

**PCORI 4th Trimester Patient-Centered Outcomes
June 2017 Engagement Meeting Report
EAIN 2603**

The Patient-Centered Outcomes Research Institute 4th Trimester Project meeting was held on Friday June 2, 2017 at the Museum of Life and Science in Durham, North Carolina. Fifty-two individuals attended the meeting, 16 were PCORI patient representatives (mothers). Participants included community activists, doulas, health care providers, and researchers from a variety of disciplines and public health. At the mothers' request, everyone was sent a PCORI shirt in advance of the meeting and asked to wear it, which everyone did.

The meeting began with a short introduction, a description of meeting goals and guidelines by Sarah Verbiest. A presentation on the Patient-Centered Outcomes Research Institute Engagement Awards and PCORI funding priorities was provided by Alicia Thomas. Kristin Tully provided an overview of EAIN-2603 stakeholder-engagement key findings, as published in the [American Journal of Obstetrics and Gynecology](#) and the [ZERO TO THREE Journal](#) and as discussed by the patient stakeholders at their March in-person research meeting. Kristin provided a summary of the extensive media coverage of the team's work, which includes publications in [Vox](#) and [Quartz](#). The team actively engages stakeholders through the "4th Trimester Project" Facebook page (2,731 followers), Twitter (704 followers), and their [website](#).

The participants were then divided into self-identified small groups and discussed ideas for new 4th Trimester PRO Measures and maternal postpartum health screening topics. After a networking lunch on-site, the participants were divided into predetermined groups to maximize the diversity of stakeholder expertise. The groups then discussed 4 proposed research study topics (See meeting agenda), including the most appropriate study populations, recruitment and retention strategies, stakeholder engagement within the proposed projects, and dissemination strategies.

Survey evaluations were sent to **all** participants to provide feedback on the format of the meeting and key areas of interest. Overall, 29 participants responded to the survey, 20 of whom fully completed the survey. In general, participants felt very positive towards the meeting and particularly enjoyed the family-friendly environment and the diversity of participants. The respondents reported feeling engaged with the meeting format (93%). Two participants mentioned they would have liked to have more time to learn about the different organizations represented by participants in the room and network. They further suggested more time be dedicated for thought and questions during the PRO Measures and Study Topic discussions. Most participants felt like they were fully able to contribute in the small group discussions (86%). Only 4 individuals mentioned they did not contribute as much as they would have liked. The reasons they offered for incomplete engagement were: some participants were directing the conversation; the groups were too large; and, it was difficult to hear side conversations. Additional recommendations for improvement from participants included using a microphone, decreasing group size, providing more variety in food, having more of an open indoor space where moms could sit with infants, and providing a better description of the purpose of the PRO measures. According to respondents, the most interesting parts of the meeting were the study ideas small group discussions (22/28) followed by the PRO measures (20/28). The participants reported highest levels of excitement about the studies on access to postpartum care (20/27) and communication and education (19/27). The July patient stakeholder webinars also provided a space for conversation about the meeting. Mothers highlighted that they loved the matching shirts, which they felt were great equalizers, and they enjoyed seeing each other. They were excited to see their ideas moving into action. If we were to hold future in

person meetings, they suggested finding a location in Raleigh or more central in the Triangle, as most mothers do not live close to the Museum of Life and Science.

The first breakout sessions addressed a draft questionnaire for a potential Patient Reported Outcome Measure on the **Transition through the 4th Trimester**. Domains were

- Motherhood
- Social support
- Stressors
- Maternal-infant interactions
- Health care providers

The wording of specific items was reviewed, with suggestions noted for revision. Additionally, some questions were removed and others added. We envision these questions being administered in several contexts. Our goal is to develop a set of questions that can be used to assess how well programs / treatments are doing in improving maternal/family well-being in the Fourth Trimester. The purpose is to integrate responses into care, studies and programs, as a mechanism to begin addressing unmet maternal health needs. Additionally, the groups reviewed a list of **Pre-Visit Health Screening** topics to also be assessed in advance of postpartum clinical visits, with the objective of identifying maternal health priorities. Topics include physical, mental, and social health. Next steps in this line of work are to validate the scales, test their association with health outcomes, and support implementation if data demonstrate the value of incorporating these measures tailored to postpartum women alongside existing PROMs.

According to participants, the best aspects of the proposed comparative effectiveness research on recovery from childbirth (**maternal postpartum pain management**) were that it would:

- Address insufficient information and care in marginalized communities
- Determine the most appropriate methods of pain management, including home instructions and reminders
- Identify the most effective combination of tools for maternal physical and emotional health around this issue
- Improve knowledge on differences in pain thresholds in relation to birth preferences and pre-existing conditions like anxiety
- Understand postpartum pain in relation to existing PRO Measures

Intervention ideas that were generated include home visits to facilitate guidance on proper medication use and the development of a pain protocol for providers serving postpartum women. This issue is problematic for women due to a variety of interconnected factors, including:

- Dismissal of pain by health care providers
- Fear of "getting hooked" on medications
- Concern about the effects of medications on breastfed infants
- Divergent views on the nature of pain versus suffering

Challenges to this proposal include the normality of postpartum pain as part of the recovery process for women, although the thresholds (the levels of discomfort that do not impair function or result in poor health trajectories) are undefined. Additionally, some women have different postpartum physical requirements than others, such as caring for other children. Further, literature suggests that women of color experience disparities around pain management, but there does not seem to be literature specific to the postpartum period.

According to participants, the best aspects of the proposed **longitudinal observational study** with mom, partner and infant were that it involves the partner and could address the health needs of the whole family. Stakeholders felt that this proposed work would elevate the concept of the 4th Trimester and identify ways to best provide continuity of health care and support. A strength is the unique opportunity to assess resources that promote changing health needs over time. Some intervention and research ideas included using cohort style recruitment and retention, utilizing multiple layers of communication and engagement to promote data collections, and examining the effectiveness of lay health workers on providing services. A focus that was discussed in the monthly webinars with mom-partners was the integration of International Board Certified Lactation Consultants in pediatric practices, which is a service currently covered by health insurance, but not widely implemented. Integrated IBCLC support versus IBCLC referrals is not a condition that can be randomized, so this focus is a possible fit for PCORI funding.

The key aspects of the proposed study on **improving communication and patient education in health systems** included better provision of accessible and applicable information resources to underserved communities. The stakeholders also highlighted the importance of improving communication between patient, providers and community, including communicating well-being as more than physical health. Additional components of this work that were elevated were testable ways to address implicit bias in health care interactions, using non-traditional public health messaging platforms, and promoting the value of dyadic and community-based care. Some intervention and research ideas include a 24-hour 4th Trimester hotline, providing anticipatory guidance through a patient portal to provide timely information, and better facilitating ongoing communication with providers. Participants also suggested that women need information available “just in time” based on their needs. Further, as women so often turned to peers and friends online and in person, the concept of clinic-coordinated new mother support groups emerged as one way to extend education to families and create a sense of community. Another suggestion was to have one member of the clinical team hired and in place to focus solely on postpartum education. This person could talk with women in the waiting room, meet with them while they are in exam rooms waiting for their provider, coordinate a clinic Facebook page, coordinate support groups, etc. Educating and engaging men/fathers was mentioned as important.

According to participants, the best aspects of the proposed **improving access to postpartum care and services** study are:

- Making postpartum care access a community issue
- Having a central location of services with the options of home, office, or web-based visits
- Working with organizations in the community to ensure sustainability, serving vulnerable populations
- Integrating the care for moms and babies in one setting
- Providing more support for moms around 2-3 weeks postpartum
- Promoting social interaction/development using group sessions followed by individual care as needed.

A research idea involves investigating the differences between usual care and a “one-stop shop” for integrated postpartum health, which would entail testing the effects of the one-stop shop with a group of pregnant women and following these women through pregnancy and the postpartum periods. Another research priority was testing the impact of routine physical therapy for new mothers, as is common in France.

Thoughts about enrollment/patient engagement, incentives, communication, or data collection methods were addressed for each of the proposed studies. Common stakeholder recommendations included using transportation vouchers or child care as incentives; incorporating apps, SMS (up to two text messages daily), websites, etc. in interventions and research; continue to develop community partnerships; working on engaging leadership in inpatient settings to develop a more consistent path for postpartum care; engaging partners and family; recruiting in person during hospital visit or on the follow up phone call from the hospital as opposed to mailing a letter for a more personal touch; providing training opportunities; including incentives such as T-shirts, diapers, or cash awards; ensuring engagement is robust and systematic, including community health researchers. Existing technology devices such as iPads and Fitbits were discussed for data collection, although the appropriateness of these and the other ideas will vary based on the target groups for the proposed studies (not all potential participants would have access to wireless internet). Information that can be provided back to study participants during participation, such as findings from assessment of breastmilk samples, is desired. Ways to elevate the communities from which participants are drawn (especially HRSA neighborhoods) was identified as critical; training local individuals in the tested methods of health care delivery and incentives such as employment training were suggested. Mothers noted that if they received information back about how the studies they were participating in were helping other moms, they would be motivated.

To conclude, other priority areas that were mentioned by stakeholders from the June 2, 2017 engagement meeting, were: bias in family planning education and sexually transmitted disease treatment, mental health care and medication compliance during pregnancy and postpartum period, parents of children with special healthcare needs/disabilities, employment and education resources in the 4th Trimester to address the emotional and financial costs of childcare, tailored provision of postpartum health information, engaging partners in a 4th Trimester conference type format, and studying the effectiveness of virtual reality interventions with moms in pain. Special populations that require different, additional postpartum support are: women who have had an infant loss; parents of hospitalized infants and/or of children with disabilities; LGBTQ families; foster carers; women of color (historical trauma); and rural families. An area to expand is enabling doula training and support to increase the number of health care providers who represent the families they serve, by race and ethnicity.

At the end of the day, all of the participants expressed an excitement about the work ahead in exploring the issues and challenges raised during the meeting. There was a strong sense of solidarity and engagement. Many of the mothers were eager to stay involved in upcoming research proposals and projects. All of the other stakeholders articulated an appreciation for the energy and perspective that patients/consumers brought to the conversation and work.