

COMMUNITY CHALLENGES ENGAGING WITH MMRCs: TRANSPARENCY, DATA AND LEGISLATIVE BARRIERS

BACKGROUND

The United States (U.S.) has the highest maternal mortality rate among high-income countries;^{1,2} moreover, significant racial and ethnic disparities exist in maternal mortality.³ MMRC data has shown that 60% of these deaths are preventable.¹ Maternal mortality review committees (MMRCs) are in a unique position to collect and analyze information on maternal deaths to identify opportunities for prevention.^{4,5} MMRCs are intended to be multidisciplinary committees that conduct comprehensive reviews of pregnancy-related deaths to prevent future deaths.⁴⁻⁶ **However, MMRCs have struggled to identify, engage, and meaningfully include diverse community members who can speak to the essential context, including the strengths and needs of the communities they represent.**

In 2021, the Black Mamas Matter Alliance (BMMA) conducted an environmental scan of nine state MMRCs in the U.S. to gather information

about the opportunities and challenges MMRCs face as they work to broaden committee membership and community engagement. The purpose of this scan was to capture the challenges and opportunities as described by community members who have engaged, or attempted to engage, with MMRCs in an effort to help strengthen the capacity of public health leaders, including those administering and serving on MMRCs, and to better integrate strategies toward equitable practices across MMRC processes.

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PARTICIPANTS OF ENVIRONMENTAL SCAN DISCUSSIONS AND CONVERSATIONS

BMMA KINDRED PARTNERS AND COLLABORATORS (N=11)

Black women-led organizations and individuals who are guided by birth justice, reproductive justice, and human rights

COMMUNITY REPRESENTATIVES (N=11)

Members of state MMRCs who represent local community constituents

OTHER MMRC MEMBERS (N=8)

Chairs, coordinators, and abstractors of select state MMRCs

More information on the project and findings have been reported elsewhere,⁷ but this issue brief highlights one of three major themes that arose from these conversations: the challenges experienced due to **lack of transparency, inconsistent data provision, and legislative barriers as inhibitors to community involvement.** The brief centers the experiences of KP/Cs and

community representatives (henceforth referred to as “participants”) in reporting the findings. We also share potential opportunities for improvement that CDC and MMRCs can take to better integrate and value the expertise of community members in the MMRC process.

KEY FINDINGS: LACK OF TRANSPARENCY, INCONSISTENT DATA PROVISION, AND LEGISLATIVE BARRIERS AS INHIBITORS TO COMMUNITY INVOLVEMENT

Participants discussed the barriers they faced in attempting to join MMRCs, which included lack of transparency in the recruitment process and legislative barriers around compensation, background checks, and the number of seats available for community members on MMRCs.

In addition, participants described the challenges of helping their communities due to inconsistent and/or delayed reporting of MMRC findings and their lack of involvement in the creation of MMRC recommendations.

CHALLENGES AND STRATEGIES ENGAGING WITH MMRCs AS IDENTIFIED BY COMMUNITY MEMBERS

CHALLENGES

Participation in MMRCs can be detrimental to communities:

- Culture and environment are unwelcoming and harmful
- Harmful and disrespectful conversations about patients
- Community representatives carry burden of teaching about racism and discrimination
- Centering of provider narrative, not the deceased birthing person

STRATEGIES

- Ensure proportional representation and BIPOC leadership
- Eliminate burden of proof mentality for evaluating racism and discrimination
- Integrate family interviews
- Improve orientation of MMRCs
- Institute anti-racism trainings
- Provide training and guidance on trigger tools

The following **CHALLENGES** were identified by participants:

1

Lack of knowledge, transparency, and diversity in the MMRC recruitment process

Participants described a lack of knowledge and transparency on how decisions were made around who was invited or allowed to join MMRCs. Participants said that information on MMRC applications (if they even exist), nominations, and selection processes was not readily available, accessible, or openly communicated to the public. One participant exemplified this sentiment by stating that MMRCs were **“so secretive that it’s prohibitive,”** which ultimately prevented new membership or diversity on the committee. Knowledge about and nominations for MMRCs were thought to only be reserved for a select few, which were usually colleagues of clinical members on a committee. Participants expressed that MMRCs were mostly white and clinical and that more Black, Indigenous, People of Color (BIPOC), community representatives, and birth workers who use holistic birthing practices were needed to ensure a diverse committee that is more representative of the communities it aims to serve.

2

Lack of timely and consistent access to data and communication of recommendations

Participants expressed that communities need access to and awareness of timely MMRC data for their own advocacy and organizing efforts. They stated that having significant multi-year data, reporting, and publication delays hindered community members from optimally serving their communities. Moreover, the lack of community representation on MMRCs also inhibited the development and inclusion of recommendations for prevention that were responsive to community needs.

3

Legislative hurdles and lack of structural support like compensation impede community participation

Participants discussed state laws that prevented or limited MMRCs from adding community members to the committee. Legislation often only allowed one or two community members to join the MMRC and even then, community members faced barriers to joining such as lengthy background checks that required credit reports, work history, and other vetting strategies. Participants stated the process was **“overwrought and created a lot of bureaucratic barriers,”** thus further prohibiting community inclusion. Lack of compensation and other financial support to participate in all day MMRC meetings was another challenge, which most other members who were salaried, clinical or health department MMRC members did not face.

The following **OPPORTUNITIES FOR IMPROVEMENT** were identified:

1

Institute open calls for recruitment

Participants recommended that all MMRCs should implement open calls for applications to provide equal access to membership and increase transparency of the recruitment process. In addition, community groups should be consulted for input on the application process.



Compensate community members

Participants advocated for MMRCs to work with their local legislative bodies to secure compensation for community members. This was essential for community members who often were not compensated by their jobs while serving on the committee like some of their health department, physician, and clinical staff counterparts. Compensation can be an important strategy to increase equity and bolster community engagement.



Increase accountability, frequency, and transparency of communications

Participants stated that MMRCs should prioritize the provision of timely, consistent, and clear data to lay audiences. This could be done by working with local communities and anti-racism experts to develop and disseminate a communications plan that includes press releases, public campaigns, and infographics that multiple groups can understand and use. These efforts could be supported through the provision of additional resources and funding for MMRCs to have increased capacity to review cases and dedicated anti-racist experts who help MMRCs disseminate information in a timely manner. In addition, participants discussed the need for oversight and accountability around data releases.



Involve community in the creation of recommendations

Communities need to be involved in the creation of MMRC recommendations. While MMRCs are charged with developing recommendations to prevent maternal mortality, community members were often expected to implement the recommendations despite not being included in the discussion or development of those recommendations. As one participant said, ***“when community members’ voices weren’t truly heard, the recommendations still tended to come back to the status quo.”*** Overall, participants identified the need for collaboration between communities and MMRCs to develop and create a plan of accountability to determine who is responsible for implementing the recommendations.

CONCLUSION

Participants presented a variety of challenges and potential opportunities for MMRCs to integrate equitable practices throughout their processes. They maintained that all conversations regarding maternal deaths, policy solutions, and improvements needed to address the systems contributing to maternal mortality should start and end with communities. Community members have the expertise and ability to bring new solutions to MMRCs. However, this requires incorporating BIPOC leadership and proportional representation* onto MMRCs to shift power to community members, and to move beyond token efforts to diversify membership.

Integrating equity into MMRCs requires systemic change and that can only be achieved when the communities who are most impacted are meaningfully engaged throughout the data collection, review, recommendations, and implementation phases. State and local MMRCs need funding, training, and support to accomplish this, and CDC has the opportunity to provide these supports to MMRCs in their pursuit to create a more equitable review process. Below are brief recommendations that participants identified as useful starting points for both CDC and MMRCs to consider in addressing the identified challenges including lack of transparency, inconsistent data provision, and legislative barriers as inhibitors to community involvement on MMRCs.

* The intent of this recommendation is to broadly increase community representation on an MMRC by encouraging MMRCs to shift its representation and leadership towards the Black and Brown people who disproportionately represent maternal deaths nationally. This recommendation is not intended to be applied as a formula to fill a quota on an MMRC.

RECOMMENDATIONS



Listen to and center the experiences of community members



Provide additional funding to MMRCs



Diversify membership and meaningfully engage communities



Increase transparency of MMRC processes and data



Provide training, guidance, and resources to strengthen the capacity of MMRCs

REFERENCES

1. Petersen E, Davis N, Goodman D, Cox S, Mayes N, Johnston E, et al. Vital signs: pregnancy-related deaths, United States, 2011–2015, and strategies for prevention, 13 states, 2013–2017 [Internet]. Centers for Disease Control and Prevention; 2019 May [cited 2021 Sep 3] p. 6. (MMWR Morb Mortal Wkly Rep). Available from: <https://pubmed.ncbi.nlm.nih.gov/31071074/>
2. Tikkanen R, Gunja M, FitzGerald M, Zephyrin L. Maternal mortality and maternity care in the United States compared to 10 other developed countries. [Internet]. The Commonwealth Fund; 2020 Nov [cited 2021 Sep 3]. Available from: <https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/maternal-mortality-maternity-care-us-compared-10-countries>
3. Hoyert D, Miniño A. Maternal mortality in the United States: Changes in coding, publication, and data release [Internet]. Hyattsville (MD): U.S. Department of Health and Human Service; 2020 Jan. Report No.: 2. Available from: <https://pubmed.ncbi.nlm.nih.gov/32510319/>
4. St. Pierre A, Zaharatos J, Goodman D, Callaghan W. Challenges and opportunities in identifying, reviewing, and preventing maternal deaths. *Obstet Gynecol*. 131(1):138–42.
5. Report from maternal mortality review committees: A view into their critical role. Building US capacity to review and prevent maternal deaths [Internet]. CDC Foundation; [cited 2021 Sep 13] p. 50. Available from: <https://www.cdcfoundation.org/sites/default/files/upload/pdf/MMRIARepor.pdf>
6. Review to Action. *7 Things To Know About Maternal Mortality Surveillance and MMRCs* [Internet]. Review to action: Working together to prevent maternal mortality. [cited 2021 Sep 13]. Available from: <https://www.reviewtoaction.org/learn/7-things-to-know>.
7. Black Mamas Matter Alliance Research and Evaluation Department. *Maternal Mortality Review Committees: Sharing Power with Communities*. Atlanta, GA; 2021 Nov.

SUGGESTED CITATION:

Black Mamas Matter Alliance. *Community Challenges Engaging with MMRCs: Transparency, Data and Legislative Barriers Issue Brief*. Atlanta, GA. July 2022.

This project was supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) through the CDC Foundation. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, CDC Foundation, or the U.S. Government. Foundational support for the work was also provided by the Association of Maternal and Child Health Programs.



THE BLACK MAMAS MATTER ALLIANCE (BMMA) is a national network of Black women-led organizations and multi-disciplinary professionals that work to ensure all Black Mamas have the rights, respect, and resources to thrive before, during, and after pregnancy.

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