



MoMMA's Voices

Patients with Lived Experience Integration

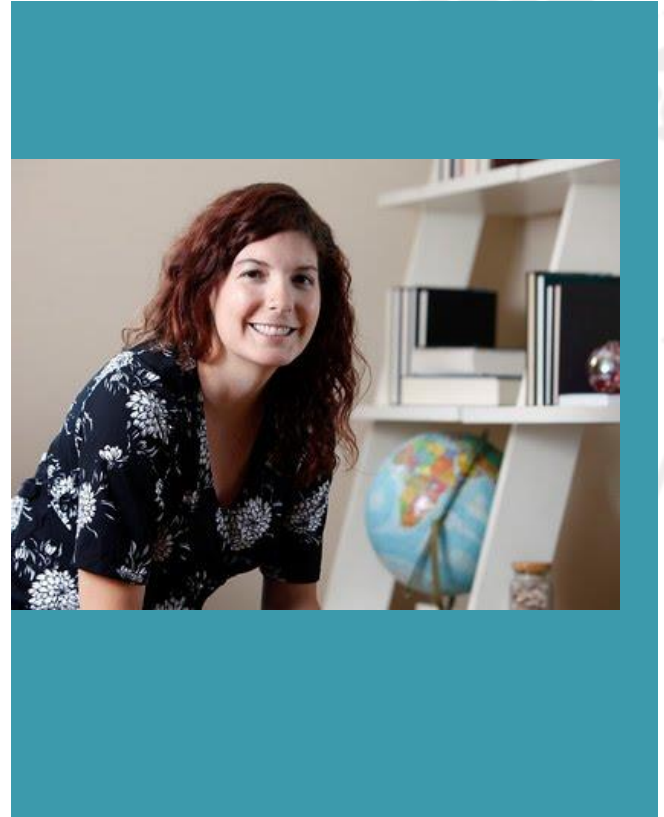
Presented to

PA PQC

Emily Taylor

Engagement and Outreach for MoMMA's Voices
Program Coordinator for AFE Foundation

Emily is a maternal health advocate and patient family partner in North Carolina. She is a survivor of an Amniotic Fluid Embolism after the birth of her first child in 2018. She was in the non-profit gastrointestinal and patient engagement space for 6 years before joining MoMMA's Voices in 2022. She works with other certified PFP's in the matchmaking process, and does outreach with providers, PQC's, and corporate leaders. Integrating patients with lived experience in every level of QI work is her passion!



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Bekah Bischoff

Bekah Bischoff serves as the Patient Family Partner Coordinator for the MoMMA's Voices Coalition, assisting patients and family members going through the online training to prepare them for working with individual providers or organizations on maternal health process improvement.

Following her own near-death experience and postpartum recovery with the birth of her second child due to severe preeclampsia and HELLP syndrome, Bekah is passionate about helping moms identify and heal from their traumatic birth experiences. She recognizes the importance of sitting beside each hurting mother in the isolation that comes with pregnancy trauma. Her work centers on helping empower these women to transform their pain to purpose.

In 2018, she collaborated with the Association of Women's Health, Obstetric, and Neonatal Nurses (AWHONN) for legislative policy work, where she learned how much she loved meeting with policymakers to advocate for maternal health legislation and to ensure mothers are given a seat at the table. She specializes in storytelling for advocacy. She enjoys using her years of professional experience as an educator to help teach mothers how to effectively share their story to implement change through the MoMMA's Voices Lived Experience Integration™ framework.



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Emily's story

- Easy pregnancy of first child
- Healthy, normal, “boring” pregnancy
- Induced at 37 weeks due to unknown cause of hypertension, tested negative for preeclampsia
- After 14 hours of labor my water broke
- Anaphylactic type reaction from my Amniotic Fluid
- DIC- 18 units of blood transfusions
- Cardiac arrest
- Heart Failure
- Kidney Failure
- Lung Collapse
- ECMO for 4 days
- Great care from healthcare providers
- Total of 11 days in the hospital
- CDI and pancreatitis developed after



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Evelyn's story

- Evie's first picture
- Born at 37 weeks and got down to 4lbs
- Feeding tube and oxygen
- Took an ambulance to UNC for cooling therapy
- Diagnosed with HIE
- In the NICU for 10 days
- Unable to breastfeed
- Dealt with motor and speech delays
- Eye surgery at 10 months old
- I went through major mom guilt, PTSD, depression, and anxiety
- PFP training helped understand how to process these experiences and use them to teach others
- If you want to work with patients, you have to start with patients!



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The Scariest Day of My Life

Bekah Bischoff



Bekah's Story

- Debilitating heartburn
- Excessive weight gain, despite not eating
- Upper right quadrant pain
- Extreme Fatigue
- Headaches
- Fluid loss
- Seeing stars
- Summary: Dismissal. I was almost a statistic
I never knew was a possibility



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Learning to Live with a Lived Experience

- Learned this wasn't rare after USA Today's Investigation "Deadly Deliveries" in 2018
- Sharing with legislators
- Found my voice and passion for the pain
- Hearing from mothers every day helping them identify and heal
- Merck for Mothers "Reverse" on Vimeo



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The purpose of MoMMA's Voices is to amplify patient and family voices - especially those who have been historically marginalized - ensuring they are equipped and activated as partners to improve maternal health outcomes.

Momma's voices are engaged as partners wherever maternal health improvements are needed.

Learning Objectives

- Discuss the importance of engaging people with lived experience in your hospital team's efforts.
- Identify strategies and resources for engaging people with lived experience as part of your hospital team
- Examine best practices for engaging and working with people with lived experience.
- Share MoMMA's Voices Resources.



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What we do

Community of Learning

- The Lived Experience Integration into QI Community of Learning (COL) was an eight-week educational series created by MoMMA's Voices and funded by AIM. The program ran January to May 2022 and served three cohorts of 23 AIM state and jurisdiction-based teams, Indian Health Services facilities, and other healthcare entities.

Topics Covered

1. Best practices in patient engagement
2. Patient Engagement Philosophy
3. Creating a patient engagement culture
4. How are you positioned to create a patient engagement culture?
5. Onboarding
6. Funding and compensation
7. Develop a 90 Day Action plan

<https://www.mommasvoices.org/col>



Resource to see where you stand with patient engagement

Lived Experience Integration Scorecard

How do you measure up?

We are going beyond patient engagement to ensure patients' lived experiences are truly *integrated* into quality improvement work



www.mommasvoices.org/lei-scorecard

Fill out for a drawing for a free pass to our Lived Experienced Integration Foundations Training!



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What we do

Provider Training coming soon!

The **Lived Experience Integration Foundations™** is a framework designed to help organizations integrate patient perspectives into maternal healthcare practices and quality improvement initiatives. The **Lived Experience Integration™ Provider Training** is a self-paced online course designed to teach quality improvement teams how to listen and learn from patients and families. We believe that patient perspectives hold the key to unlocking new solutions and insights. Continued Education Credit will be available.

In addition to what we cover in the Community of Learning, we talk about:

- Understanding the Patient Perspective
- Go more detailed into onboarding and recruitment
- Discuss the importance of a state liaison role
- Break down PFP training and our match making process



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What we do

Patient Family Partner Training

- Offering training for patient family partners on how to effectively work together to improve outcomes in maternal health in a self paced online platform.
- Provide direct coaching and mentoring to help our patient family partners heal from their birth experiences and learn how to use their voices to impact change.
- Connect with other patient family partners and build strong community.
- To date we have **62** Certified PFPs since May 2021 and have provided **47** “matchmaking” services to providers.
- We offer continued support and training to PFPs with continuing education training and providing coaching and support before/after engagements.

Continued Education

- Advanced training for patient family partners geared more specifically to their interests
 - MMRC, AIM Bundles, Quality Improvement, Research, Policy
- Launching in October!

Please reach out to Emily.taylor@preeclampsia.org if you are interested in the training for your patients with lived experience!



PFP Testimonials on training and engagements



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Matchmaking and Engagements

Matchmaking request template <https://www.mommasvoices.org/pfp-request?eId=95f5dbc3-4ca9-448c-afb5-cfdc68fe27f7&eType=EmailBlastContent>

Tips to be matched successfully:

1. Don't ask for unicorns. Instead, think of including several voices to cover the topics you want covered
2. Offer some sort of compensation
3. Fill out the survey after the engagement! We survey our PFPs and our providers
4. The more details you can give us, the better the PFP will have the chance to succeed



Patient Integration

- Examples of patients with lived experience roles in hospitals
- Recruitment
- Compensation
- Things to avoid
- Take in consideration – the patient perspective



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What Trained Patients and Family Partners Bring to the Work

- Share personal stories, leading to a more focused commitment by improvement teams
- Identify pieces of the process that are confusing or missing from a patient/family perspective
- Participate in information/data gathering
- Discuss and analyze findings
- Focus Groups and Surveys
- Assist in developing action plans and recommendations
- Contribute to the design and content of materials (hospital signs and brochures)
- Provide objective feedback from the patient/family perspective
- Assist with piloting and testing new materials and processes and follow up with other patients/families to gather their opinions



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Recruitment and Compensation

- Where does the population you seek build communities?
- Local Churches
- Local Mom Groups
- Online Mom Support Groups
- Daycares
- Rehabilitation Centers
- Physicians/Doulas/Midwives
- Consider compensation for prep time, things they need to read over, and even self care time after sharing a traumatic story
- Ask if certain levels of compensation are hindering (taxes)
- Visa gift cards ok, wouldn't consider restaurant gift cards, etc
- If you can't compensate, can you buy diapers, formula, or door dash them a meal?
- \$250/hour is becoming the low end of "standard"



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Things to Avoid

- Not considering what is being asked of the patient
- Assuming, not asking – this does not lead to building trust with the patient
- Tokenism
- Judging patient's story – commenting on if they were misdiagnosed, invalidating their experience, interrupting them



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Providers need to take in consideration:

- Level of trauma the patient has been through
- Speaking about it can be triggering
- Being in a room full of HCP can be intimidating
- Patients need meaningful work, why are they there?
- Check on them for feedback on the experience, anything you can improve to make them more comfortable next time?
- In many cases, they have been ignored or pushed aside by HCP



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Q&A



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Thank You!

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