

ENGAGING THE POWER OF TITLE V FOR
EQUITY IN PRETERM BIRTH PREVENTION

Transforming Approaches to Qualitative and Quantitative Data for Optimal Community Impact

This issue brief is part of a four-part series that explores the unique power of the Title V Maternal and Child Health (MCH) Services Block Grant to support anti-racist strategies and intentionally address the roots of racial injustice in maternal and infant health, including the prevention of preterm birth. Each issue brief describes how MCH programs can disrupt structural and institutional racism and shift power toward the expertise of people who birth, communities, and the organizations a community trusts to implement solutions. The series was produced with the support of the Pritzker Children's Initiative.

First, a background story...

Experiencing her first pregnancy, Jasmine wanted to do everything possible to have a healthy baby. At the recommendation of her physician, she enrolled in the Healthy Baby Project (HBP). The HBP is an intervention program founded by a researcher who was alarmed at the high rates of preterm birth among Black women. The HBP informed Jasmine about nutrition, exercise, and prenatal care. It also connected her to other services, including stress management. Although Jasmine fully participated in this intervention program and followed all the program's guidance and recommendations, she delivered a preterm infant boy who stayed in the neonatal intensive care unit for three weeks before, thankfully, he was discharged home.

HBP staff reported Jasmine's pregnancy outcome as well as other program participants who also had preterm deliveries to the HBP researcher. The researcher was baffled. HBP staff recommended that the researcher talk to the program participants about their experiences.

In response, the program convened a focus group so that Jasmine and others could share their prenatal experiences. Jasmine said that she attended all her prenatal appointments, but she also mentioned that she experienced discrimination from her provider. Jasmine said she tried to eat

a healthy diet. However, she did not have a car and lived in a food desert. Thus, the only food available to her was whatever was on the shelf at a neighborhood liquor store. Jasmine mentioned that her younger brother was incarcerated during her pregnancy. He relied on her for financial and emotional support. The situation caused marital stress because her partner did not agree with Jasmine spending money to support her brother. Jasmine also mentioned that watching the news and social media reports about the murder of Black boys caused her to worry about how the baby boy she was carrying would be affected in his future.

The information gained from Jasmine and other focus group participants was pivotal in leading the HBP researcher to develop a new approach to lower preterm birth rates among Black women. Instead of focusing solely on individual behaviors in pregnant people, the HBP researcher shifted the focus to structural and institutional levels. It was clear that Jasmine and others had been impacted by racism at all levels - individual, structural, and institutional. With this realization, the HBP researcher recognized the importance of the community and collecting qualitative data to inform interventions at each project stage: planning, to implementation, to assessment (in other words, from start to finish).

Jasmine's story illustrates the importance of understanding communities before developing and implementing programs. Many organizations who are trying to develop and implement programs to improve birth outcomes in communities made vulnerable due to structural inequities do not regularly begin with a complete understanding of the community. They then expend time and resources on programs that fail to address the true needs of the served communities. Some stakeholders believe that it is not ethical to create programs without first fully engaging and consulting with the intended program participants. Title V programs learn valuable information about community engagement in program design from the community-based participatory research (CBPR) method.

CBPR is a partnership approach to research that equitably involves community members, organizational representatives, researchers, and others in all aspects of the research process. All parties contribute their expertise and share in decision-making and ownership. CBPR aims to increase knowledge and understanding of given phenomena and to integrate knowledge gained with interventions for policy or social change benefiting the community members.¹

Below, the authors present a program based on key tenets of CBPR. Two types of data are important. Quantitative data in CBPR relays information and values based on numerical counts, measurements, and statistical assessments. Qualitative data, also referred to as unstructured data, includes "beliefs, experiences, attitudes, behaviors, and interactions."² Qualitative data provides insights into descriptive and nuanced individual-level information.

The authors describe in the following pages a program that demonstrates the CBPR approach. Then, they focus on how to achieve an overarching goal of ensuring diversity, inclusion, and respect when translating findings from analyses or research into population-level action. The authors introduce concepts, such as 'decolonizing data,' along with key pitfalls and data limitations. The authors conclude with a discussion on how to assess data sources to ensure the data represent the 'whole story.'

Designing Data: Community Engagement and Qualitative Data as Vital to Program Success

A commitment to community partnership is integral to the [California Preterm Birth Initiative](#)'s work. This program conducts research in partnership with communities most affected by prematurity. Doing so better positions the program to:

- Truly understand the factors that drive preterm birth
- Develop effective programs and policies that work to prevent prematurity
- Improve health outcomes of babies who are born preterm.

Although the terms are often used interchangeably, "*engagement*", "*participation*", and "*involvement*" represent three different levels of contact between researchers or program designers and individual patients, clients, or the general public. The following represents an example of how community-based "*engagement*," "*participation*," and "*involvement*" are implemented in the California Preterm Birth Initiative platform:

- The Community Advisory Board is the heart of the California Preterm Birth Initiative. The Community Advisory Board is deeply engaged in research prioritization, grant proposal review, funding decisions, and advisory roles in research projects. The Community Advisory Board is comprised of 20 San Francisco, Oakland, and Fresno mothers who have had preterm births or who serve as frontline community health workers, social service providers, and/or representatives of community-based organizations.
- The [Benioff Community Innovators Project](#), a program within the California Preterm Birth Initiative, uses a community-based participatory action research model to train women with lived experiences in research protocols and methodologies. These women are partnered with students in the San Francisco State Master of Public

Health program who have additional supports from community partner organizations. This project's objective is to create space in research settings for community voices to be heard and positioned as research and community leaders. The Benioff Community Innovator Project researchers design and conduct focus groups with women with lived experience and conduct interviews with program staff and system leaders.

The Benioff Community Innovators Project analyzed data from focus groups, interviews, and literature reviews to determine findings and developed recommendations to put into action. Since then, the California Preterm Birth Initiative has continued working with the Benioff Community Innovators to support them in realizing City and County of San Francisco policy changes recommended in their report, such as prioritizing pregnant women for temporary housing. Their collective work resulted in San Francisco enacting a policy change to prioritize all pregnant women for shelter and temporary housing regardless of which trimester they were in.

For decades, research has been conducted to develop interventions for preterm birth prevention, but no major declines in rates have occurred. The California Preterm Birth Initiative advocates for research to be more informative and effective by including people most affected by preterm birth. Including those most affected to collaboratively address this epidemic of preterm birth among Black women is beneficial for all levels of research and decision-making. This inclusion principle held true during other health crises, such as the HIV/AIDS epidemic.³

People with lived experience should not only collaborate in the process of formulating research questions, but also partner in decisions at all levels, including decisions for research funding awards. Title V programs can apply elements of community-engaged research through the stages of data collection and analysis and program development.

Tips for Increasing Community Engagement in Research and Data

- **Do not assume that community-based organizations have the resources to support a project.**
 - At the onset, initiate conversations to ensure involved community-based organizations can be compensated for their budgetary needs. These entities may be anchor institutions within the community you are engaging with. Do not contribute to burnout or inability to fully support the community during a project or when the project ends.
 - AMCHP recommends compensating all family and community stakeholders for their expertise and time at the same rate they would compensate an expert consultant.
- **Ensure that community-centered research questions are developed.**
 - Determine whether the community entity has already established the research questions that need to be answered. If research questions have not been generated, work diligently with the community entity to discuss what is needed. Be sure to identify all aspects of the research or project goals and objectives.
 - Include a community representative with a substantive role on the project/research team.
- **Provide participants with support to meet their unique needs.**
 - Supports may include food, transportation, compensation, childcare, and translation services.
- **Conduct early planning for disseminating summaries, findings, and the development of implementation plans for recommendations, if warranted.**
 - Plan with participants how the community will be informed of the project/research outcomes. This includes determining the communication methods to be used to ensure appropriate community reach and translation.
 - Develop an implementation plan to turn recommendations and proposed strategies into actions and outcomes. Implementation plans should include a process for sharing back results, information, and updates with the community served and clear, shared expectations of input and approval by community members. With respect to data, consider working with the community to build community capacity to read, interpret, and understand the implications of data and to use project data to empower advocacy for desired change.

Considering Data: Opportunities for Representation, Inclusion, and Respectful Translation

Important dialogues about data are occurring more often than ever about who and what is included in or missing from enumeration (e.g., Census) and survey data (e.g., cross-sectional, population representative). In addition, the data elements collected and how the data are interpreted or used are becoming vital components in data inclusivity discussions. Why? Because data are used to describe, count, assess, and evaluate nearly everything, everyone, and every process. It is essential to include qualitative and quantitative data with community engagement at all levels of program research and inquiry. Additionally, individuals conducting MCH analyses and research must also determine whether data are right for use, the data limitations that can impact interpretations, and how to design data and data collection processes to be more inclusive, particularly for underrepresented populations. Set out below are some examples of how these considerations come into play:

➤ **ISSUE: Representation in Census Data:** Every 10 years, the Census Bureau is required to conduct a census, also known as the decennial census. The objective is to count the entire U.S. population in their primary residences. Decennial census data are used to inform decisions regarding the number of U.S. Representative assignments in each state, government grants and funding distributions, and planning and development of businesses and housing. The data are also used to inform many community-based or local service and advocacy needs. An ongoing issue with the decennial census, however, is that populations that may benefit the most from accurate representation are historically undercounted. The 2010 census undercounted the Black population by 2.1 percent, the Hispanic population by 1.5 percent, and the American Indians and Alaska Natives living on reservations by 4.9 percent.⁴ Children in the 0 through 4 age group were undercounted by higher percentages than any other age group in the 2010 census. The 2010 Census net undercount rate for children age 0 to 4 years old was: 4.6 percent of all children, 6.3 percent of Black alone or in combination with other races, and 7.5 percent

of Hispanic children compared to 2.7 percent of non-Hispanic White children.⁵

➤ **ISSUE: Call to Decolonize Data:** When demographic groups are not represented accurately, programs may not receive appropriate funding or resources, planning, or service provision. Similarly, when data elements within data sets are missing, sporadically completed, or inappropriate, the impacts are similar to having non-representative data that may ostracize and stigmatize populations. Abigail Echo-Hawk, the Director of the Urban Indian Health Institute and Chief Research Officer at Seattle Health Board, succinctly describes this problem: “Too often, data is collected and presented in a way that perpetuates the narrative of poverty and need, painting a portrait of disparity and deficit.”⁶ “From health outcomes to economic indicators to educational attainment, mainstream data collection and presentation leaves little room to showcase the many strengths of indigenous people.” The solution is a process called “decolonizing data.” Abigail Echo-Hawk describes this process: “Decolonizing data means that the community itself is the one determining what is the information they want us to gather. Why are we gathering it? Who’s interpreting it? And are we interpreting it in a way that truly serves our communities?”⁷

➤ **ISSUE: Translating & Messaging Data—Who Are You Calling a Risk Factor?** It is important for data and analysis findings to provide facts, inform actions and activities, and yield evaluative and comparative information to conduct informed assessments and decision-making. Data communicators—including researchers/analysts, public officials, and public information officers—are expected to describe characteristics or factors determined to be associated with (or not associated with) events or outcomes. They are also expected to identify these characteristics or factors as either protective or risk. Many times, these data elements/analysis factors are individual-level or

demographic characteristics; descriptions of social or physical neighborhood/ community environments; or aggregates of the socioeconomic statuses of communities and/or individuals. When translating data or analysis findings, data communicators may dutifully provide counts, percentages/rates, or results of statistical analyses. If nothing more than group memberships or surface descriptions are communicated, however, these communications may unknowingly contribute to assignments of stigma, blame, or other unfavorable attributes to individuals, population subgroups, or whole communities. Thus, information about the background or circumstances that underlie data or analysis findings are critical to include, whether relaying simple counts, percentages, rates, or interpretations of more complex analysis findings. To the right are some examples of statements of data findings with important contextual information added.



If nothing more than group memberships or surface descriptions are communicated, however, these communications may unknowingly contribute to assignments of stigma, blame, or other unfavorable attributes to individuals, population subgroups, or whole communities. Thus, information about the background or circumstances that underlie data or analysis findings are critical to include, whether relaying simple counts, percentages, rates, or interpretations of more complex analysis findings.

1

Example #1 -Data Finding: Infants of Black mothers are more likely to be born preterm compared to infants born to White mothers.

Filling in the Story: The increased likelihood of preterm infants born to Black mothers is greatly influenced by multi-levelled and historical health and societal experiences of U.S. Black women and not simply due to the mothers' Black racial categorization.

2

Example #2 - Data Finding: There are lower life expectancies for residents in defined geographic areas.

Filling in the Story: Neighborhood composition, environment, and resources have been historically and are currently defined by more than the choices and descriptive attributes of respective neighborhood residents. Allowed, and often sanctioned, actions (business zone ordinances, community economic development, residential segregation, gentrification, affordable housing, gerrymandering) also greatly influence wealth, health, power, and well-being of residents within neighborhoods.

Changing Data: Opportunities for Understanding, Input, and Change

The term "data," like the term "survey," applies to the overarching process of quantitative data collection, analysis, and interpretation. Data, as Pronto (2015) states, can "reflect a range of research aims, sampling and recruitment strategies, data collection instruments, and methods of survey administration [...] it is imperative for the consumer/reader of survey research to understand the potential for bias in survey research as well as the tested techniques for reducing bias, in order to draw appropriate conclusions about the information reported in this manner."⁸ Opportunities to have input, change, and ultimately improve data lie within understanding research components, including research aims, population sampling or counting, data collection, assessment/analysis, and translation. A deeper exploration of these components can lead to data that more accurately reflects the 'whole story' of its subjects. Using the following baseline assessments of data is a starting point for a deeper level of understanding the data and improving its quality and usefulness:

- **Representation within the data**
 - Who or what are the data aiming to describe or provide information about?
 - How well is the population(s) that data intends to describe represented in the data?
 - What information is being collected that could help provide underlying context to 'surface-level only' information?
- **Data collected to describe outcomes or events can also connect to other data/information that serves to fill in details of the 'whole story.'**
 - What data elements are being collected or asked?
 - If the data are from survey questions, have the questions been tested to assure the responses can be interpreted uniformly with minimal misrepresentation or error?
 - Are the data collected appropriate for the research question or study design?
 - Are there missing elements within the data? If so, is this "missingness" unique to specific populations or data subjects with certain characteristics? Are the questions/data elements collected applicable to all or just select populations?
- **Data collection and use is guided by ethics, need for knowledge, and useful purpose.**
 - Are the data collection processes respectful and ethical in accordance with established human participants research protections and guidelines?
 - Did the data collection, analyses, interpretation, and translation have input from persons most knowledgeable, such as subject matter experts and community members and/or persons with lived experiences related to the research topic and focus of the analysis?

- If the data are from survey responses, are/were the questions developed to correspond with the literacy level of the intended respondents and professionally translated in their primary language?

For primary data, there may be more control over the data collection and study design processes that allow for adjustments to increase data representation, informed input, and respectful translation. For secondary data, controls over the data collection process and data elements may not be present. However, the above-mentioned baseline assessments are still useful in helping people understand capabilities or limitations to expectations of data representation, validity, relevance, and usefulness. Reputable public datasets contain technical notes that describe data elements and the associated values, methods of data collection, and how the data were sampled or collected to be representative. Often, these technical notes also shed light on the limitations of the data, such as missingness, sampling method, and the reliability and validity of data. So, however boring, read the technical notes! Look for other published works that have used the same data source to review examples of how the data were used. A final recommendation is to consult with researchers who can provide information on limitations and nuances they have encountered in working with the respective data set.

Next Steps: Moving the “Whole Story” into Action

Qualitative and quantitative data should be symbiotic, not exclusive independent components, in relaying real events and experiences so that all users of the data can learn, compare, assess, and plan viable actions. Data are imperfect. Understanding how to improve data collection, analysis, and respectful translation processes should be a continuous process; this is key to all who use and are guided by the information data relays. State and territory MCH programs must embrace a community-engaged and collaborative model of asking questions, collecting and analyzing data, and disseminating answers to make a meaningful, sustained impact in improving the health of the women, children, families, and communities they serve. Efforts to engage communities in data efforts, including through the Title V Needs Assessment, is a conscious choice for MCH programs, and it is also resource intensive. However, making this investment ensures that programs are informed by analyses and also are effective and grounded in the strengths and needs of the people they are intended to serve. Moreover, the methods explored in this issue brief emphasize partnering and sharing power at levels of decision-making; this process in turn affirms the rights of communities that have been historically disenfranchised to determine and give power to their own futures.

- ¹ Minkler, M, Garcia, Analilia P., Rubin, V. & Wallerstein, N. (2012). *Community-Based Participatory Research: A strategy for building healthy communities and promoting health through policy change*. PolicyLink, CA.
- ² Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative research. *Perspectives in Clinical Research*, 4(3), 192. doi:10.4103/2229-3485.115389.
- ³ Wilson, M. G., Lavis, J. N. & Guta, A. (2012). Community-based organizations in the health sector: A scoping review. *Health Research Policy and Systems*.10, 36, Retrieved May 27, 2020 from <http://www.health-policy-systems.com/content/10/1/36>.
- ⁴ U.S. Census Bureau. (May 22, 2012). Census Bureau releases estimates of undercount and overcount in the 2010 Census. Newsroom Archives. Retrieved on May 27,2020 from https://www.census.gov/newsroom/releases/archives/2010_census/cb12-95.html.
- ⁵ Count All Kids – Census 2020. (March 2020). *The undercount of young black children in the U.S. Census*. Retrieved on May 27, 2020 from <https://countallkids.org/resources/the-undercount-of-young-black-children-in-the-u-s-census/>.
- ⁶ Montana Budget and Policy Center. (July 17, 2019). It is time to decolonize data. Retrieved on May 27, 2019 from <https://montanabudget.org/post/time-to-decolonize-data>.
- ⁷ Secaira, M. (May 31, 2019). Abigail Echo-Hawk on the art and science of 'decolonizing data.'. *Crosscut*. Retrieved on May 27, 2020 from <https://crosscut.com/2019/05/abigail-echo-hawk-art-and-science-decolonizing-data>.
- ⁸ Ponto, J. (2015). Understanding and evaluation survey research. *Journal of the Advanced Practitioner in Oncology*, 6(2), 168-171. Retrieved on May 27, 2020 from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4601897/>.