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

Jason L. Salemi, Abraham A. Salinas-Miranda, Roneé E. Wilson, and Hamisu M. Salihu

Objective. To describe the use of a clinically enhanced maternal and child health (MCH) database to strengthen community-engaged research activities, and to support the sustainability of data infrastructure initiatives.

Data Sources/Study Setting. Population-based, longitudinal database covering over 2.3 million mother–infant dyads during a 12-year period (1998–2009) in Florida. Setting: A community-based participatory research (CBPR) project in a socioeconomically disadvantaged community in central Tampa, Florida.

Study Design. Case study of the use of an enhanced state database for supporting CBPR activities.

Principal Findings. A federal data infrastructure award resulted in the creation of an MCH database in which over 92 percent of all birth certificate records for infants born between 1998 and 2009 were linked to maternal and infant hospital encounter-level data. The population-based, longitudinal database was used to supplement data collected from focus groups and community surveys with epidemiological and health care cost data on important MCH disparity issues in the target community. Data were used to facilitate a community-driven, decision-making process in which the most important priorities for intervention were identified.

Conclusions. 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.

Key Words. Record linkage, hospital discharge data, comparative effectiveness research, community-based participatory research, disparities

Through the 2009 American Recovery and Reinvestment Act (ARRA), the U.S. Congress appropriated \$1.1 billion for comparative effectiveness

research (CER), which was designed to promote informed decision making through the acquisition, utilization, and synthesis of data (Dreyer et al. 2010). According to the Institute of Medicine, effectiveness and sustainability of a national CER program would be best achieved through the development of “large-scale, clinical and administrative data networks to facilitate better use of data and more efficient ways to collect new data to inform CER” (Institute of Medicine 2009). To that effect, in 2010, the Agency for Healthcare Research and Quality (AHRQ) awarded eight, 3-year state data infrastructure development grants to improve clinical and race/ethnicity data in all-payer statewide hospital discharge data systems (Agency for Healthcare Research and Quality 2012). The enhanced data repositories have permitted states to generate evaluative measures of clinical outcomes for use in public reporting and value-based purchasing, and to assess health care system performance (clinical data grants). Additionally, the data have been instrumental in improving the ability to measure population health disparities and inform decisions regarding health programs and priorities (race/ethnicity grants). However, a key marker of the success of any data infrastructure initiative is the degree to which the new data systems are useable, sustainable, and capable of continued growth beyond the life of the original grant. Given the limited time frame of development awards, grantees were encouraged to devise creative approaches to engage stakeholders and identify funding mechanisms to support ongoing use of the data.

This paper will describe how the University of South Florida’s (USF) CER data infrastructure award resulted in the creation of a clinically enhanced and validated maternal and child health (MCH) database covering over 2.3 million Florida births (mother–infant dyads) spanning a 12-year period. Specifically, we will discuss how USF proposed to integrate the enhanced database into research involving community–academic partnerships, which resulted in the university being awarded a community-based participatory research (CBPR) grant from the National Institutes of Health (R24 MD008056-02). Then, we will describe how the database was used during the CBPR grant to produce detailed epidemiological and economic data on

Address correspondence to Jason L. Salemi, Ph.D., Department of Family and Community Medicine, Baylor College of Medicine, 3701 Kirby Drive, Suite 600 (MS: BCM700), Houston, TX; e-mail: jason.salemi@bcm.edu. Abraham A. Salinas-Miranda, M.D., Ph.D., Roneé E. Wilson, Ph.D., and Hamisu M. Salihu, M.D., Ph.D., are with The Maternal and Child Health Comparative Effectiveness Research Group, Department of Epidemiology and Biostatistics, College of Public Health, University of South Florida, Tampa, FL. Hamisu M. Salihu, M.D., Ph.D., is also with the, Department of Family and Community Medicine, Baylor College of Medicine, Houston, TX.

MCH disparity issues for a disproportionately disadvantaged community in the Tampa Bay area. In the last few decades, community-engaged research strategies including CBPR have emerged as some of the most promising approaches to bridge the gap between science and practice through stakeholder engagement and targeted local action to address health disparities (Wallerstein and Duran 2010). CBPR is highly compatible with translational science because it purposely incorporates community engagement into health services research and health care decision making, which increases the chances that interventions remain not only cost-effective but also culturally relevant (Fagnan et al. 2010; Tapp and Dulin 2010; Mullins, Abdulhalim, and Lavallee 2012). To promote wider community representation, CBPR researchers often keep methods simple and intuitive for community members, resulting in an almost exclusive adoption of qualitative techniques (e.g., focus groups [FG] and key informant interviews) and, less often, quantitative community surveys aimed at gathering new behavioral data. However, for CBPR initiatives to generate a more complete evidence base on the determinants of health and health disparities, multiple and diverse data sources are needed. We will discuss how integration of large, statewide administrative and clinical databases into data-gathering efforts for CBPR can help to empower underserved communities and simultaneously encourage sustainability and use of newly developed data systems.

MATERIALS AND METHODS

Design

To illustrate the use of our enhanced MCH database, we adopted a descriptive case study framework that first describes the construction of the database, and then the integration of the database into CBPR activities. The CBPR project utilized a mixed-method data collection process in which elements of various qualitative and quantitative methods (e.g., structured interviews, FGs, person-or encounter-level databases) are combined and analyzed in the context of a single study (Yin 1994; Creswell and Plano Clark 2007; Crowe et al. 2011). In accordance with the recommended typology for this type of research, we used a triangulation multilevel model that assesses factors at various levels (e.g., individual level, community level, health care level) (Tashakkori and Teddlie 1998; Teddlie and Tashakkori 2009) in an effort to meet the project's goal of prioritizing MCH issues whose high level of health disparity threatens the longevity and quality of life of mothers and babies in the target community.

Formative Research Group

To maximize the impact and value of the 3-year AHRQ infrastructure grant, a formative research group (FRG) consisting of a diverse group of clinicians, researchers, and students was established to ensure community outreach, instrument development, and data-integration plans adhered to project goals. Another important function of the FRG was to ensure an early and intense focus on sustainability. *Sustainability* was intended to encompass a data and research infrastructure (1) that exists and is utilized beyond the initial grant timeframe, and (2) that is adaptable and capable of responding to and addressing new clinical and public health questions (Shediach-Rizkallah and Bone 1998; Felt-Lisk et al. 2012). The FRG developed and implemented a sustainability plan with activities that included enhancing existing partnerships; forging new academic–community partnerships; developing interagency efforts to routinely update, validate, and expand data sources; and identifying funding opportunities to use and expand our data and research infrastructure beyond the life of the grant.

Creating an Improved All-Payer Hospital Discharge Data Infrastructure

The primary objective of AHRQ's data infrastructure grants was to produce the evidence base for CER. In Florida, that constituted the development of an all-payer, clinically enriched, longitudinal MCH database created by linking together mother and infant data from vital records (birth and death certificates) and hospital discharge (inpatient, ambulatory, and emergency department) data. The target population for the initial linkage and CER study included infants born to Florida resident women over a 12-year period (from January 1, 1998 through December 31, 2009) and that had a valid birth certificate record. Data were linked using a stepwise deterministic data linkage strategy that incorporated partial and crossover agreement (Salemi et al. 2013b). Linking algorithms and evaluation protocols were developed and reviewed by an interagency working group, including USF, the Florida Department of Health, and the Florida Agency for Health Care Administration. The AHRQ data infrastructure award resulted in the creation of an MCH database covering 2,347,738 infants born over a 12-year period in Florida. Over 92 percent of all eligible birth certificate records were linked to both maternal and infant hospital encounter-level data, and those infants captured at birth were followed up for a minimum of 1 year to a maximum of 12 years.

Supporting Use and Sustainability through Community-Based Participatory Research

As communities strive to translate health knowledge into practice, the appropriateness and feasibility of approaches are determined by their capacity to respond to health needs, factoring in the economic realities of their communities. In this context, large linked public health databases with sufficient geographic granularity can be used not only to generate epidemiological and clinical evidence but also to overcome a critical barrier to progress—the lack of cost analysis in CBPR—by providing relevant health care cost data (Viswanathan et al. 2004). Our CBPR project is grounded in nearly 15 years of an existing community–academic partnership between USF and REACHUP, Inc., a 501(c)(3) nonprofit community-rooted organization in Tampa, Florida, that advocates for and mobilizes risk reduction services to mothers and children within the local health care system (REACHUP Inc 2014). Funded by a the National Institute on Minority Health and Health Disparities (NIMHD), our protocol adopts a multilevel, mixed-methods approach to integrating qualitative, quantitative, and economic measures into a “next generation CBPR model” (further described in the Discussion section). Figure 1 describes this approach to data collection and its role in generating community-driven, evidence-based interventions. Within the CBPR framework, Florida’s enhanced database served as a tool to inform community members of important aspects of MCH morbidity, mortality, and health disparities, and to generate data on the health care cost burden resulting from those health indicators in the target community. In addition, Florida’s AHRQ-funded database served to:

- Expand the breadth of information shared within the community–academic partnership between USF and REACHUP, Inc.
- Construct a multifaceted evidence base for community action by (1) producing MCH morbidity, mortality, and health disparities data that are relevant in the target community; (2) conducting an assessment of individual-, community-, and health care-level demographic, sociobehavioral, and organizational risk factors; and (3) assessing the economic burden imposed upon health care facilities in the community due to adverse MCH conditions and determinants.
- Supplement data gathered through FGs and community interviews (Figure 1) to further a community-driven triangulation and interpretation of the data and determine rankings of MCH disparity issues on importance and changeability metrics, as well as the potential savings (health and economic) that could be associated with intervention strategies.

Figure 1: Multilevel, Mixed-Methods Data Collection Strategies for Our Community-Based Participatory Research Project

RESULTS

Expansion of Community–Academic Efforts to Eliminate MCH Health Disparities

When USF and REACHUP, Inc. conceptualized an expansion of their partnership in the form of a CBPR initiative to target MCH disparities, the enhanced MCH database was used to generate previously unavailable multi-year rate and trend data on health indicators that qualified the target community (a socioeconomically disadvantaged region encompassing five zip codes) as bearing a disproportionate health burden of MCH morbidity and mortality and as having significant MCH racial/ethnic health disparities. Furthermore, the availability of a clinically enriched, validated statewide database to integrate into the proposed 3-year CBPR project (“Toward Eliminating Disparities in Maternal and Child Health Populations”) was considered by the eventual funding agency (NIMHD) as a critical strength of the approach. The three-pronged objective of the funded initiative was to (1) lead a community-driven identification of a priority MCH disparity issue through community needs assessment and asset mapping, (2) determine an evidence-based intervention that addresses the condition identified, and (3) design a pilot study to implement the intervention.

To ensure equal community representation throughout the project, a Community Advisory Board (CAB) was created, comprising 25 trusted leaders (e.g., consumers, community residents, health care providers, community advocates, representatives from community-based and faith organizations), who are committed to improving the health and quality of life of residents in the target area. The goal of the CAB was to provide feedback on the study protocol, ensure the cultural appropriateness and relevance of research/intervention activities, and facilitate community adoption. Community members were trained by academic researchers using a tailored curriculum in CBPR that prepared them to engage actively in the generation of evidence through a mixed-methods framework that included FGs, community interviews, and epidemiological/economic analysis of the MCH database.

Generation of Evidence for Community Action

As part of data collection and evidence generation, and to explore fully the sociobehavioral and environmental determinants associated with adverse MCH outcomes, our CBPR approach focused on assimilating new evidence from a variety of information sources: (1) community-level data collected through FGs and a social assessment that included a zip code-level investigation of poverty, education, and employment indicators in the target area; (2) individual-level data from community surveys; and (3) analysis of extant epidemiological and economic data from the MCH database.

Focus Groups. FGs were conducted with women/mothers, men/fathers, and children 12–17 years of age primarily to capture the leading health-related issues in their communities. A total of 78 residents of the target population participated in the FGs. Each FG facilitator asked participants to consider issues separately as they pertain to three distinct MCH subgroups: children and adolescents, non-pregnant women of child-bearing age, and pregnant women. A simple summary of FG findings are presented in Table 1. FGs also explored perceived risk and protective factors associated with various health outcomes in the target population and initiated discussion over potential solutions to reduce adverse outcomes and eliminate racial/ethnic disparities in the participants' neighborhoods.

Community Surveys. A computer-assisted, community-based, participatory survey was designed to assess determinants of health-related quality of life

Table 1: Focus Group Findings on the Leading Health-Related Issues in the Target Community

<i>Maternal and Child Health Populations</i>	<i>Leading Issues*</i>
Risks for child and adolescent health	<ul style="list-style-type: none"> • Childhood obesity • Lack of physical exercise • Self-concept issues (low self-esteem)
Risks for women's health	<ul style="list-style-type: none"> • Low health literacy • Lack of adequate parenting skills (parenting stress) • Low educational level • Lack of self-esteem • Financial problems
Risk for pregnancy	<ul style="list-style-type: none"> • Emotional health, including chronic stress, depression, and the role of unhealthy affectionate relationships • Lack of good nutrition • Lack of physical exercise • Preexisting medical issues ongoing during pregnancy • Social connections issues, including lack of support system, lack of baby's father involvement during pregnancy, and other relationship issues with partners • Lack of health insurance before pregnancy • Low health care quality offered to women

*Concurrent themes that emerged in two or more focus groups.

(HRQL) in the community and to examine the role of social determinants of health throughout the life course. Validated scales were used to measure health and quality of life, behavior and lifestyle factors, stress, racism and discrimination, social support, adverse childhood experiences, family resilience, and sociodemographic factors (Cohen, Kamarck, and Mermelstein 1983; Cohen and Williamson 1988; Sherbourne and Stewart 1991; Cohen, Kessler, and Gordon 1995; Felitti et al. 1998; Taylor 2000; Thompson et al. 2000; Steptoe and Feldman 2001; Cagney and Browning 2004; Tendulkar et al. 2012; Centers for Disease Control and Prevention 2013). Two hundred and one subjects were recruited from 23 different geographic areas within the targeted five zip-code area. Data were captured utilizing droidSURVEY software installed on portable Android tablet computers. Bivariate analyses were conducted to determine how childhood, adult, and socioeconomic factors correlated with the number of unhealthy days due to physical or mental ill-

ness, reported over the last 30-day period (a proxy for HRQL). Survey results are presented in Table 2.

Epidemiological and Economic Analysis of an Enhanced MCH Database. The MCH database created using AHRQ CER data infrastructure funds was ideal for supplementing FGs and community surveys with *objective* epidemiological health indicators (e.g., inadequate prenatal care, teenage pregnancy, preterm birth, low birth weight, gestational diabetes, congenital anomalies) and health care cost estimates specific to the target community. A table describing the frequency, rate, and direct medical costs associated with each condition by person (e.g., racial/ethnic subgroups), place (e.g., for each zip code in the target community), and time (e.g., 5-year trend analysis) was created by academic partners and shared with the CAB. For dissemination to community members, this information was simplified further and translated into various data visualization objects that were shared with community members. For example, prevalence and cost data were presented to community decision makers using an interactive “packed bubble” diagram. Each bubble represented a sociodemographic and behavioral risk factor (e.g., teenage pregnancy) or a clinical MCH outcome (e.g., preeclampsia). Bubble size was directly correlated

Table 2: Community Survey Findings on Factors Associated with the Number of Unhealthy Days Due to Physical or Mental Illness Reported in the Previous 30-Day Window

<i>Factors</i>	<i>r</i>
Childhood factors	
Supports while growing up	−.221**
Adverse childhood experiences	.306**
Adult (current) factors	
Perceived stress	.410**
Experiences of discrimination	.152*
Lack of sleep	.532**
Alcohol use	.160*
Reported medical issues (composite)	.502**
Socioeconomic factors	
Household annual income (in U.S. dollars)	−.174*
Perceived social standing (On a scale from 1 to 10, where do you think you stand at this time in your life, relative to other people in your community)	−.233**

r = Pearson correlation coefficient.

p* < .05; *p* < .01.

with prevalence, and the bubble color gradient symbolized the magnitude of cost associated with each factor. This proved to be an effective tool to facilitate the community's ability to understand complex quantitative epidemiological and economic information.

Maternal conditions during pregnancy associated with greater health care costs (infant and maternal costs combined) were as follows: prepregnancy obesity, anemia, gestational diabetes, gestational hypertension, and prepregnancy hypertension. Behavioral factors associated with increased costs included suboptimal weight gain, tobacco use, and to a lesser extent drug use. Adverse pregnancy outcomes that represented the greatest costs were low birth weight, preterm birth, and small-for-gestational age, and their downstream complications (e.g., jaundice, feeding difficulties). Although for simplicity's sake these conditions were presented to the community as separate, their interdependent, co-occurring nature was explained, and multifactor statistics were also provided (data not shown).

CAB members discussed the importance of these findings for their own community, while considering the cultural (e.g., African American strengths) and historical context (e.g., exposure to racism and discrimination). Based exclusively on the prevalence and health care cost-burden portion of the analysis, community members felt greater cost savings would be realized if interventions were targeted toward women with particular characteristics: of young or advance maternal age, unmarried, black race, less than high school education, and those that lacked father involvement during their pregnancy.

Community-Driven, Decision-Making Model for Priority Issue Determination

Following compilation of results from FGs, community surveys, and the epidemiological/economic analyses, the next step was to devise a final decision-making model to improve clarity among the most important MCH disparity issues upon which an intervention should be developed. The nominal group technique (NGT) was used to facilitate a final community-driven decision, which simultaneously incorporated issue ranking and prioritization (Allen, Dyas, and Jones 2004; Harvey and Holmes 2012). In our study, the NGT was used to promote effective and timely group participation in the decision-making process by strengthening areas of consensus and narrowing the field of disagreement. The hallmark of this phase was the creation of a Community Priority Index (CPI), which was used to prioritize health issues by combining subjective and objective markers into a single measure (Salihu 2015). Briefly, community members were first presented with the complete list of

issues (those collected across FGs, community surveys, and extant database analyses) so that they could rank each issue using Likert-type, 3-point scaled questions representing metrics of importance and changeability (*for importance*: 1 = not important, 2 = intermediate importance, 3 = very important; *for changeability*: 1 = not changeable, 2 = intermediate changeability, 3 = highly changeable). Then, for each health issue, we calculated the CPI as *mean importance score* $\times$ *mean changeability score*. The CPI ranged from 1 to 9, but was standardized from 0 (lowest priority) to 1 (highest priority), providing a single measure that guided the selection of health issues that were viewed as most important and changeable by community members. The health issues identified for pregnant women were a lack of affection (CPI = 0.87), stress (CPI = 0.85), and nutritional issues (CPI = 0.78). For women's health in general, the top priorities were low health literacy (CPI = 0.87), low educational attainment (CPI = 0.78), and lack of self-esteem (CPI = 0.72); and for children and adolescents the top priorities were obesity (CPI = 0.88) and low self-esteem (CPI = 0.81).

DISCUSSION

Enhanced State Data for CBPR: A Successful Pathway to Sustainability and Impact

Florida was among eight states that were effective in using AHRQ CER data infrastructure funding to substantially enhance the clinical content or improve the validity of race/ethnicity data within large, statewide administrative and research databases. However, to maximize the value and impact of these federal investments in data infrastructure, success was also measured by the ability of each project to exert a sustainable influence on the research field(s) involved. In this paper, we have described the process by which enhanced state data were used to secure additional, multiyear funding through the integration of the database into community-engaged research strategies. This approach offers current and future grantees a model for promoting the long-term use and sustainability of their newly established state databases. The database has been instrumental in helping to empower an underserved and underrepresented population in Florida, giving them the tools to make evidence-based decisions regarding prioritization of issues most important to longevity and quality of life *in their neighborhoods*. Furthermore, the enhanced database will continue to be used in developing community-rooted, cost-efficient interventions with real-world effectiveness.

Toward a Next Generation CBPR Model

Community-engaged research methodologies, including CBPR, are regarded as valid, effective approaches to preventing disease and promoting health, particularly within marginalized communities that bear a disproportionate burden of morbidity and mortality (Wallerstein and Duran 2006; Israel et al. 2010; Minkler 2010; Wallerstein, Yen, and Syme 2011).

Through the intimate involvement of community members in all aspects of decision making and implementation activities on matters that affect their own lives, CBPR is well-suited to generate tailored, culturally appropriate solutions to reduce health disparities. Moreover, successful collaboration between academic researchers and community partners empowers individuals, increases public trust, and builds a capacity and readiness for research that maximizes the sustainability and effectiveness of interventions.

We contend that the next generation of CBPR methods should fully explore multiple data sources to ascertain the social, economic, and environmental determinants of health. Community and academic partners must be capable of generating and integrating evidence from various sources of information, including qualitative (e.g., FGs), quantitative (e.g., epidemiological), and economic (e.g., cost-effectiveness) data. Although FGs and personal interviews can be conducted relatively quickly to produce important qualitative evidence, many communities lack reliable, long-term epidemiological and economic indicators to further inform the decision-making process. The integration of our clinically enhanced data infrastructure into CBPR demonstrates how community groups can readily access scientific evidence in a manner that permits concerted decision making for social action and simultaneously ensure a sustained, meaningful use of clinical and administrative data networks for the provision of evidence-based, quality health care.

Interpretation of our approach should be considered in light of several data and process limitations. First, although the enhanced database was an important source of information for decision making in the CBPR project, it relies primarily on a combination of International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM) diagnosis codes and information on birth certificate records to identify sociodemographic and behavioral characteristics, as well as clinical outcomes. We have published previously on the suboptimal accuracy and completeness of these data sources (Salemi et al. 2011, 2012). Second, the cost information contained in our database represent only the direct medical care costs

from specific revenue-generating centers that are associated with the institutional portion of a hospital stay (Rogowski 1999; Salemi et al. 2013a). Thus, we are unable to calculate physician costs, indirect costs, or the remaining components of the overall costs to society due to the MCH issues under consideration. Therefore, it was particularly difficult to appropriately explain to community members the importance and relevance of the economic data being presented. Lastly, the evidence generated using the MCH database was only a portion of the overall evidence base for the CBPR project. It was difficult when epidemiological data conflicted with community members' established beliefs or feelings that emerged in FGs, to adequately weight the relative importance of each data source. Despite these limitations, our experience indicates that integrating enhanced databases into community-engaged research activities can empower underserved communities with a reliable source of health data and can promote the sustainability of newly developed data systems.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Appendix SA1: Author Matrix.