AMETHIST@Penn
Engagement Considerations Report

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What is AMETHIST?

The goals of Advancing Maternal Empowerment and Transforming Health through Implementation Science and Training (AMETHIST) are to:

- *Advise IMPROVE investigators in engaging diverse and sometimes marginalized communities*
- *Guide the process of implementation research, including the selection of theories, models, frameworks, strategies, and outcomes*
- *Accelerate implementation skills development in emerging and established maternal health scientists*
- *Advance knowledge about successfully conducting implementation research.*

Principle Investigators

Rebecca Hamm, MD MSCE

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Letter from AMETHIST@Penn Engagement Core Leadership team

We are honored to be writing to you after our first year leading the AMETHIST@Penn Engagement Core. From the outset, the AMETHIST@Penn Engagement Core team agreed that our meetings with Centers of Excellence (CoEs) and other IMPROVE investigators would be a collaboration, with each of our meetings designed to minimize traditional academic hierarchies, learning from individual sites and their community-engaged models and partners. After a year, we are privileged to feel more comfortable and at home with the amazing investigative teams whose work we will highlight in this report. Each meeting with our CoE teams has been inspiring and educational. We are beginning to see the connections forming between our CoEs, allowing them to learn from one another and further their work. In our first AMETHIST@Penn Engagement Considerations Report, we'll share community engagement themes that emerged during our meetings. We are excited to explore these themes further in the years to come.

Sarita Sonalkar, MD

Micki Burdick, PhD

Elizabeth Howell, MD, MPP

What is the AMETHIST Engagement Core?

The goal of the AMETHIST Engagement Core is to work together with sites to ensure that community and stakeholder engagement suffuse the activities of the AMETHIST Implementation Science Hub and sites' research projects.

Engagement Core Co-Leads

Sarita Sonalkar, MD, MPH (she/her) is an Associate Professor of Obstetrics and Gynecology at the Perelman School of Medicine and the Program Director of the Complex Family Planning Fellowship at the Hospital of the University of Pennsylvania. She is the co-chair of DISPEL, the Obstetrics and Gynecology Health Equity Working Group. Her research, clinical, and programmatic projects include optimizing access and equity in contraception, abortion, and early pregnancy loss, implementation of postpartum family planning programmatic interventions internationally, and integration of HIV prevention and family planning services. She completed her undergraduate education at the University of Pennsylvania, medical school at Rutgers-New Jersey Medical School, her obstetrics and gynecology residency at the University of California – Los Angeles, and her complex family planning fellowship and Master's in Public Health at Boston University.

Micki Burdick, PhD (they/them) is an assistant professor of Women & Gender Studies at the University of Delaware. They received their PhD in Rhetoric and Gender Studies at the University of Iowa in 2023. Their research utilizes a reproductive justice framework to explore medical systems, reproductive technologies, and reproductive politics -with a specific focus on abortion and maternal health equity.

Elizabeth Howell, MD, MPP (she/her) is the Chair of the Department of Obstetrics & Gynecology at the Perelman School of Medicine. Previously, she was a Professor of Population Health Science & Policy, an OB/GYN, and the Founding Director of the Blavatnik Family Women's Health Research Institute at the Icahn School of Medicine at Mount Sinai. She is an NIH-funded OB/GYN health services researcher, and her major research interests are the intersection between quality of care, disparities in maternal and infant mortality, and morbidity and postpartum depression and its impact on underserved communities. She has served on several expert committees including the Institute of Medicine, the NIH, the Joint Commission, ACOG, and international external scientific advisory boards. She co-chaired the Alliance for Innovation on Maternal Health Working Group on Reduction of Peripartum Racial Disparities, and served on the Governor's Taskforce on Maternal Mortality and Disparate Racial Outcomes for New York State and the New York City Maternal Mortality and Morbidity Steering Committee for the New York City Department of Health. She testified in Congress for maternal health care legislation. She currently co-chairs the National Quality Forum Committee on Maternal Morbidity and Mortality.

What is the Engagement Enhancement Collaborative?

The Engagement Enhancement Collaborative is a group of health and community engagement experts organized by Co-Leads of the Engagement Core and meets with each CoE site at least once per year. In year one, 2-3 sites were intentionally grouped together for each meeting based on parallels among their target populations. While each site refreshes the EEC and the other CoE(s) on their overarching goals and aims, the primary focus is a discussion on mechanisms by which they engage their community partners, sustain relationships, and ensure that the community's voice is present throughout the research process.

Themes and Lessons Learned

Each site created robust community partnerships and connected research with on-the-ground impact this year. We co-learned with CoE sites at four meetings in February, June, September, and December 2024, aiming to group sites with similar populations and/or goals and outcomes. While this was not always possible due to scheduling constraints of the sites and the EEC members, we successfully extracted overarching learnings developed through conversation amongst the groups.

Below, we describe overarching concepts that emerged in our meetings and explore what we learned from site reporting activities. These concepts, co-learned with our sites, place the groundwork for the next 6 years of generative activity that the AMETHIST Engagement Core will support.

Building Trust with Black Communities

Through our conversations and meetings with CoE sites, we learned best practices for engaging with communities through trust-building, a critical aspect of implementing community engagement in research projects.

Lessons: We learned that deep relationships with community partners are not necessarily about quantity but about sustainability. Rather than one type of community organization, sites worked with a variety, including community-based organizations, community-serving systems, faith-based organizations, policy and advocacy organizations, and policymakers. ***The opportunity to build an inclusive and equitable care system, a goal of many sites in the IMPROVE network, is only possible through trust.***

A primary topic of conversation throughout site visits and EEC meetings was mechanisms of building academic-community trust in postpartum healthcare. This highlights the necessity for a more holistic and culturally relevant approach to healthcare, emphasizing the need for addressing community voices into the work. One mechanism to achieve trust included informal discussions held by research scientists that allow mothers to pinpoint their most pressing needs during the postpartum period. These differ from structured interviews in that they allow women to decide what they want to discuss and share. ***This type of engagement illustrates a mechanism by which researchers might interact with the communities they aim to study and serve, building trust alongside a research process.***

We learned that to uplift the voices of Black women with lived experience of maternal health complications, there must be robust infrastructure put in place. ***Sites can build trust by partnering with existing community organizations.*** These organizations can advise researchers on navigating and existing within the community spaces and populations they serve and guide sites through the appropriate actions toward effective interaction and engagement.

Creatively and Authentically Developing Equal Research Partnership with Communities

Along with building trust, we learned from sites and their engagement with community partners, that *these partners must be implemented into research project designs from the project's inception.*

Lessons: We learned that community partners must play an integral role in shaping research questions, ensuring studies are culturally relevant and aligned with community needs, and participating in study design and implementation. Novel yet effective mechanisms for engagement with community groups included options for providing feedback through anonymous Post-It notes, pre- and post-surveys, and engagement through sharing meals in bright and joyful spaces, often away from the academic center and within the community itself. *We learned that **relationship building does not always align with meeting grant timelines and recruitment goals - infrastructure for grant activities in the community needs to be built.***

Community members within the sites have supported the refinement of study designs that best align with the needs and realities of communities. ***An important aspect of community engagement is to be creative and nimble in offering multiple modalities of engagement.*** For example, monthly office hour slots to discuss research project progress, distribution of surveys to capture engagement strategies and members' overall satisfaction with ongoing projects, and creation of a WhatsApp group for informal check-ins. Creativity allows community members to feel invested and involved in the research process and interested in attending more meetings and events than is expected of them.

Community-based organization leaders act as principal investigators throughout many of the IMPROVE sites. A board of local leaders, community organizations, hospital partners, government entities, and academic institutions provides guidance and insights, fostering trust and ensuring alignment with community needs. ***Transparency, mutual respect, and shared ownership are key to this work.*** As an example, we found it compelling that sites have adopted flexible scheduling and alternative communication methods to accommodate collaborators. We have learned that creative solutions to administrative and organizational issues within research projects/teams are possible when involving community partnerships.

Best practices within community engagement and efforts to address health disparities are grounded in collaboration and inclusivity, focusing on building strong relationships with diverse stakeholders to serve populations in need. These important engagement techniques are reflected across projects and cores within each IMPROVE site.

Transcending the Bureaucracy of Research Infrastructure to Partner with Communities

Alongside involving community partnerships in early inceptions of research projects and finding creative ways to do so, we learned from IMPROVE sites that *community partners must engage at every level, including reviewing existing interventions, helping to create and test online platforms, incorporating feedback on intervention content, and making sure community understands the work being done.* This is not always an easy task, and research bureaucracy often results in barriers to access

Lessons: When working with academic and community PIs, it is important to work in tandem from the project's inception, including grant writing and developing aims. *It is essential to operate with the goal that community PIs have an equal voice to academic team members throughout the process.* To operationalize this model, the community PIs need biosketches oriented towards their practical/community expertise, and many of the academic institutions we engaged with help community members obtain Commons IDs using SAM.gov. This process was considered essential to the research process and outcome but was described as tedious and requiring modification to be streamlined.

A significant common challenge has been explaining the difference between community-engaged research and a Community Advisory Board (CAB) to the Institutional Review Boards (IRBs). CAB members are often not in roles of conducting research or in contact with participants and are, therefore, not considered research personnel for the purposes of IRB submissions. However, some community members may also be researchers, assisting in directly recruiting participants and collecting and analyzing data, and as such, need research training. Traditional Collaborative Institutional Training Initiative (CITI) training is often not applicable to CAB members, and community CITI training has been developed for this exact purpose through the University of Pennsylvania. *Identifying these shared challenges sites face regarding IRBs, defining research personnel, and ethical training requirements will allow us to better support sites in overcoming aspects of research bureaucracy in the future.*

AMETHIST has begun to organize a workgroup bringing members of the CoEs and their community partners together to discuss ways we can collectively work to improve processes around incorporating community partnership into funding mechanisms. Members of the workgroup have started to contribute to an advocacy statement addressing specific issues and suggestions as well as call for changes in the grant space to better support and accommodate the inclusion of community partners and their voices in the grant-writing and funding process. We plan to include community partners as co-authors and engage funders in the writing and editing process.

Incorporating Indigenous Ways of Knowing

This year, a major focus of our AMETHIST Engagement Core learning involved Indigenous communities and the various frameworks, discourses, and practices that come with this work. ***Many sites embraced the intersection of Indigenous-centered knowledge, health practices, and community engagement.***

Lessons: An essential aspect of ***discussions centered around barriers related to transportation***. Attending pregnancy care visits often requires traveling vast distances, and sites identified a lack of trust in utilizing non-Indigenous drivers, given that tribal authorities cannot charge them for crimes they commit on reservation land. ***Ideal alternative transportation mechanisms were suggested, including doulas, care navigators, other support people in the community, or drivers hired from the community.***

Future Directions in the Next 6 years of the Engagement Enhancement Collaborative

We have learned that CoE investigators welcome opportunities to connect with each other through structured conversations over shared challenges***. Future directions include the possibility of asynchronous communication, storytelling sessions, and structured interactive workshops related to the overarching topics of Building Trust, Incorporating Indigenous Ways of Knowing, Creatively and Authentically Partnering with Communities, and Transcending the Research Bureaucracy to Effectively Partner with Communities***. In addition, we seek to continue to discuss and hold sites and ourselves accountable when it comes to community engagement practices, as the work being done across the IMPROVE initiative directly impacts maternal morbidity, mortality, and health disparities in the United States.