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Practice Summary & Implementation
Guidance

Patient Family Partner Certification

The Patient Family Partner Course offers training for those with a lived experience (or their care people) on how to effectively work together with healthcare providers and other stakeholders to improve outcomes in maternal health.

Cutting-Edge

Emerging

Promising

Best



Location

Type

Status

National

Service Coordination/Integration,
Health Equity

Home-based

Population Focus

NPM



Date Added



Women/Maternal Health,
Families/Consumers

Maternal Health Outcomes

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Section 1: Practice Summary

PRACTICE DESCRIPTION

MoMMA's Voices is a national coalition of patient advocacy organizations and individuals with "lived experiences" –or those that represent them –using their voice to reduce maternal complications in pregnancy and the postpartum period. We look at cross-cutting issues such as quality and consistency of healthcare delivery, patient-provider communications, racial disparities, inadequate research funding, and other leading contributors to adverse outcomes in pregnancy and the postpartum period. We invite all those who experienced, or whose love one experienced, any of the leading causes of death, near misses and severe morbidity (e.g., preeclampsia, hemorrhage, amniotic fluid embolism, placenta accreta, cardiovascular disease, maternal mental health, and other complications of pregnancy) to participate. As advocates to eliminate maternal mortality and severe morbidity, the coalition's overarching goal is to provide a home and platform for the patient voice to actively engage in efforts to make childbirth safer in the United States. The coalition provides training and tools to prepare "champions for change."

MoMMA's Voices was created in 2018 from the shared vision that all patient advocacy organizations that are focused on the top contributors of maternal mortality and morbidity should have a voice at the table. A diverse representation of key stakeholders was a priority for forming the coalition's founding decision-making body. The Executive Council began with the following nonprofit organizations: Preeclampsia Foundation, AFE Foundation, National Accreta Foundation, 2020 Mom, Black Women's Health Imperative, Shades of Blue Project, and Every Mother Counts. The Executive Council has since expanded to include two representatives from Maternal Near-Miss Support Facebook group and Sisters in Loss Support Services. Additionally, the coalition currently has another 10 patient-advocacy nonprofit organizations as members. Through this network of organizations, we are able to offer training that small organizations would not have the capacity or resources to develop and/or host on their own.

This training is aimed at their constituents, volunteers, survivors, family members, friends, and community members in order to prepare them to be effective "Patient Family Partners" (PFP). PFPs are also known as maternal health advocates, patient family advisors, or lived experience consultants in some areas, but we have tried to encourage the adoption of the "partner" aspect of this work. The goal of patient engagement is a true partnership, where both those who represent the lived experience and healthcare providers are working together side-by-side toward the same goal.

The Champions Training Center is a community Facebook group and online training platform. The Champions Training Center is intended for those with a lived experience, or those that represent them, to come together in a place to support one another in this work that we do as "Patient Family Partners." Our online training platform for patients takes an in-depth look at different ways patients can be engaged to effect change. We produce theme-based modules that include articles, worksheets, presentations, and discussions from topic experts. The core modules include, Advocate Readiness, Storytelling, Navigating Media, and Understanding Quality Improvement. There is a soon-to-launch CE program that includes modules such as, Understanding Review Committees, Explaining AIM Practice Bundles, Best Practices for Support, Co-Designing Research, How Legislation Impacts Policy, and more. The content is created by fellow PFPs and subject matter experts and then reviewed by a committee of seasoned PFPs. All aspects of this process keep a health equity lens on what is being created, who is creating it, and who is reviewing it.

When a family experiences a severe maternal event, often they have the desire to turn that pain into purpose. For some Patient Family Partners, the extremely traumatic event impacted their mental health and



consequently has added a layer of mistrust to providers. This mistrust can manifest into aggression towards professional teams (doctors, nurses, etc.) and when that happens it can be very difficult to work together effectively. We advise all professional teams to provide similar training to all Patient Family Partners that they work with. In order for them to be effective partners, they need to be provided an understanding of their role and of trending projects and practices so they can contribute to multi-disciplinary teams. Our training starts with evaluating emotional readiness and continues to explain quality improvement projects where Patient Family Partners can be engaged.

Based on the research-supported premise that patient advocacy and involvement in healthcare will contribute to better outcomes, MoMMA's Voices created a program to achieve that goal.

MoMMA's Voices was created right in the middle of planning the first Champions for Change Summit that was focused on the Preeclampsia Foundation. With an extremely short notice, we added Every Mother Counts, AFE Foundation, 2020Mom and National Accreta Foundation to the event that trained about 100 maternal health advocates. Those five organizations hosted the first event and immediately worked to ensure that the leadership of the coalition had diverse representation by adding Black Women's Health Imperative and the Shades of Blue Project to form the MoMMA's Voices Executive Council. Feedback from the executive council and key stakeholders is that the Champions for Change Summit is great, but there needed to be a way to offer the training that was more accessible and didn't require the same time and resources needed to attend an annual in person event. Following that, we worked to adapt and expand the event training into an online resource that would not be limited to only those that could attend in-person events. This virtual platform also opened the possibility of PFP training to many who were not previously able to access it because of financial, child care, or other reasons.

In designing the training, we initially gathered feedback from our advocates over the course of 2 years on what they wanted to learn more about and what information would help them be more effective in their roles. We took that feedback, organized by theme and researched who would be good presenters of the topics. Then we presented the themes and proposed presenters to the Executive Council for their approval and feedback of what their organizations need as well.

The framework of the program is an online training platform (consisting of targeting modules) and community connection platform. It also involved strong relationships with other patient advocacy organizations as well as community organizations. The PFPs are trained and then matched with engagement opportunities throughout their own communities as well as nationally. Some organizations send their own patient advisors through the training so they are better prepared to speak and make an impact.

Following an engagement, surveys are automatically sent to both the PFP and the engagement organizer. The survey documents the sentiment following the event so that improvements can be made to maximize positive impacts. Currently, the meaningfulness rating of the engagements is 4.9/5 (<https://www.mommasvoices.org/impact>).

Survey Questions:

For Providers: "How meaningful was the PFP engagement to your project?", "How well did the PFP inspire to take one or more action?", "How prepared did you feel the PFP was for this opportunity? How well do you feel the PFP was received as a contributor?"

For PFPs: "How meaningful was this experience for you?", "How prepared did you feel for this opportunity?", "How confident are you that your contribution will inspire change?"



Supporting Quotations/Citations About Patient Advocacy Generally:

"Patient and family engagement offers a promising pathway toward better-quality health care, more-efficient care, and improved population health." (Carman KL, Dardess P, Maurer M, et al. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs*. 2013;32(2))

"Patient and family engagement also appeals to principles of equity, by recognizing patients as valued partners in developing safer health care systems" (Sharma AE, Rivadeneira NA, Barr-Walker J, Stern RJ, et al. Patient Engagement In Health Care Safety: An Overview Of Mixed-Quality Evidence. *Health Affairs*. 2018;37(11)).

CORE COMPONENTS & PRACTICE ACTIVITIES

MoMMA's Voices goal is to elevate the perspectives of the often unheard -- of maternal health conditions and populations. The Champions Training Center focuses on training maternal health advocates to be effective partners in improving outcomes for moms and babies. The core components of this program are that it is a self-paced, online training course that provides theme-based modules. The modules establish a solid foundation for telling their stories and for advocating while also expanding on various topic areas.

Topics include advocate readiness, storytelling, navigating media, quality improvement, MMRCs, research, and more. Once the Patient Family Partners are trained, they are provided with "engagements" through a matchmaking process. Providers, organizations, hospital groups, PQCs, MMRCs, etc. contact MoMMA's Voices and request a Patient Family Partner with certain conditions or attributes. Once their request is submitted, the Engagement Team searches the database of trained PFPs and makes the connection. MoMMA's Voices provides the PFPs with an opportunity to prepare for upcoming engagements with one-on-one mentoring/training sessions.

Core Components & Practice Activities		
Support	Social Media and Interactive Webinars	MoMMA's Voices has social media groups where achievements can be shared, and connections can be made. There are also webinars that usually are followed with Q&A and discussion for community building and bonding.
Training	Self-paced, online training course	Theme-based modules geared toward topics relevant to maternal health advocacy (storytelling, QI, MMRS, research, etc.)



Matchmaking	Matchmaking forms and engagement-prep sessions	Providers, organizations, hospital groups, PQCs, MMRCs, etc. contact MoMMA's Voices and request a Patient Family Partner with certain conditions or attributes. Once their request is submitted, the Engagement Team searches the database of trained PFPs and makes the connection. Pre-engagement, one-on-one training is also provided.
Outreach	PFP Engagement	Network with external stakeholders to share that we are training PFPs to be effective partners, offer to train their current or targeted PFPs and work to find opportunities for further patient engagement.

HEALTH EQUITY

40% of our current PFPs identify as non-white and are from 28 states. Our PFPs share their stories and represent the lived-experience perspective on advisory councils, MMRS, PQCs, research, and over 50% of the events were speaking engagements and have reached over 138,000 people through these various engagements. 47% of the PFPs matched identify as non-white.

These engagements not only reach a large number of people, but they are also highly regarded and have received a “meaningfulness” rating of 4.9/5 to-date. We train our PFPs on how to share their stories and let their voices be heard. The more diverse stories that are shared with providers, the more equitable the care they can potentially provide. Bias, even unconscious bias, can affect the healthcare quality that people receive.

Sources for Unconscious Bias:

Marcelin JR, Siraj DS, Victor R, et al. The Impact of Unconscious Bias in Healthcare: How to Recognize and Mitigate It. *The Journal of Infectious Diseases*. 2019;220(2):S62–S73.

EVIDENCE OF EFFECTIVENESS

We developed our evaluation process using Results Based Accountability Framework. Our team reviews all of the data on a quarterly basis, updating our factors, results and making adjustments. We take into account all of the data including enrollments, completions, participant reviews, demographics and further engagement data. Following an engagement, surveys are automatically sent to both the PFP and the engagement organizer. The survey documents the sentiment following the event so that improvements can be made to maximize positive impacts. Currently, the meaningfulness rating of the engagements is 4.9/5 (<https://www.mommasvoices.org/impact>).



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Additionally, there is room for comments. These comments are often shared with the participants in the form of a "Thank You" note to either the PFP or the provider. If the comment is not appropriate for a "Thank You" note, then the comment is used as constructive criticism to make any alterations necessary to better prepare for the next engagement.

We also have recently begun asking PFPs to provide a screenshot or photo from the engagement to share on social media to create a sense of community and provide insight to others into the impact that our PFPs are making.



Section 2: Implementation Guidance

COLLABORATORS AND PARTNERS

MoMMA's Voices works with patient advocates (patient family partners), patient advocacy organizations (e.g., AFE Foundation, Preeclampsia Foundation, End Sepsis, 2020 MOM, etc.), providers/community organizations, hospital groups, PQCs, MMRCs, etc. to improve maternal health outcomes by integrating the patient voice into healthcare.

Partner/Collaborator	How are they involved throughout practice processes?	Does this stakeholder have lived experience/come from a community impacted by the issue?
Patient Family Partners (PFPs)	PFPs are trained to share their stories and then matched with engagements.	Yes, the PFPs either are personally impacted by a lived experience or are the family member/loved one of a person with a lived experience.
Providers/ Community Organizations, Hospital Groups, PQCs, etc.	This group incorporates those with lived experiences into their decision-making efforts in order to improve outcomes or derive feedback.	No, this group does not have a lived experience. They are listening to those with a lived experience in order to gain insight.
Member Coalitions	This group is made up of patient advocacy organizations (e.g., AFE Foundation, Preeclampsia Foundation, End Sepsis, 2020 MOM, etc.). They provide their members the training in order to help them learn to tell their lived-experience stories.	Yes, the members of the coalition organizations generally have lived experiences.



REPLICATION

Replication for our program looks a little different than most traditional programs. We look at how many organizations are utilizing our training for their communities. In addition to patient advocacy organizations utilizing our training, we have also had state PQCs purchase vouchers for their patient family partners to become certified. In addition to the 78 PFPs that are fully trained, currently enrolled in the program are 166 enrollees representing many organizations, including The Preeclampsia Foundation, AFE Foundation, Mom Congress, National Accreta Foundation, Maternal Near Miss, and others.

INTERNAL CAPACITY

Program Director and Instructor: This individual is a maternal health advocate with many years working in the maternal health field and a lived experience.

Instructor: This instructor is a lifestyle expert and television personality. She has a passion for maternal health.

Instructor: This instructor is a maternal health advocate and patient family partner. She uses her years of professional experience as an educator to help teach mothers how to effectively share their story to make it impactful. She works with many maternal health organizations, media outlets, and legislators regarding the field of maternal health.

Instructor: This instructor is a director of communications. She has worked for many years in social media and assisting with research studies on patient engagement and the psychological impact of traumatic pregnancy experiences.

Instructor: This instructor has 15 years of experience in healthcare quality improvement, managing multi-state projects as well as directing statewide hospital initiatives. For the past 12 years, her focus has been on using quality improvement methodology to optimize partnerships with patients, families, and consumers – both at the point of care, and in organizational planning and development.

Instructor: This instructor is a program director in maternal health. She has had many speaking engagements and also has had multiple scholarly articles published in the maternal health field.

Patient Family Partner Coordinator: This individual uses many years of experience working in the healthcare field and a lived experience to work with the trained PFPs, prepare them for engagements, and match them with opportunities.

The team works together to both create and record the lessons that the PFPs will take. Once the courses are recorded, they are uploaded to the PFP course dashboard. Enrollees then take the self-paced lessons by watching the recordings and submitting related work. We have team members designated to contact enrollees and offer help and encouragement at various stages of the course. We also send gentle reminders to those who seem to have stalled in their progress. Once the course is completed, the newly certified PFPs fill out a survey and have an exit interview with a MoMMA's Voices team member. They are then added to the certified PFP database and receive a pin and certificate in the mail.



PRACTICE TIMELINE

For more information on this practice's timeline and specific practice activities, please contact Nicole Purnell directly at nicole.purnell@preeclampsia.org.

PRACTICE COST

It took about \$35,000 to start the program. The perpetual costs are less including additional cost in staff to maintain the courses, facilitate PFP issues and questions, and also to record new videos. For more detailed information, please contact Nicole Purnell at nicole.purnell@preeclampsia.org.

LESSONS LEARNED

We learned how important “healing” is as part of the process. Many people desire to advocate for a cause/condition before they are mentally prepared. Allowing time to process the trauma before engaging in advocacy is imperative. We have also learned that clear communication and description of expectations between providers and PFPs is necessary for a successful engagement. We have also learned that there are different learning styles. We are in constant communication with the PFPs while they are in training. Some people prefer more of a self-paced approach while others enjoy the hands-on nature of someone walking you through the process.

NEXT STEPS

We are working on a Continuing Education component, which would delve deeper into certain engagement-types (e.g., PQCs and MMRCs) that PFPs may encounter. Moving forward, we are translating the course into Spanish and also adding English subtitles.

