may mean you have a blood clot
- Temperature of 100.4°F or higher, bad smelling vaginal blood or discharge may mean you have an infection
- Headache (very painful), vision changes, or pain in the upper right area of your belly may mean you have high blood pressure or post birth preeclampsia

**GET  
HELP**

My Healthcare Provider/Clinic: \_\_\_\_\_ Phone Number: \_\_\_\_\_  
Hospital Closest To Me: \_\_\_\_\_

## Appendix D. Facilitation Guide

Question	Prompts
<p><i>(Note: Pass out the poster if not already done – give them a few minutes to review it)</i></p> <p>1. Have you seen this poster before today? <i>(Can ask them to raise hand)</i></p> <p>No --&gt; What are your first reactions to this poster?</p> <p>Yes --&gt; Where did you receive this poster? Do you have a copy in your home? If yes, are the green and yellow sections filled in with your personal and provider details?</p>	<p>Have you seen it before, is it something that draws your attention?</p>
<p>2. What do you think the main messages are from this poster?</p>	<p>What are the key takeaways?</p>
<p>3. What do you like about this poster?</p>	
<p>4. What don't you like about this poster?</p>	
<p>5. What is confusing about this poster?</p>	<p>They can circle words that are unclear. <i>(Collect marked up copies at the end of the session)</i></p> <p>Ask if there are words or concepts they don't understand.</p>
<p>6. Does this poster feel like it would be helpful to you, or other women you know?</p>	<p>If yes, how would it be helpful?</p> <p>If no, why might it not be helpful? Explore barriers around implementing some of the actions suggested.</p>
<p>7. Do you have suggestions on ways this poster could be most impactful?</p>	<p>Ask about any formatting changes.</p> <p>Besides the format of the poster, what can medical providers do to help make this poster more helpful?</p> <p>Where are some good places for a poster like this to be placed so that women can see the information?</p>
<p>8. Has your doctor ever discussed high blood pressure with you?</p>	<p>If yes, please describe when and how the information was provided.</p>
<p>9. Did you experience a medical concern before or after birth?</p>	<p>For example, a doctor, friend, community health worker, etc...</p>

<p>Yes --&gt; Who did you call? What made you decide to call? What worked well or didn't work well?</p> <p>No --&gt; Who would you call if you had a medical concern after giving birth?</p>	<p>Note if they don't know who they would call.</p>
<p>10. Do you have suggestions about how to help women know how and when to get help if they have a medical concern before or after giving birth?</p>	<p>Where and how should this type of information be provided? (examples: fridge magnets, social media, etc...)</p> <p>What conversations between women and medical providers would be helpful?</p> <p>When should those conversations occur?</p>
<p>11. Do you have any other suggestions of how to support mothers' health before or after giving birth?</p>	<p>What do we need to know to support your community?</p>