

Infant Mortality in African American Infants and Infants in Rural Areas Study

November 19, 2018

Community and Consumer Experience Subgroup Meeting Summary

[Version 1/4//2019]

Location: Maryland Health Care, Commission Room 100, 4160 Patterson Ave., Baltimore, MD 21215, Remote access available

Attendance

Megan Renfrew
Ben Steffen
Lara Wilson
Yolanda Ogbolu
Pam Kasemeyer
Andrea Williams

Purpose of meeting: Discuss and refine subgroup goals, responsibilities, and key steps to accomplish those tasks, with goal of providing staff guidance for development of a clear work plan for subgroup activities.

Welcome & Introductions

Megan Renfrew, MHCC staff, invited all meeting attendees to introduce themselves and share their background with the group.

Overview of Meeting purpose and agenda

Megan reviewed the study purpose, tasks, timelines, and work group organization (see [discussion guide](#) for more detail).

Discussion of subgroup purpose and goals

Megan described her vision for this subgroup as outlined in the original charter. She also shared David Mann's table for potential tasks for all the subgroups contained in the [discussion guide](#). She then invited discussion about the purpose of the group.

The group noted the importance of focusing on personal experience and voices from the community, both men and women. Several group members noted that stories should be collected in a way that is meaningful and rigorous way, not anecdotal, so that stories can't be dismissed. Another group member noted that academic methodology, and the pressure towards quantitative analysis, may be too high a bar for some of our work. There is power in story for helping contextualize why our recommendations matter when we are explaining them to legislators and others.

We need to look through the lenses of the people who receive the services. Programs need to speak to their experience. Too often, groups like this focus on the provider view point—this work should be grounded in the experience of the communities

Idea: Convene focus groups with families in the community, and a group on families with adverse outcomes. Also a focus group with leaders of on the group programs in the community. We'd need to do that in both rural and urban areas.

Megan mentioned her meeting with Mayor's office of African American Men and its leader encouraged her to create a video as a potential output of this work. Lara talked about the work that the MD rural health association is doing to create a video. She thinks it is important to share a face and a voice with the story that support the data we find.

There is a shared experience between the African American community in urban and rural areas—there is a lot of difference, but the mortality rates are the same.

There are 2 prongs here: consumer experience (“what happened to me”) and Community engagement (i.e. advocacy, motivation, and ownership-“how will we make sustainable change happen”). Narrative/story can drive people to action. Narrative and data are complimentary sources of information. But once actions are determined, how do we get people aligned so that change happens and is sustainable.

Can we take a strength-based approach? Can we also have a focus group that looks at positive outcomes and strengths leveraged in the community to help make positive outcomes happen?

How is community engagement different than community impact (how a program impacts a community)?

- Experience—listening: surveys, focus groups, etc.
- Engagement--# served. OR excitement/ownership/advocacy & creation of perception of active role in the outcome
- Impact—Difference made through programs

The community and community organizations are most likely going to feel engaged if they have a role in developing the recommendations and it is relevant to them. How can we build the capacity of community organizations? What recommendations could we make about what supports community organizations need to strengthen and sustain this work?

Data and consumer experience

The work of this group is intertwined with other groups and there need to be pathways for interaction and feedback. For example, is the data analytics group is going to look at hospital experience data from infant and OB units or will that work be limited to more traditional surveillance data sources? Statistics need to focus on what is relevant to the patients/consumers—often groups like this focus on statistics and program interventions that don't feel very relevant to these families.

It is rare that parents fill out the standard patient experience form for labor and delivery. One participant said that normally a nurse asks the questions and fills out the form (with variation in how the nurses ask the questions). This is not a true reflection of the patient experience. And, many people of color do not fill out these forms at all.

Andrea Williams is working with Johns Hopkins School of Nursing on potentially developing a tool to specifically measure the birth experience of underserved communities with clinical staff. There are challenges in capturing better data.

Recommend using the state definition of rural for data analysis, since this is a state workgroup.

Are social determinates being looked at in the data analytics group, e.g. transportation, income generation, education, poverty? Yes. Other subgroups should consider these issues as well.

Life course perspective: How can we work with younger girls in the community so that we can help them before we get to bad outcomes? This did come up in September 17th, in a conversation about preconception health and reaching people in schools.

What impact do you hope this workgroup and recommendations will have?

We should stay focused on the unique communities (African American and Rural)—there are general issues relevant to infant mortality, but we should keep the focus on the needs in these communities. Our recommendations should be specific to those needs.

Evaluation/prioritization of ideas.

Summary of meeting:

- It sounds like we want interaction between the content in this group and the data analytics group. Can we look at consumer experience data? What is available, usable, and relevant?
- Focus groups: potentially 1 on families that experienced adverse outcomes and 1 with program leaders.
- The importance of narrative in making potential impact of recommendations real and encouraging action.
- Engagement plan—how do we help local communities feel ownership over the final work product of this group?

Additional discussion and questions:

- This is a launch conversation. It would be helpful to share the information from this meeting, and get feedback from others.
- The March of Dimes and other organizations have parental support groups (NICUs, etc.). How could we leverage those resources, and could we get some of these groups at the table?

Megan will plan for next steps based on the content of this meeting.