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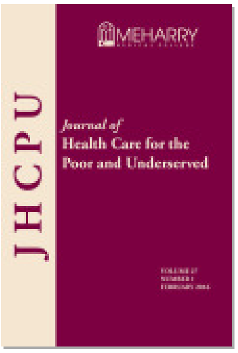

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ORIGINAL PAPER

Issues and Solutions for Collecting Biological Specimen in Longitudinal Studies: Experience from the Community Child Health Network Research Network

Patricia O'Campo, PhD
Rhonda BeLue, PhD
Heidi Borenstein, BSc
Maxine Reed-Vance, RN, MS
Robin Gaines Lanzi, PhD, MPH
Peter Schafer
Loretta Jones, MA
Richard Woolord

Abstract: The inclusion of biomarkers in studies of stress and health outcomes is of growing interest, including for community-based participatory research (CBPR) studies. Yet the perspectives of participants and communities have been infrequently consulted to inform the biomarker collection process. The objective of this paper is to describe the process and outcomes of using CBPR in framing biomarker collection in a study of allostatic load in a maternal and child health population. Through analysis of focus group data, we identify aspects of CBPR that facilitate increased community trust and endorsement related to collecting biological samples, and also provide a community perspective that is often overlooked in the literature. We found that a CBPR approach facilitated greater understanding among community members about the importance of biomarkers, while simultaneously informing the design of a biomarker data collection protocol that was responsive to the desired scope and data collection procedures that reflected community priorities.

Key words: Community-based participatory research, biomarkers, data collection, allostatic load.

***PATRICIA O'CAMPO** is director of the Centre for Research on Inner City Health at St Michael's Hospital, Toronto. **RHONDA BELUE** is an associate professor of Health Policy and Administration at The Pennsylvania State University. **HEIDI BORENSTEIN** is a research student at the Centre for Research on Inner City Health at St. Michael's Hospital, Toronto. **MAXINE REED-VANCE** is director of clinical affairs and quality assurance at Baltimore Healthy Start. **ROBIN GAINES LANZI** is an associate professor at the School of Public Health, University of Alabama at Birmingham. **PETER SCHAFER** is a senior policy associate in Health Policy at the New York Academy of Medicine. **LORETTA JONES** is the founder and CEO of Healthy African American Families, in Los Angeles. **RICHARD WOOLORD** is co-chair of the Eastern Baby Love Plus Consortium, in North Carolina. Please address all correspondence to the Centre for Research on Inner City Health, c/o Patricia O'Campo, 30 Bond StreetToronto, Ontario, Canada, M5B 1W8.*

Over the past two decades there has been growing interest in the inclusion of biomarkers in research on health disparities in maternal and child health.[1–9] Biomarkers offer a unique opportunity to supplement self-reported data with biological indicators of health and well-being. In the area of stress, biomarkers help measure what is happening inside a person's body in response to stressors. Chyu and Upchurch[10] proposed the measure of allostatic load as an "index of cumulative physiological dysregulation" that "captures how the cumulative impact of physiological stress responses from person-environment interactions causes wear and tear on the body's regulatory systems, which in turn can lead to disease outcomes and health disparities."[p.575] A variety of studies of stress have since adopted this measure.[2,3,9–13]

However, collection of complete and high-quality biomarker data poses challenges. Community members may be reluctant to give specimens due to lack of understanding regarding what is being collected and its importance or role in the study. Socioeconomically disadvantaged communities, as well as communities of people of color and women may also distrust medical research, given historical experiences with racist, sexist or classist biases.[13] Meanwhile, quality control in obtaining, storing, and shipping samples, particularly when study participants are asked to obtain multiple specimens following a specific time schedule, may also be difficult, especially in communities facing particular social and economic challenges.[14–16]

Seeking input and true partnership from communities may be a productive approach to address these concerns, as when studies adopt principles of community-based participatory research (CBPR).[17–19] Community-based participatory research is the process whereby researchers and members of affected communities co-create evidence to inform positive change. A recent systematic review on the benefits of research conducted by such partnerships revealed that it tends to "ensure culturally and logistically appropriate research," "generate professional capacity and competence in stakeholder groups," and "result in productive conflicts followed by useful negotiation."[20][p.20]

The current study was designed and implemented as part of a multi-site CBPR network known as The Child and Community Health Network (CCHN). The CCHN is an academic-community partnership funded by the Eunice Kennedy Shriver National Institute on Child Health and Human Development (NICHD). The CCHN proposed to conduct a longitudinal observational study at five sites across the U.S. to collect multi-level data, including biomarkers of allostatic load, in order to understand better how stress and resilience influence maternal, paternal, and child health outcomes. Each site had two principal investigators (PIs): an academic PI paired with either a community PI who represented community-based organizations (three sites), or with a major community health care provider (two sites). While putting together the grant applications, the university PI at each site approached an organization that provided services to low-income maternal and child health populations, asking whether they would co-create the research. Four partnerships were relatively new at the time the grants were awarded, and one was based on a collaboration of over 10 years. Brief descriptions of partnerships and selected economic and demographic characteristics of the sites follow.

Washington D.C. In Washington D.C., the Georgetown Center on Health and

Education and the Workforce at Georgetown University approached two organizations: Washington Hospital Center, the largest private hospital in the national's capital, and Developing Families Center, which offers family-centered women's and children's health care, child care, family resources and support, confidential counseling, and adult education through a collaboration among service providers. Socio-demographically, census data for Washington D.C. from 2006 show that 13% of families with children under 18 in the household were at or below 130% of the official poverty line, and 22% resided in single-parent households; 12% were Hispanic; and 55% were African American.[21]

Baltimore, Maryland. Johns Hopkins Bloomberg School of Public Health worked with Baltimore Healthy Start (BHS), having established that partnership more than 10 years before grant writing. Baltimore Healthy Start seeks to improve the health and well-being of pregnant and postpartum women, their babies, families, and communities by providing comprehensive, supportive services in the communities where they live, taking a Life Course (i.e., developmentally and socially contextualized) perspective on health[22] During its 22-year history, BHS has provided services to over 15,000 pregnant and postpartum women in some of the most distressed communities in Baltimore. Census data for Baltimore from 2006 show that 16% of families with children younger than 18 in the household were at or below 130% of the official poverty line, and 21% resided in single-parent households; 4% were Hispanic; and 58% were African American.[22]

North Carolina. The East Carolina University campus of the University of North Carolina worked with the North Carolina Baby Love Plus Program (BLPP), an initiative that aims to lessen prenatal health disparities by reducing infant morbidity and mortality by educating people on early prenatal care; increasing access to available services; and promoting strong and healthy communities. The BLPP helps women and families increase their chances of having healthy and happy babies. Census data for this largely rural area show that 17% of families with children under 18 in the household were at or below 130% of the official poverty line, and 16% resided in single-parent households; 5% were Hispanic; and 66% were African American.

Lake County, Illinois. Evanston Northwestern Healthcare Research Institute worked with the Lake County Health Department and Community Health Center, which provides diabetes prevention, cancer screening, women's health, and pediatric care services. At the Lakehead area, 10% of families with children under 18 in the household were at or below 130% of the official poverty line, and 16% resided in single-parent households; 10% were Hispanic; and 10% were African American.

Los Angeles, California. Cedars-Sinai Medical Center and the David Geffen School of Medicine at the University of California, Los Angeles, worked with Healthy African American Families, an organization that seeks to improve health outcomes among African American, Latino, and Korean communities in Los Angeles (LA) County by enhancing quality of care; and to advance social progress through education, training, and collaboration with community members and organizations, people in academia, researchers, and government. Census data for 2006 show that 21% of families with children under 18 in the household in LA County were at or below 130% of the official poverty line, and 16% resided in single-parent households; 46% were Hispanic; and 19% were African American.[23]

The CCHN study focused on the role of stress in health disparities among groups of mothers and children. One study measure was allostatic load. To assess load, CCHN proposed to collect biologically relevant data and drew on its community-university partnerships to finalize the set of biomarkers, which included saliva samples, parental DNA, bloodspots, participant weight and measurements (i.e., assessment of waist-to-hip ratio), and blood pressure. The objective of this paper is to describe the process and outcomes of using CBPR in framing the collection of biomarker data. Specifically, we analyze data obtained in focus groups with study team members in order to identify traits of CBPR that facilitated increased trust and endorsement from the community related to biological sample collection. These data also provide a community perspective on sample collection that is not often discussed in the literature.

Methods

Data were obtained during three focus group sessions conducted via teleconference (the main means of communicating across study sites) with CCHN research team members who had been responsible for planning and designing the study and collecting data. The goal was to learn more about their experiences and perceptions related to CBPR biological specimen collection. Held in 2012, the three focus groups were made up of the following individuals: (Focus Group 1) CCHN Steering Committee members, including academic and community representatives from each site, plus the principal investigator from the CCHN Data Coordinating and Analysis Center (DCAC) and the NIH scientific officer (NICHD) (n= 12); (Focus Group 2) research site coordinators from each site (n=8); and (Focus Group 3) the CCHN Community Committee members (representing community partners at each site who are part of the research team, although one academic partner was also a member) (n=7). All focus groups were conducted by an independent trained facilitator. Participants were asked the following questions:

1. Did using a CBPR framework to design the study facilitate community engagement around the collection of biomarkers with regard to the importance or collection of biomarkers or facilitation of changes/improvements to our original ideas around biomarker data?
2. What were the challenges and barriers to collecting biomarker specimens with regard to completeness and timeliness of data collection or procedures and equipment failures?
3. Were there issues of distrust coming from the community about biomarker data collection?

Analysis. Participant responses were audio-recorded, with permission, and transcribed verbatim. We then conducted content analysis to examine the resulting data.[24] Themes emerging from content analysis were organized by responses to the questions listed above. We used descriptive statistics to assess participant reports about collecting biological data.

Results

How did a CBPR framework facilitate community engagement around the collection of biomarkers? One major theme emerged on this issue, namely the usefulness of three components of the CCHN study in providing timely and salient information about community perspectives on biomarker collection: community advisory boards, community-based PIs, and CCHN community structures (e.g., community-academic partnerships at the different sites). Community advisory boards (CABs) were made up of community stakeholders and community PIs and were configured differently at each site. Their purpose was to gain input on study processes. Together, the CABs and community PIs were instrumental in shaping acceptable biomarker collection protocols and procedures for the communities. For example, at several sites, the CAB helped negotiate whether, how, and by whom, blood pricks would be administered.

> When we brought it to the community before the actual biomarkers began and asked them what they thought about the heel prick on the babies' feet to get the biomarkers . . . they felt that unless it was a trained nurse doing a heel prick on a baby, they didn't feel that it was safe. They didn't think that just anybody should be able to collect that information. [research site coordinator]

Because having a nurse doing data collection for the study was not an option and also the input via the CCHN Community Committee and CAB members, collecting blood via infant heel pricks was removed from the protocol.

Some sites also expressed concern in community meetings about finger prick blood collection. While this measure was retained, CAB members were able to communicate these concerns, which minimized potential problems in the collection of these specimens.

> I think that perhaps without the community piece, it would have been very difficult in our city to get finger sticks done. . . . The big deal was the finger sticks for us in the community . . . [In] collecting the blood spots, the fathers' fingers were sometimes callused and we had a difficult time getting the needle in there and getting the finger to bleed, because the needle wasn't strong enough or big enough. [steering committee member]

Focus group data also show that CAB members rallied overall support for the study, which positively influenced collection.

> Our . . . community board really encouraged us to do a lot of outreach . . . and so we were able to do newsletters, keep in contact with participants, build . . . a good rapport so that . . . the biomarkers were something they sort of wanted to do, because they [the community] felt connected. . . . that was really helpful. [steering committee member]

Together, CABs and community PIs helped people understand biomarker collection procedures. Staff with the CCHN worked with CAB members to explain the protocol and to answer questions, which eventually eased community concerns.

> We had a discussion about biomarkers [with the CAB and community PI] and not only about the biomarkers but the anthropometric markers that we did. We talked about the differences. We had them [CAB members] actually participate, we pricked our fingers and showed what was going to happen in the home and assured them. . . . One of their concerns was training. They didn't want anybody to be hurt and so we assured them that the interviewers were going to have sufficient training to be able to carry out the procedures for the biomarker and the other measurements correctly. [steering committee member]

Focus group participants also pointed to the specific value of community PIs, who knew locals and their concerns.

> Our community Co-PI was so involved with the community as well as with what we were doing . . . and had the relationship with them already established so she was able to share [their views] with us. . . .We need to do it this way. [community committee member]

A second, independent theme arose with regards to facilitation of sample collection by CBPR: that is, how CBPR allowed community concerns over collecting samples from fathers to be expressed. Two factors emerged: hesitation among fathers, and lack of comfort among mothers. Father biomarker data were not originally part of the CCHN central study hypotheses about stress effects. The CABs, community PIs, and fathers themselves were apprehensive about what would be done with father biomarkers, since the study focused on maternal-child health.

> Fathers were concerned. Was [the biomarker data] going to be used to track them as far as their DNA goes? Was this going to be a new way of collecting DNA? [community committee member]

> That's why they didn't want to do the dad's blood samples in XX because they thought that anytime you have a blood sample or saliva, you can get DNA . . . they know about that, because the government had just passed this law that if you were arrested, then DNA would be taken through a swab in your mouth. So, you got the saliva and the blood prick. So they said, "No way" because they believed that no matter what we said, that if push came to shove, that some Black man would be charged with something because his DNA was stored. [steering committee member]

Focus group participants also described discomfort and doubt on the part of mothers over father sample collection.

> They [the mothers] didn't think that they would be able to get their fathers to do that. They didn't think the father would be interested in it. They didn't say necessarily that it was mistrust or something; they just felt the father would not be involved in that level. [community committee member]

Focus group data showed that the CABs facilitated a lot of discussion of this issue of fathers' samples, revealing issues specific to low-income groups. For example, some

CABs believed that fathers’ biomarkers should be collected because fathers were most likely uninsured, and information arising from collection might yield health information they would not otherwise get.

> At least if we had collected [data] like blood pressure and hemoglobin A1c on the dad and got some information, we would be able then to refer them and they could get health benefits if they needed it sooner. [community committee member]

After such discussions, and after assessing the financial cost of additional data collection, only one site chose to collect biomarker data on fathers, with clear support from their CAB. However, there was a general consensus that father biomarker collection would be helpful not only to understanding stress and its impact on families, but also in assisting individual fathers.

A third theme that emerged was the advantage of CBPR in getting practical benefits for study participants in exchange for biomarker sample collection. Specifically, a recommendation came from the communities that study participants, especially those who did not regularly see a primary health care provider or lacked health insurance, would benefit from knowing whether the biomarker data pointed to a need for follow-up assessment, such a high blood pressure. While CCHN was not qualified to provide diagnoses to individuals, it did establish “alarm values for biomarker data—that is, values considered out of the clinically normal range, such as blood pressure above 140/90—and then shared the information with study participants about why seeking professional follow-up could be helpful. Study participants could then impart their alarm value findings to local health care providers. The CCHN research staff did express concern about how easy it would be for some participants to take this follow-up action. Providing the feedback to study participants about alarm values was also time-consuming.

> [There were] problems getting people to referrals—no action after referral to a doctor. Where does our job end? After the first, second, or third referral? What is our responsibility to get the [person with a high] alarm value treated? What if they go to the doctor and don’t get proper treatment. We know of one participant who went to the doctor with multiple alarm values and received no medications. We don’t want to leave someone hanging out there with high blood pressure. [community committee member]

Nonetheless, the establishment of alarm values and the communication of these values to study participants were practices that came directly from CBPR activities.

What were the challenges and barriers to collecting biomarker specimens? The main theme that emerged in response to this second question from focus group participants was logistics. Participants described several logistical issues faced at the study sites that had the potential to hinder complete biomarker collection, and how CBPR sometimes could, and sometimes could not address those issues.

For example, community input only partly anticipated complications with collection and return of saliva samples by study participants. Study participants had been asked to collect these samples three times (morning, afternoon, night) on a day of their choosing. The instructions were complicated, as they included pick-up and drop-off instructions in addition to details about sample collection and storage. From the beginning, some study participants were uncomfortable with the collection methods, especially spitting in the small tube provided.

> One issue [was] spitting in the tube. Going forward, I would, I would suggest maybe using another type of collection device. Then, if they wanted to actually collect their saliva that way or even if we could collect it using the Q-tip method or some other type of swab. I think that would omit some of the barriers that we had. [steering committee member]

Community research team members and CAB members who knew their study populations well were also able to anticipate that samples would not come back from some participants unless study personnel picked them up. One study site that was particularly responsive decided to pick up the samples. Due to budgetary constraints, however, the rest of the sites asked participants to mail saliva samples back to the study office in pre-addressed, prepaid envelopes. Thus, despite the insight into participant preferences gained through CBPR structures, collection methods varied and were not always optimized.

> So, what was going on was interviewers had different approaches. So, some felt that mailing them ahead of time before the interviewer [made the home visit] was a good approach. Some would drop off the saliva collection materials the day before the interview. [site coordinator member]

> When the participants mailed saliva to us, we mailed them the gift card. Some of them got complaining that they didn't receive the gift card. [site coordinator committee member]

Saliva sample collection remained a challenge throughout the study, despite attempts at problem solving. Other logistical hindrances included sample collection on the premises of crowded housing, and based on features of participants' housing.

> When it came time to do biomarkers in the home, they [data collectors] just had a hard time, because if there were little kids present, they would play with the equipment. And so that kind of slowed them down (site coordinator member)

> Sometimes it was difficult when the space was limited in terms of multiple families living in the house. And then the carpet was an issue as well, pulling it [back] for the weighing [on portable scales] . . . but it wasn't an overburden. [site coordinator committee member]

Was there distrust coming from the community about biomarker data collection? While there were many matters to negotiate among community and academic partners, and this process of negotiation took weeks and sometimes months, in general, partners who shared their experiences in the focus groups felt that the study processes had ensured that there was no distrust between community members and study personnel.

> Nobody actually said they really had any distrust issues. I think by the time the interviewer came to the home after being enrolled and everything, the participants were pretty trusting, and we were pretty trustworthy for them. [site coordinator committee member]

There were, however, study procedures that made participants feel uncomfortable. These included the aforementioned issues of father sample collection and the tubes for saliva sampling. Another procedure that led to debate was the length of time that biomarkers would be stored. Communities were uncomfortable with storage over five years and with collection and storage of DNA. Early on, DNA was proposed as part of the protocol.

> [Community participants] talked a little about who was going to own this DNA, what was going to happen to it? What happens is someone finds that their gene markers will make money-because they talked about Henrietta [HeLa cells]. . . . they [the community] didn't want us to hold onto the DNA for 20 years, only for five. [site coordinator committee member]

> From the community perspective, DNA being stored at the NIH doesn't necessarily mean secure. [steering committee member]

Due to these concerns, DNA was not included as a bio specimen in the study. Participants also expressed discomfort with the lack of continuity among interviewers during the follow-up period.

> Because the changes in staff we had, we couldn't keep the one interviewer with the same participant all the time . . . we had a couple of requests that the participant wanted the same interviewer . . . [site coordinator committee member]

However, the implication on the part of focus group members was that while continuity would be preferable to the community, a lack of continuity was not enough to destroy the trust built up through the overall CBPR approach.

> So, I don't know if it'd be distrust, but, when we did call to schedule interviews, participants would say I thought this person [named] was coming out . . . We did have a problem with certain interviewers. [site coordinator committee member]

Discussion

While many scientific studies now include biomarker data, research participants are not always fully informed about or comfortable with the collection and use of these specimens. We have described the process by which local communities, through a

CBPR framework, were able to reach agreement about the types of biomarkers that were acceptable to collect, as well as important details about collection protocol.

While academic partners originally proposed collection of individual DNA and use of infant heel pricks, these were eventually dropped as a result of the CBPR negotiation process. Parental blood spots were used to assess cholesterol level and hemoglobin A1c in mothers. Due to community concerns about sample collection resulting in physical pain for participants, all biomarkers were collected by staff with previous relevant data collection experience (e.g., nurses or community health workers), or they received training before they collected the data. The data collectors were also from and/or familiar with the local community. Finally, via the CBPR channels, participants at the study sites expressed their wish that biological data be kept only for five years.

These findings support the recommendation of Erwin et al.[25] that in order to recruit diverse community members to participate in biospecimen banking, researchers must carefully shape the educational and promotional plan to meet the community's specific needs and demonstrate that the study includes credentialed scientists and trusted institutions to mediate fears of exploitation from participants. Better yet, considering joint ownership of data, and conducting joint data analysis and interpretation of findings could give communities more power, which can also help avoid many of the trust issues that are reported to be common in biomarker research.[26]

We also know that in much research communities are rarely consulted about their motivation for participating in research studies or what they hope to gain by taking part in specific studies. Our focus groups pointed to a difference in CBPR in that communities can express practical gains they might accrue through participation. In this case, community feedback led to a recommendation that participants be provided with individual feedback when alarm values were obtained during sample collection. Participants were informed about any alarm value as soon as results were available and encouraged to seek follow-up from health care professionals. Staff assisted with locating assistance for participants who did not have a primary care provider.

We also found that research participants are not always fully informed about or comfortable with the collection and proposed use of biological specimens. This was the case in the debates at the study sites over collecting biological samples from fathers. The specific social context of people living at these sites made a difference to men's comfort with saliva sampling. Some men connected this technique with policing techniques and their own position and histories as African Americans who might interact with law enforcement. Thus, some research goals on the part of academics and the motivation to participate on the part of community members could be at odds. While academics seek to maximize the rigor of their study designs and data collection, the reasons for and methods of maximizing data quality are not always made clear to study participants.

Finally, some of the problems identified by study participants—such as lack of interviewer continuity across interviews—are standard challenges with any longitudinal study. This information could have been shared proactively with study participants ahead of time for clarity and comfort.

A limitation of this study is that while we sought to represent the perspectives of community participants, we did not ask them questions. Rather we relied on focus groups with CAB members, site coordinators, and Executive Steering Committee members. Staff with CCHN did, however, ask all study participants to rate their comfort with the collection of biomarkers. Overwhelmingly, study participants reported high levels of comfort: 95% were very or somewhat comfortable with blood spot collection, 88% were very or somewhat comfortable with saliva collection, and 96% were very or somewhat comfortable with body measurements.

Our study provides new data supporting the value of CBPR as a useful approach for ensuring that communities are well-informed about study goals, endorse the protocols before they are implemented, and receive feedback when research data indicate there may be a clinical problem that warrants medical follow-up. Further, the CBPR process increases the sense of shared ownership, so that interpreting the findings from research about important health concerns, such as maternal-child health disparities, will engage both community and academic partners and lead to future planning to improve community health outcomes.

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