MTAP LIVED EXPERIENCE ADVISORY GROUP

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Maternal Telehealth Access Project: Collaboration and Innovation for Equity and Healthy Families (Grant # H7EMC37564) is a collaborative initiative with several partnering agencies aimed at ensuring that women at highest risk are receiving quality maternal care services via telehealth during the COVID-19 pandemic. The project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an Award totaling $4,000,000 for one year with 0% percentage financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

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EXECUTIVE SUMMARY

This report provides an overview of the Lived Experience Advisory Group (LEAG) for the Maternal Telehealth Access Project (MTAP).

As the lead evaluator for MTAP, RACE for Equity developed an equitable, results-based evaluation approach based upon the Results-Based Accountability framework and the application of core principles of Culturally Responsive Evaluation (CRE).\(^2\)\(^3\) RACE for Equity contributed significantly to the success of the LEAG with expertise in these evaluation approaches and community engagement principles, recognizing that any solution to expand telehealth services must be informed by and responsive to the lived experience of people giving birth and their caregivers.

An important aspect of this approach involved establishing the LEAG which engaged 13 mothers, doulas, health aides and advocates from communities impacted by maternal health inequities to ensure quality, useful and credible evaluation findings. LEAG members participated in seven monthly meetings from October 2020-May 2021. The LEAG reviewed and provided feedback on:

- MTAP evaluation questions
- Data collection activities
- MTAP monthly summary reports

LEAG members described their experience as empowering, inclusive, enlightening, informative, inspiring, and safe. The LEAG enjoyed the sense of community, working as a collective, and the learning opportunities. However, LEAG members wanted more information about MTAP grantee activities and data as well as more opportunities to engage in the MTAP evaluation beyond monthly LEAG meetings.

LEAG members emphasized the importance of having a space to share their voice, concerns, and experiences. Most LEAG members agreed that they gained new knowledge, established new relationships, and would participate in similar advisory group opportunities. They shared that they would use the skills and information gained to better serve their community and communicate with other health professionals.

The successes of the LEAG were possible because of:

- RACE for Equity facilitation and community expertise
- Community partnership in decision-making
- Dedicated funds and resources
- Culturally responsive planning and process
- Providing LEAG member compensation

The findings in this report demonstrate the importance and feasibility of building an evaluation team that has a meaningful connection to the lived experience of the maternal health stakeholder community most impacted by existing health inequities exacerbated during the COVID-19 pandemic. Community members with the lived experience are eager, capable, and uniquely qualified to provide meaningful and insightful feedback to all phases of an evaluation.
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The Maternal Telehealth Access Project (MTAP) was a multi-sector, collaborative initiative to increase equitable access to quality perinatal services and supports via telehealth and distant care services for people during pregnancy, childbirth, and postpartum during the COVID-19 pandemic. MTAP was a one-year project supported by the Health Resources and Services Administration through CARES Act emergency funding in May 2020. The project focused on serving individuals and populations in Black, Native American, Latinx, rural and frontier communities.

As the lead evaluator for MTAP, RACE for Equity developed an equitable, results-based evaluation approach based upon the Results-Based Accountability framework and the application of core principles of Culturally Responsive Evaluation (CRE). The purpose of the evaluation was to understand how well MTAP funding met the needs of the intended communities and to understand how well MTAP met the intended goals and objectives of the telehealth project.

CRE principles emphasize the importance of engaging stakeholders that are representative of the populations the project serves. Therefore, the equitable, results-based evaluation approach included engaging community members in the LEAG as a critical component of the evaluation team to ensure that the evaluation was informed by and responsive to people giving birth and their caregivers.

### Role of the LEAG

The role of the LEAG was to provide recommendations and key information to the MTAP evaluation team throughout the evaluation process to ensure quality, useful and credible evaluation findings. Advisory group participation and engagement in the evaluation underscores the culturally responsive approach, which recognizes that any solution to expand telehealth services must be informed by and responsive to the lived experience of people giving birth and their caregivers.

### Definition of Lived Experience

In the context of MTAP, lived experience refers to community members with recent experience with pregnancy and/or perinatal services, their families, and their network of support (doulas, lactation consultants, etc.), who are most impacted by maternal and infant morbidity, mortality, and racial injustice. People with lived experience may or may not have used/received any telehealth services or MTAP services.
CREATING THE LEAG

A LEAG planning team consisting of five leadership members and staff from the MTAP evaluation team met weekly in virtual meetings beginning in July 2020 to prepare for monthly LEAG meetings. We reviewed the literature on engaging people with the lived experience in an evaluation advisory group and utilized the CRE engagement steps to guide our planning, timeline, and activities.

MTAP collaborative partners who understand the cultural and historical contexts of the communities which MTAP was trying to reach supported culturally responsive principles and initial strides towards a LEAG engagement process. Community-based collaborative partners suggested:

- LEAG members should only interact with a small group of culturally responsive evaluators to reduce likelihood of unintentional harm among already impacted community groups.
- The LEAG should not include members who experienced extremely traumatic birthing journeys such as stillbirths or infant loss to avoid re-traumatization.
- Our team should consider language justice, which is the right to communicate in a preferred language, and our capacity to provide, or not to provide, translation or interpretation during LEAG meetings.

We developed and shared an e-nomination flyer with maternal health partners about the nomination process, expectations of LEAG members, and compensation. LEAG participants could receive up to $1800 over the course of the advisory group to review documents, attend virtual LEAG meetings and give feedback to the evaluation team. Nominators were encouraged to prioritize Black, Indigenous, Latinx, geographically marginalized, or rural community members as nominees. The LEAG nomination form remained open over the 9-month MTAP period recognizing that LEAG members may not attend every meeting or stop attending because of important work, parenting, family priorities, or other barriers.

We conducted phone interviews to learn more about nominee interests and to screen for concerns around trauma. Eligible nominees were invited to officially join the LEAG and attend an orientation.

We offered two virtual meeting times for the LEAG orientation to ensure that each member had the opportunity to participate. The orientation provided an opportunity for introductions, learning more about fellow LEAG members, and an overview of MTAP, the evaluation team, and the purpose of the LEAG. The initial meeting was also used to develop agreements around the meeting structure, process, and times. We re-shared the agreements at the beginning of each LEAG meeting to provide a space for any additions or amendments while continuing to build trust and respect among group members.
LEAG Monthly Meetings

Seven monthly LEAG meetings were conducted via Zoom from November 2020 until May 2021. During the 1.5 to 2-hour meetings, LEAG members reviewed and provided feedback on the MTAP Monthly Summary Reports, the evaluation questions, data collection, and implementation updates.

The MTAP Monthly Summary report is an internal summary of MTAP collaborative partner activities and updates. The summary report is intended to provide a quick overview of the month’s activities and offer a structured opportunity for the collaborating partners and the LEAG to respond to challenges identified, provide feedback on the work by project charge, and make any pivots needed to continue the MTAP work.

By engaging in monthly LEAG meetings, we anticipated LEAG members would:

- Establish trust and build connections with LEAG members and the LEAG planning team
- Review and apply community agreements
- Describe the purpose of MTAP
- Describe the role of MTAP collaborative partners
- Describe the role of the funded projects
- Describe the role of the evaluation workgroup
- Describe the purpose of the LEAG including scope of work and contributions to the evaluation
- Review and respond to the evaluation questions for MTAP
- Review and respond to the MTAP monthly summary report
- Review and respond to the evaluation process of collecting community stories

LEAG Meeting Pulse Checks and Experience Survey

We periodically solicited feedback from the LEAG on how meetings were going, the level and utility of information being shared, and general feedback. LEAG members also shared more detailed feedback on their experience in a final LEAG Experience survey.

Key Costs for Replication

Key costs for replication of LEAG activities include Advisory Group members’ compensation of $40 an hour to review documents, attend virtual LEAG meetings and give feedback to the evaluation team. Additional costs include funding for MTAP staff and collaborative partner resources in time, knowledge, skills, and access to virtual technology. Over the course of MTAP, our team met more than 30 times and held about 10 meetings with LEAG members including 3 orientations, 7 LEAG sessions, and sub-committee meetings.
We received 19 LEAG nominations, 13 of which accepted the nomination and attended LEAG meetings. Attendance at the seven LEAG meetings ranged from 7-11 members, with three LEAG planning team staff. Nine of the 13 LEAG members attended all or all but one meeting.

The 13 LEAG members are parents, doulas, community health workers and advocates from communities impacted by maternal health inequities. LEAG members joined the advisory group because of their passion for supporting families, in connection to their careers in maternal health, to share their personal experience and hardships related to pregnancy or postpartum, and because of their desire to provide education, awareness and direct support to families, mothers, and babies.

LEAG members live in Florida (n=5), North Carolina (n=2), South Carolina (n=2), Arizona (n=1), California (n=1), Washington (n=1), and Georgia (n=1). Six LEAG members described their community as rural. The majority of LEAG members identified as Black/African American (n=11), one member identified as white, and one member identified as Latinx.

**LEAG Meeting Activities**

Over the course of the advisory group meetings, the LEAG reviewed and provided feedback on the MTAP evaluation questions, 5 monthly summary reports, and strategies to collect community stories. The monthly report was the primary vehicle to share information about MTAP project activities. We documented LEAG feedback and shared with MTAP collaborating partners.

The qualitative anecdotes “Stories from the Field,” in the monthly summary reports provided examples of short-term MTAP successes and prompted rich discussions in the LEAG meetings. LEAG members shared their perspectives and personal narratives related to the Stories from the Field, which ensured that the lived experience was considered throughout the MTAP process and in the phases of the evaluation. LEAG members discussed their lived experiences giving birth in hospitals, the challenges of buying and using fetal dopplers, and delivering a baby during COVID-19. The stories from the field provided an important opportunity for the LEAG to create tangible connections between their lived experience and implementation of MTAP activities.

The monthly report also included MTAP activity descriptions and available quantitative data, such as number of people and populations served and service delivery areas. For example, the LEAG reviewed a map of MTAP service areas and noticed a lack of representation of states near the Mexican border. This prompted a LEAG member to ask how MTAP prioritized the Latinx community if the service areas were not near the Mexican border. With this type of pointed feedback, the lead evaluator brought the LEAG concern about serving the Latinx community to the MTAP leadership and implementation team as an opportunity for critical reflection.

A highlight engagement activity included three LEAG members who participated in a panel on lived experience during a virtual Skills Institute hosted by a sister project, the Maternal Health Learning and Innovation Center. These LEAG members shared their experiences in maternal health to a national audience of maternal health leaders and practitioners. Another LEAG member shared her story in a maternal health video vignette. By participating in these opportunities, the maternal health community learned the importance of engaging people with the lived experience in maternal health equity and system improvement efforts.

The MTAP project ended in April 2021, however, three LEAG members agreed to join the Maternal Health Learning Innovation Center evaluation stakeholder group.
LEAG Experience Results

LEAG members shared their reflections and feedback on their experience as part of the advisory group in an open discussion and short survey. Nine LEAG members participated in the discussion and described their experience as beneficial, empowering, collaborative, inclusive, enlightening, interesting, informative, detailed, inspiring, and safe. LEAG members enjoyed the sense of community, working as a collective, and the learning opportunities within MTAP. Suggestions for improvement included meeting more than once a month, increased data and contextual information in monthly reports, more opportunities for networking and communication (team building events or social networking groups), and increased involvement in broader MTAP meetings.

Ten LEAG members responded to the follow-up LEAG Experience survey. The survey asked LEAG members how much they agree or disagree with six statements, see Table 1. 1=strongly agree and 4=strongly disagree. Nine out of ten LEAG members felt very strongly that they were listened to and valued the experience on the LEAG. Fewer LEAG members felt strongly that their feedback on the monthly report was useful, with one LEAG member disagreeing that their feedback on the monthly report was useful.

Table 1. LEAG Experience Survey Results

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean</th>
<th>Number who strongly agree or agree^a</th>
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<tbody>
<tr>
<td>I understand the purpose and goals of the Maternal Telehealth Access Project</td>
<td>1.42</td>
<td>10</td>
</tr>
<tr>
<td>I felt that my contributions were valued by the MTAP evaluation team and partners</td>
<td>1.33</td>
<td>10</td>
</tr>
<tr>
<td>I felt that my feedback on the MTAP monthly summary report was useful to the overall evaluation</td>
<td>1.67</td>
<td>9</td>
</tr>
<tr>
<td>The MTAP evaluation team and partners listened to my concerns and feedback</td>
<td>1.17</td>
<td>10</td>
</tr>
<tr>
<td>The MTAP evaluation team and partners responded to and/or acted upon my concerns and feedback</td>
<td>1.33</td>
<td>10</td>
</tr>
<tr>
<td>I valued my experience on the LEAG</td>
<td>1.17</td>
<td>10</td>
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^a. 1=strongly agree and 4=strongly disagree

LEAG members shared that they gained knowledge of maternal health inequities, maternal health funding, and maternal health organizational strategies to address telehealth throughout the country. Further, LEAG members shared they would use the information gained to better serve their community and communicate with other health professionals. LEAG members emphasized the importance of having a space to share their voice, concerns, and experiences. Despite the challenges of incorporating LEAG feedback into MTAP implementation processes, members ultimately felt heard and that their voices were valued. One LEAG member disagreed that they gained new knowledge of maternal health and two
LEAG members disagreed that they established new relationships outside of LEAG meetings; however, ten out of ten agreed that they would participate in similar advisory group opportunities.

Table 2. LEAG Experience Survey Results (2)

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<tr>
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<th>Mean</th>
<th>Number who strongly agree or agree b</th>
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<tbody>
<tr>
<td>I gained new knowledge in evaluation</td>
<td>1.33</td>
<td>10</td>
</tr>
<tr>
<td>I gained new knowledge of maternal health</td>
<td>1.50</td>
<td>9</td>
</tr>
<tr>
<td>Participating in the LEAG promoted my personal and professional growth</td>
<td>1.17</td>
<td>10</td>
</tr>
<tr>
<td>I established new relationships with other LEAG members outside of the LEAG meetings</td>
<td>2.08</td>
<td>8</td>
</tr>
<tr>
<td>After participating in the LEAG, I would participate in similar advisory group opportunities</td>
<td>1.42</td>
<td>10</td>
</tr>
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b. 1=strongly agree and 4=strongly disagree

**Strengths and Successes**

Success of the LEAG was supported by the dedication and engagement of LEAG members, skilled facilitation and culturally responsive engagement strategies by the evaluation team, and allocated funding.

By engaging MTAP community partners in the planning process, we recruited 13 LEAG members who are connected to communities most impacted by maternal morbidity and mortality during the COVID-19 pandemic. Further, by acknowledging the challenges of attendance for pregnant and postpartum individuals and continually accepting new nominations, three members joined in January 2021 allowing other members to rotate off while maintaining a quorum of participation. This recruitment and continuous engagement strategy aligned with CRE practices in trust-building, community engagement, and shared decision-making.

Overall, LEAG members were engaged and actively participated in the monthly meetings. LEAG members asked insightful questions, provided important feedback, and demonstrated their commitment to improving maternal health outcomes. Zoom enabled us to reach a more geographically diverse audience than would have been possible if we met in person.

Finally, the weekly planning meetings and funding were critical to the success of the LEAG. Funding was used to support the process, resources, and time for more than 30 LEAG planning meetings and ten meetings with LEAG members (orientation, LEAG sessions, and sub-committee meetings). Dedicated funding for LEAG members was essential to enable their participation and expertise, and RACE for Equity helped bypass barriers of an academic institution such as paying LEAG members directly in a more timely manner. Based on the literature review findings and the professional experience of our team, dedicated resources and funding for an advisory group is relatively rare but a significant factor to the LEAG success.
Limitations

Given the wide scope of the MTAP project and the number of collaborative partners (12) and corresponding mini-grantees (91), it was a challenge for the evaluation team to be up-to-date on all aspects of project activities, and to further distill and communicate all aspects to the LEAG. While organizing LEAG meetings around the MTAP monthly summary reports provided structure for the meetings, the reports often lacked adequate quantitative data to understand or contextualize progress towards meeting goals and objectives. This was due in part to the complexity of the project and mini-grants, lack of pre-defined measures of success, and limited time to identify and implement efficient and effective bidirectional feedback to and from the LEAG. More time would have allowed LEAG members to be more involved co-leading meetings and for co-construction of the evaluation instruments, increasing potential impact of the LEAG and their expertise. Additionally, another improvement may have been to better plan for use of LEAG feedback up front, by prioritizing LEAG as a standing item on leadership team meetings and including LEAG updates in all MTAP communications. The MTAP monthly summary report was not effective in moving feedback into program improvement.

Finally, we agreed that including the LEAG in all MTAP evaluation workgroup meetings and some MTAP meetings, such as the MTAP kick-off meeting, earlier in the process may have improved the overall LEAG experience. As a lesson learned, our team agreed that in the future, there was potential utility in inviting the LEAG to other MTAP meetings, while maintaining principles of harm reduction and culturally responsive engagement.
CONCLUSION

The findings in this report underscore the importance of engaging people with the lived experience as a mutually beneficial learning opportunity and experience. In the review of the literature, only one example existed about engaging people with the lived experience in the context of a maternal health evaluation. However, the MTAP LEAG findings suggest that people with the lived experience are eager and excited to provide feedback to an evaluation and have the capacity to make meaningful and insightful contributions to all phases of an evaluation.

Despite the significant challenge of COVID-19 which eliminated the possibility of in-person meetings and exacerbated existing challenges of community engagement, the MTAP evaluation team successfully engaged 13 LEAG members in seven monthly meetings. With more time, an equitable, culturally responsive approach would deepen trust-building, community engagement, and shared decision-making in the process.

Ultimately, including the LEAG in the MTAP evaluation demonstrated the importance and feasibility of building an evaluation team that has a meaningful connection to the lived experience of the stakeholder community most impacted during the COVID-19 pandemic. This is especially possible with dedicated funds to support the planning, process, resources, time and LEAG member compensation.
REFERENCES


