

### **Transformative Use of an Improved All-Payer Hospital Discharge Data Infrastructure for Community-Based Participatory Research: A Sustainability Pathway**

#### **Take Away Points**

- A multifaceted approach to combining statewide healthcare data on maternal and child health (MCH) with community-based participatory research (CBPR) empowers underserved communities to identify, prioritize, and address top risks for MCH; and enhances sustainability and utility of a statewide data infrastructure.
- CBPR methods should not be limited to qualitative methods as often done; researchers and communities must explore multiple data sources to understand the social and environmental determinants of health, and build their capacity to integrate and interpret evidence from multiple sources.

#### **The Issue**

Success markers for large scale data infrastructures include their continued use and long-term sustainability. In 2010, the University of South Florida (USF) received a three year state data infrastructure development grant to improve clinical and race/ethnicity data in all-payer statewide hospital discharge data systems. USF used this grant to develop a statewide clinically enhanced and validated maternal and child health (MCH) database that linked mother and infant data from vital records with hospital discharge data for about 2.3 million infants born to Florida resident women over a period of 12 years. As part of the strategies to ensure the usability and sustainability of the data infrastructure beyond the life of the AHRQ grant, USF proposed, and later received funding from the National Institutes of Health, to implement community-based participatory research (CBPR) to help communities identify and prioritize MCH issues and outcomes associated with high levels of health disparity that threaten the longevity and quality of life of mothers and babies.

#### Source

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#### **Study Methods and Design**

The purpose of the study was to describe the use of a clinically enhanced MCH database to strengthen community-engaged research activities, and to support the sustainability of data infrastructure initiatives. The researchers employed a descriptive case study approach, using a multilevel mixed-method design with three levels of data on health disparities in a socioeconomically disadvantaged region encompassing five zip codes in Florida. At the organizational level, the MCH database provided data on the epidemiological assessment of birth outcomes disparities in the target community, including rates of pre-term birth, low birth weight, etc. Community level data came from two sources: Focus group sessions with 78 residents (i.e., women/mothers, men/fathers and children 12-17 years) on their perceptions of the risk and protective factors that contribute to adverse health events and racial disparities in health outcomes in the community; and social assessment (by zip code) of poverty level,

educational attainment and employment data for the target area. At the individual level, community members (n=201) completed surveys on behavioral and psychological variables (e.g., adverse childhood experiences) while the MCH database provided data on the clusters of socio-demographic, behavioral and health conditions that contribute to higher maternal and child care costs. Following data collection and analyses, a community advisory board reviewed the findings. Community action involved the use of a Nominal Group Technique (NGT) to generate a Community Priority Index (CPI) to facilitate community interpretation and decision making on the emergent findings.

### Key Findings and Limitations

Analysis of focus group data identified childhood obesity, lack of physical exercise, low health literacy, lack of good nutrition and emotional health (e.g., low self-esteem and stress) as top risks for child, adolescent and maternal health. Similarly, the survey identified lack of support while growing up, perceived stress, alcohol use and lack of sleep, and socio-economic factors (e.g., household income) as factors that impact health-related quality of life. Analysis of the MCH database revealed that pre-pregnancy obesity, anemia, and gestational diabetes are epidemiological health indicators related to maternal and infant health care cost in the region. The findings were triangulated across the data sources and shared with a community advisory board who discussed the importance and implications of the findings for their own community vis-à-vis the cultural and historical contexts. Also, the NGT process generated CPIs to help communities identify and select health issues that they view as most important and changeable. Health issues identified for pregnant women included lack of affection and stress; top issues for women's health in general were low health literacy and low educational attainment; while top priorities for children and adolescent health were obesity and low self-esteem.

*“Integrating statewide all-payer, hospital-based databases into CBPR can empower underserved communities with a reliable source of health data, and it can promote the sustainability of newly developed data systems.”*

The study is not without limitations. For example, the MCH database used relied on sources with “suboptimal accuracy and completeness” (e.g., ICD-9-CM and birth certificate records) for information on sociodemographic, behavioral and clinical outcomes. Also, the authors do not discuss the relative importance of each data source, nor proffer suggestions for resolving potential inconsistencies between evidence provided by the MCH database and data from focus groups.

### Final Thoughts

- Integration of the MCH data with a comprehensive CBPR approach resulted in new applications and additional funding to enhance the sustainability of the data infrastructure.
- CBPR using a multilevel approach yielded meaningful data that enhanced community-driven interpretation of determinants of health disparity, decision making on key health issues to prioritize and address, and community-based interventions to address these issues.