

Lay Summary

Working in close collaboration with patient-partners, we held a two-day virtual conference April 23-24th, 2021 entitled “Perinatal Connect Conference: Engaging with Rural Communities to Improve Maternal Mental Health Outcomes”. Depression during the perinatal period is the most common complication of pregnancy and childbirth, affecting 1 in 8 women in the United States. Women in rural areas are disproportionately more likely to experience depression during the perinatal period. The purpose of the conference was to convene multi-stakeholders including patients, providers, researchers, and health systems leaders to accelerate perinatal depression patient-centered outcomes research in rural communities.

The conference included speakers from the Patient-Centered Outcomes Research Institute (PCORI), PCORI-funded researchers and their patient-partners, and health systems leaders working to create and implement programs and policies that provide equitable access to care for postpartum patients in rural communities. The conference also had four separate patient-led panel discussions that followed each of the plenary sessions and focused on the following themes: 1) engaging rural communities, 2) improving maternal mental health outcomes, 3) engaging health systems to improve care and 3) addressing social and structural factors impacting maternal health outcomes in rural communities. Highlights from our breaks throughout the conference included a guided meditation led by Karen Grajczyk-Haddad (University of Iowa) and yoga led by Meredith Caskey (University of Iowa). Visual notes were recorded by Johnine Byrne from See Your Words LLC and synthesized into a stakeholder-driven strategic roadmap infographic with input from our patient and clinical partners.

The conference began with a welcome led by the co-PI’s of the PCORI engagement award, Drs. Kelli Ryckman (University of Iowa) and Karen Tabb (University of Illinois). Next, Courtney Clyatt, Senior Program Officer for PCORI Engagement Awards presented an overview of patient-centered outcomes research and comparative effectiveness research at PCORI which included highlights of PCORI’s portfolio on maternal health. Our first plenary session for April 23rd, 2021 was entitled “Engaging Rural Communities” and included a presentation from Dr. Carol Janney Director of Research at Pine Rest Christian Mental Health Services in Michigan. Dr. Janney provided an overview of engaging rural communities in mental health research based on a PCORI Tier I engagement award titled “Building a pipeline to improve mental health care, self-management, and outcomes in rural communities.” Dr. Madhavi Nagalla, an attending psychiatrist at Pine Rest, also spoke about the importance of day programs for the perinatal population and the development of a partial hospitalization program for perinatal mood disorders in Grand Rapids, Michigan.

Following the session, a patient-led panel discussion was facilitated by Kaitlin Wilcox a member of the Iowa Community Advisory Board and Sheila Raila a member of the IDEA Women’s Health Coalition from Illinois. The first part of the discussion focused on the barriers for accessing mental health care services in rural communities. The two largest barriers that were identified were stigma and access to mental health care services. Participants shared their stories around feelings of shame and stigma in getting help for mental health conditions. Barriers around access to care included transportation issues, lack of providers and lack of training for first responders. There were stories shared of three month and longer wait times to see a mental health professional. Potential solutions were also discussed, some of which work in other communities, and include the use of case managers or peer support programs and integrating mental health services as part of routine postpartum follow-up appointments.

The second plenary session for April 23rd, 2021 was entitled “Improving Maternal Mental Health Outcomes” and included a presentation from Dr. Sharon Ruyak, Assistant Professor, University of New Mexico, Jennifer Williams, Chair of the New Mexico Chapter of Postpartum Support International, Dr. Pilar Sanjuan, Assistant Professor, University of New Mexico and Susan Aguayo, Founder and CEO of Kassy’s Kause. Dr. Ruyak and team presented on “A Journey to Empowerment and Health: Building the New Mexico Perinatal Mental Health Improvement Network” a PCORI Pipeline to Proposal, Tier A award. The goal of the network was to bring together women who had experienced perinatal mood disorders, healthcare providers and researchers to develop a partnership, strategic plan, communication plan, research training, and comparative effectiveness research questions focused on improving healthcare and quality of life for women with perinatal mood disorders. Susan Aguayo shared the story of her daughter who suffered from a perinatal mood disorder and ultimately took her own life. Out of this tragedy she founded Kassy’s Kause a foundation in New Mexico dedicated to connecting people to the mental health resources they need. Together this collaborative effort is a first step in identifying and overcoming barriers to care for women suffering from perinatal mood disorders.

Following the session, a patient-led panel discussion was facilitated by Stephanie Adamson a member of the Iowa Community Advisory Board and Rachael McKinney a member of the IDEA Women’s Health Coalition from Illinois. Participants were asked to share the biggest obstacles to receiving mental health care during and after pregnancy. Themes that emerged included lack of knowledge about depression and anxiety, lack of transportation and services in rural counties, lack of obstetricians and family healthcare providers initiating mental health conversations with their patients, and time to prioritize yourself over your baby to get mental health services. Others mentioned that women with mental health issues and substance use disorders are afraid to seek help because they feel their children may be taken away if they admit they are having these problems. The next part of the conversation focused on strategies and resources for improving mental health outcomes. Some of the strategies mentioned included utilizing telehealth, destigmatizing mental health, home visiting programs, and support groups. Participants largely agreed that maternal mental health care should be incorporated into new baby visits.

Day 2 of the conference (April 24th, 2021) began with a welcome and summary of the previous days’ sessions and discussions led by the co-PI’s of the PCORI engagement award, Drs. Kelli Ryckman and Karen Tabb. The keynote address was provided by Patricia Carrillo the Program Coordinator at the University of Kansas’ Center for Public Partnerships and Research (CPPR). Ms. Carrillo described the Kansas Connecting Communities project, which since 2019, has been supporting program implementation and perinatal providers’ access to training and technical assistance related to the screening of and treatment for perinatal mental health and substance use disorders. She described the collaborative care approach and how Kansas Connecting Communities provides training events, toolkits, technical assistance, and a consultation line that helps providers get the resources they need to better serve the mental health needs of their patients.

Next was a plenary session on “Engaging Health Systems to Improve Care in Rural Communities”. Our speaker was Ms. Tira Mays the Government Programs Coordinator at Broadlawns Medical Center in Des Moines, Iowa. Tira spoke about her experience working with underserved and under-insured populations and assisting them with access to affordable and quality health care. She specifically, spoke about ways to engage and connect quality healthcare resources to underserved populations including people of color, unemployed, under-employed, homeless, impoverished, and single parents. She spoke about the barriers these individuals face and that even when they receive care, they often have worse outcomes. She

shared some ways health care organizations and programs can connect with these populations to provide better access to care. She also shared her experiences serving on the executive board for “Count the Kicks” a mobile application that provides a free, easy, and reliable way to monitor a baby’s well-being in addition to regular prenatal visits. “Count the Kicks” has been instrumental in reducing the rate of stillbirth by educating mothers on the importance of tracking fetal movement throughout pregnancy. Following the session, a patient-led panel discussion was facilitated by Suzanne Peppers a member of the Iowa Community Advisory Board and Ruby Carpenter a member of the IDEA Women’s Health Coalition from Illinois. The panelists shared their experiences in engaging with the healthcare system to receive support for perinatal mood disorders. The discussion focused on some of the barriers to receiving care identified in Day 1 and some ways to encourage and educate both patients and providers. Specifically, the idea of patient-centered care models that are designed to empower each patient to ask questions and advocate for their healthcare. Also discussed was implementing programs and policies that focus on prevention through depression screening and extended Medicaid benefits to support longer postpartum access to care.

The second plenary session of Day 2 was entitled “Rural Maternal Health: Examining Social and Structural Factors Impacting Health Outcomes” and included a presentation by Dr. Stephanie Radke, Clinical Assistant Professor, University of Iowa. Dr. Radke described the disparities in maternity outcomes that exist for rural residents and discussed the social and structural factors that can promote or hinder good health in pregnancy in rural communities. She also described solutions for reducing rural disparities that included increasing the capacity of rural family physicians to provide mental healthcare services in pregnancy, providing better access to telemedicine psychiatric services, and standardizing screening for mental health conditions during pregnancy care. Following the session, was the last patient-led panel discussion facilitated by Amy Woods a member of the Iowa Community Advisory Board and Meghan Kirkpatrick a member of the IDEA Women’s Health Coalition from Illinois. Both shared their experiences with depression and access to care and why they think it’s important that they contribute to patient-centered outcomes research. The discussion largely focused on education for providers in rural areas on how to recognize and refer their patients with depression or anxiety for treatment. There was also discussion on the timing of postpartum mental health screening and how to encourage moms to receive screening and treatment.

Overall, the conference had 447 registrants with 170 individuals who attended some part of the conference live. Among registrants there were 15 countries represented and 40 states. Attendees included patients or caregivers, individuals affiliated with a community-based or advocacy organizations, clinicians, researchers, and policy makers. The discussion and visual notes from the conference were used to develop a stakeholder-driven strategic roadmap infographic for engaging in patient-centered outcomes research. The roadmap was reviewed by the Iowa Community Advisory Board and the Illinois IDEA Women’s Health Coalition. The roadmap was updated to reflect suggestions from patient and clinical partners. The strategic roadmap outlines how rural access programs are a bridge to collaborative mental healthcare that have substantial opportunity to improve maternal mental health outcomes. The effectiveness of these programs needs to be assessed with specific focus on education that addresses mental health stigma, insurance coverage that includes a full year of postpartum care and building trust within the community. The conference has better prepared a wide range of stakeholders to engage in patient-centered outcomes research and comparative effectiveness research on perinatal depression in rural communities. Registrants of the conference will receive follow-up emails that outline their access to all session videos, a written conference summary, visual notes, and the finalized stakeholder-driven strategic roadmap.