

MoMMA's Voices

Lived Experience Integration Forum

Presented to

Alaksa Perinatal Quality Collaborative

April 13, 2023

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MoMMA's Voices

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.

Member Organizations



MoMMA's Voices is a program of the Preeclampsia Foundation. Funding is provided by :

- Merck for Mothers, as part of their worldwide 10-year initiative to assure no woman dies giving life
- Alliance for Improvement in Maternal Health (AIM), a program of ACOG
- Premier, Inc through the Premier Perinatal Improvement Collaborative

4th Trimester ArizonaHAFE FoundationHAllo Hope FoundationLAPS Foundation of AmericaMCherished MomMDr. Shalon's Maternal Action ProjectMEnd SepsisH

Every Mother Counts Healing our Hearts Foundation HER Foundation (HG) Let's Talk PPCM Maternal Near-Miss Support Mom Congress National Accreta Foundation PCOS Challenge PPROM Foundation PUSH for Empowered Birth PUSH Birth Partners Save the Mommies (PPCM) Shade of Blue Project Sisters in Loss The Obstetrics Initiative Urban Baby Beginnings



What We Do

- •Train and certify patient and family partners
- •Cultivate relationships with major societies and stakeholders
- •Identify and negotiate opportunities for patient representation
- •Foster meaningful collaboration by matching trained patients with
 - Research opportunities
 - •Media opportunities and speaking engagements
 - •Quality improvement projects

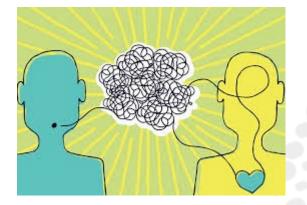


Learning Objectives

- 1. Describe the difference in hearing and listening.
- 2. Illustrate the importance of equipping patients to be their own advocates.
- 3. Describe the benefits of having the lived experience integrated in QI activities.
- 4. Describe various ways to become a Champion at your facility and beyond.



Hearing vs. Listening



- Is there a difference?
- Have you ever listened with ½ an ear while doing something else? I'll go…Listening on a work call, with kids in the car after school, trying to order dinner on the CFA app, while texting. Sounds familiar?



They are Different!

HEAR OR LISTEN (TO)?

HEAR

Hearing is *an event*. Something which happens to us as a natural process.

> Suddenly I heard a noise.



Did you **hear** the thunder last night?



The line is very bad. I can't **hear** you. LISTEN (TO) Listening is an action.

Something we do consciously.



I **listened** very carefully **to** what she said and wrote it all down.



Do you **listen to** the radio in bed?



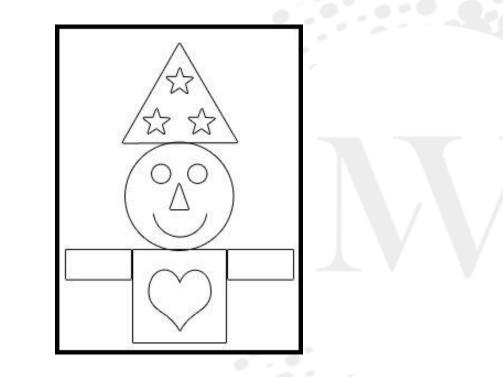
George! **Listen to** me! I have something important to tell you.

CAMBRIDGE UNIVERSITY PRESS











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Asking Questions to Seek Information and Clarify Understanding

- •How effectively did you understand the description of the picture?
- •Was your understanding of the description you received the same as your partner's understanding of the description they relayed?
- •How did you confirm you had correctly understood your partner's description?
- •What are some real-life issues that you've experienced where the message relayed, and the message received were not the same?

- •Why this matters:
 - ★ Poor Listening Results in misunderstandings–listen attentively!
 - ★ The quality of the final product or deliverable is highly dependent on the quality of the team's listening to one another-collaborate! Let the patients and their families be a part of the process
 - ★ Think about this from the lens of the patient and in your everyday role



Real People. Real Stories.

•"If my doctor had listened to me, and done a simple urine sample, my child would be here today"

•"You could die if you're not watched closely". 30 Minutes later, another nurse was prepping her for discharge as she was saying she didn't feel well and didn't want to go home...the patient eventually ended up back in the ER with postpartum preeclampsia.

•"You're a new mom, just get rest. That's why you're tired. You'll be fine."...hours later that mom was back in the ER with postpartum preeclampsia. •"Delivery is the cure. You are fine.". After discharge, the patient on the 6th day had complete vision loss, confusion, and bleeding.

•Patient said-"I have this pain in my rib cage and don't feel well." Patient is told-"Well, he's like a monkey swinging on your ribs, and you look cute."

•Listening matters. Our trained PFP's have taken their experiences and what could've gone differently and want to make a difference for others.



Train and Certify PFP

- Certification Training:
 - Advocate Readiness
 - Sharing Your Story
 - Creating Your Professional Presence
 - o Quality Improvement
- Continuing Education:
 - Perinatal Quality Collaboratives
 - Maternal Mortality Review Committees
 - AIM Patient Safety Bundles
 - More to come!



What do PFPs say?



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Why do Patients and Families Want to Get Involved?

- · Help others
- · Be a voice for those without one
- A way to remember a loved one
- Finding purpose from a difficult situation

What inspired YOU to do this work?



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

•Assist in developing action plans and recommendations

•Contribute to the design and content of materials

•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

AHA Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors, HPOE.org



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Lived Experience Integration Faculty



























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Lived Experience Integration into QI Communities of Learning



Important Tips for Integrating Patients

- •Listen without judgement "Leave your suitcase at the door"
- •Recognize the trauma and bravery they are bringing to you
- Don't focus on medical jargon

•Possess an open mind to recognize what a provider may see as a successful delivery, the patient may view as trauma

•Grief is the loss of all the things the pfp wanted it to be.







How Does the Process Work ?

- Play Matchmaker
- Find a CPFP!
- Feedback, Data Collection
- Our Impact





Working Together in Quality Improvement & Research

Organization: ADVISORY COUNCIL Focus Groups **PATIENT SATISFACTION SURVEY** Employee onboarding Ambassadors **Patient Led Research** Patient Advocacy Ponferences Grand Support Speakers rounds Groups Simulation



Working Together in Quality Improvement Through Simulation



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How Can I Help My Patients?

- •Share personal stories, build trust and a connection. We know that **most**
- genuinely care about their patients.
- •Discuss what is happening to the patient and/or the support person/family. Help to bridge that gap.
 - •Communicate, communicate, communicate! Don't assume they understand. Remember they are likely overwhelmed.

•Educate about postpartum preeclampsia, how to check their blood pressure, signs to look for. Equip them to be advocates. Showing them you care.

Build trust and establish rapport.







Use brief verbal affirmations like:

Demonstrate concern.

Ask specific questions.



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You Can Do It!

- Identify shifts that needs to be made and be a champion in ensuring they are changed. (I.E. Delivery is the cure, high blood pressure only has to be X amount, lay on your left side in the dark and recheck).
 - •Bedside hand off..is it happening? How are you communicating with other staff about a patient (PCA Story)

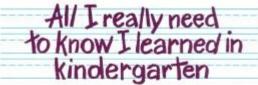
•We can't teach those who don't want to learn, but YOU can make a difference! Let us help you!





How Can MoMMA's Voices Help You?

- Train your patient family partners
- Help match patient family partners
- Register your PQC program team for Community of Learning
- Get trained on Lived Experience Integration (Let us talk about the hard topics!)
 All Treally need
 - o Online Course
 - o Workshops
 - o Classes





Lived Experience Integration Scorecard



MoMMA's Voices





Merck Video

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Thank you!

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