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Increasing Participation in Genomic Research and Biobanking Through Community-Based Capacity Building

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Abstract

Achieving equitable minority representation in genomic biobanking is one of the most difficult challenges faced by researchers today. Capacity building—a framework for research that includes collaborations and on-going engagement—can be used to help researchers, clinicians and communities better understand the process, utility, and clinical application of genomic science. The purpose of this exploratory descriptive study was to examine factors that influence the decision to participate in genomic research, and identify essential components of capacity building with a community at risk of being under-represented in biobanks. Results of focus groups conducted in Central Harlem with 46 participants were analyzed by a collaborative team of community and academic investigators using content analysis and AtlisTi. Key themes identified were: (1) the potential contribution of biobanking to individual and community health, for example the effect of the environment on health, (2) the societal context of the science, such as DNA criminal databases and paternity testing, that may affect the decision to participate, and (3) the researchers' commitment to community health as an outcome of capacity building. These key factors can contribute to achieving equity in biobank participation, and guide genetic specialists in biobank planning and implementation.

Introduction

Achieving equitable minority representation of participants in genomic research is one of the most difficult challenges faced by researchers today (Redwood & Gill, 2013). Investigators set targets for representation by gender, race, ethnicity and socioeconomic status, but actual minority enrollment often fails to meet these projections (Frieden, Centers for Disease, & Prevention, 2011). In clinical research overall, the causes of under-representation are thought to be associated with historical transgressions in research, (Corbie-Smith, 1999a, 1999b;

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Conflict of Interest Statement:

Elizabeth Gross Cohn, Maryam Husamudeen, Elaine L. Larson and Janet K. Williams declares that they have no conflict of interest. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients being included in this study.

Lombardo & Dorr, 2006; Reverby, 2008, 2010) mistrust (Suther & Kiros, 2009), personal preference (Sullivan, McNaghten, Begley, Hutchinson, & Cargill, 2007) and lack of access, either being unaware of studies or not offered enrollment (Gill, Plumridge, Khunti, & Greenfield, 2013). However, when diverse populations are not represented in genomic sequencing studies, it limits the ability to recognize normal and pathologic variants, reduces the generalizability of the results, and may ultimately advance science for some but not for all, thus exacerbating health disparities for minority populations (Frieden et al., 2011). In genetic testing, this situation is illustrated by current controversy in the use of BRCA1/2 testing which demonstrates significant disparities in utilization between black women and their white counterparts (Gracia-Aznarez et al., 2013; Halbert et al., 2012; M. J. Hall & Olopade, 2006; Hilbers et al., 2013; Schuster et al., 2013; Zhang et al., 2013). On the one hand, researchers suggest that the difference in preventative and diagnostic testing is attributable to patient preference (Halbert et al., 2012) while others cite limited access and lack of knowledge as the root cause, with the consequence of disparities persisting in cancer diagnosis and treatment (M. Hall & Olopade, 2005; M. J. Hall & Olopade, 2006).

As genomic sequencing is increasingly used in research with the anticipation of informing clinical health care options, a new set of decisions and dilemmas face both participants and researchers. These include how health care providers interpret and communicate results, and the on-going need for the counseling and education of those receiving them. Enrollment of a diverse population in sequencing studies is a critical element in their utility (R. Kittles, 2012; Rotimi, 2012). Accurate interpretation of whole genome and whole exome sequencing results is dependent on establishing the incidence of variants in populations overall and associating them with development of disease states or responses to treatments. To accomplish this, a broad sampling of ancestries is necessary. However, this broad sampling of populations has been difficult to achieve in our nation's biobanks (Buseh, Underwood, Stevens, Townsend, & Kelber, 2013; Pang, 2013; Thiel, Platt, Platt, King, & Kardia, 2013). This is especially true in the case of healthy volunteers where the possibility of the release of personal medical information (not only about individual participants but also their families) may alter the risk and benefit balance for those considering enrollment (Pang, 2013).

At the same time a variety of medical practitioners, including genetic counselors and genetic specialists, seek the most appropriate ways of explaining, introducing, and using genomic information in health care. How genomic information will be translated and used in fields such as nursing (Calzone et al., 2013; Daack-Hirsch et al., 2013), social work (Kingsberry, Mickel, Wartel, & Holmes, 2011), education (Williams, 2012), health assessment (Rosenkotter et al., 2011), public health (Gilmour, Graham, Reimer, & Van Domselaar, 2013; Pang, 2013), and public policy (Bowen, Kolor, Dotson, Ned, & Khoury, 2012; Brand, 2012; Khoury et al., 2011; Williams, 2012) are still being considered and explored. These challenges raise the important clinical and practical question, how can we translate the language and the science of genomics into health care practice that benefits diverse communities? This topic is being highlighted by the National Human Genome Research Institute (http://www.genome.gov/), the National Institutes of Nursing Research (https://www.ninr.nih.gov/newsandinformation/jnsgenomics), the National Institute of Mental Health (http://www.nimh.nih.gov/about/organization/dnbbs/genomics-researchbranch/

index.shtml) and the National Institute of Minority Health and Health Disparities, all with a particular focus on health equity.

The National Institute of Nursing Research recently convened a workshop and subsequently issued a consensus statement and blueprint (Genomic Nursing State of the Science Advisory et al., 2013) which suggested a framework to build capacity within the nursing profession for the use of genomics to address the health needs of the public for prediction, prevention and treatment. Equal in importance to building provider capacity, building community capacity will be necessary in order for individuals and communities to understand and use genetic and genomic information to improve health outcomes (Kirk, Tonkin, & Skirton, 2013; Pashayan et al., 2013).

In public health, capacity building for research can be defined as equipping an existing community (defined either along geographic boundaries or by shared interests) to understand and participate as partners in research (Hacker et al., 2012; Lemke et al., 2010; Wilkinson, Ells, Pencheon, Flowers, & Burton, 2011). Community capacity building has been described as activities to improve the ability and infrastructure of an organization or community to provide services and programs (Israel, Schulz, Parker, & Becker, 1998) and to collaborate in community-based research (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011). Hacker et al. identified the factors necessary for research capacity building as establishing partnerships, assuring sustainability, a multidirectional transfer of knowledge, and shared goals that incorporated the health of the community as a primary outcome (Hacker et al., 2012). Spruill et al. developed and demonstrated the success of community-based approaches to recruiting Blacks and African-Americans for genetic research in communities at risk for diabetes, where her target numbers for recruitment and enrollment exceeded the expectation and prediction (Spruill, 2004). Large scale biobanks such as CARTaGENE (Awadalla et al., 2013) and Applied Genetic Medicine (Godard, Marshall, & Laberge, 2007; Knoppers et al., 2010; A. M. Laberge & Burke, 2009, 2010; L. Laberge et al., 2010) in Canada have recognized the critical importance of early community engagement at the inception of their biobanks, as part of the plan for successful recruitment and enrollment of minority communities.

In anticipation of creating an urban biobank at a large academic health center we undertook a capacity building approach for collaborative genomic research in Harlem, New York. This study was conducted as part of a larger national study examining minority participation in genomic biobanking funded by the Robert Wood Johnson Foundation Nurse Faculty Scholar Program (Cohn, 2012). The full study explores the individual, structural and societal barriers that affect the rates of minority participation in genomic research in communities and across the nation. The purpose of this exploratory descriptive study was to examine factors that influence the decisions of members of a low-resourced, urban community regarding participation in capacity building for genomic research.

Methods

Design

We used a qualitative design employing focus groups to explore the attitudes, knowledge and expectations about genomic research and biobanking. Focus groups are used to gain access and insight into 'sensitive topics', where participants may feel more comfortable exploring a topic in a group setting (Kevern & Webb, 2001). In specific, we believed that the focus group methodology would establish the current state of knowledge, attitudes and expectations which is the first step in meeting people where they are for the purposes of capacity building. Consistent with the principles of community-based research (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011) the academic researchers and community members shared equally in the planning, recruitment, implementation, and facilitation of the focus groups, coding of the transcripts, interpretation and presentation of the results, and dissemination of the findings. This work leveraged an existing partnership—the Communities of Harlem Health Revival—a collaborative effort of academic institutions and community based organizations which has provided education and services to meet community identified needs since 2004. Previous work focused on service to the community in the form of health fairs, church blood pressure screenings and designated walking trails in local parks. This study marked a transition from providing a service in the community to discussing partnership opportunities for genetic and genomic research.

Setting

The study was conducted in Central Harlem, an under-resourced inner-city urban community that is predominately Black and Hispanic, and which consistently reports significant health disparities in all the major categories of chronic conditions such as cardiovascular disease (Harlem Hospital Center, 2013), neurologic disorders (Harlem Hospital Center, 2013), cancer (Edwards et al., 2013), and obesity (Harlem Hospital Center, 2013) and in acute conditions such as asthma (Findley et al., 2003; Kwon et al., 2006; Nicholas et al., 2005; Pesola et al., 2004) when compared with similar groups both locally and nationally (Edwards et al., 2013).

Procedure for development of semi-structured interview guide

We received baseline demographic data from directors of two of the largest biobanks in our area, documenting what groups were most likely to be under-represented. We then took that information to the community and began a dialogue about this topic in a series of meetings with key informants including local clergy, 'first ladies' (wives of reverends, pastors or ministers who are considered trusted and influential church leaders in their own right), directors of local community organizations and informal community centers in Harlem, and the Director of a local advocacy group for Alzheimer's Disease. In the planning phase we described why the topic of biobanking was one that the community might be interested in, and how focus groups work as a research method. These key informants provided input before and during the development of the protocol including ways to introduce this sensitive topic to the community. We were aware from previous work that these key informants serve

as influential resources in the community, and that it was important for them to know about this study from the start. These key informants advise community members (formally and informally) and could encourage or discourage participation in this study and research overall. Results from these sessions were used to plan the study and develop the focus group guide.

In developing the focus group guide, we determined whether there were previously published studies or literature on the enrollment of healthy minority community members into research biobanks. One study described the demographics of men volunteering to obtain genomic testing for biobank enrollment and found a significant difference in participation rates among healthy male volunteers and those who were diagnosed with cancer (Patel et al., 2012).

This supported our assumption that members of the community who were not seeking clinical answers (healthy volunteers) may be less likely to participate in biobank research. With this in mind we incorporated questions about health benefits and risks to healthy volunteers. The focus group guide was developed following principles of Krueger & Casey (2000, 2009) and in partnership with the community key informants. Krueger's guidelines frame the role of the researcher as facilitator and suggest that the flow of the discussion and exploration be conducted in a natural and non-judgmental way. Focus group questions were developed to solicit viewpoints on biobank research participation and expectations by the community. To evaluate the focus group questions for relevant contact we vetted them at an Advisory Board of a P50 Center of Excellence for Research on Ethical, Legal and Social Implications of Psychiatric, Neurologic, and Behavioral Genetics located at Columbia University and funded by the National Human Genome Research Institute (Appelbaum, 2013, 1P50HG007257-01) of which one investigator (EC) is a member. In this review, a suggestion was made to add *decision scenarios*. Decision scenarios are used at the beginning and again at the end of each session to determine if participants changed their mind as a result of participation. Participants would be asked "knowing what you know now, would you enroll yourself or your child in a biobank?" The focus group guide was subsequently reviewed by a qualitative researcher who specializes in community-based focus group research in minority populations (Jackson, 2013) resulting in culturally-tailored language modifications. We pilot tested the focus group guide with the staff of a community-based organization in Harlem that provides services to women and children to confirm that the questions were balanced and could be easily understood with the information and background we provided, and did not contain unnecessary jargon. After pilot testing, we elected not to include the decision scenario in this study because we did not actually have the ability to enroll anyone in biobanks, and it ended up being a distractor from our intent, which was to build capacity. Rather, we decided to focus on factors that contribute to encouraging partnership with the community for biobanking research in the future, which was more in line with the intent of the research. The study was approved by the Institutional Review Board at Columbia University Medical Center.

Participants

Adults from the Harlem community were recruited through purposive and convenience sampling via email listservs from local organizations, printed flyers distributed to neighborhood barbershops and beauty parlors, community-based organizations, community health advocacy organizations, and local houses of worship. The study was a conducted as a collaborative effort where an informal community leader was a equal member of our research team, and the research was endorsed by formal community leaders, so we had sufficient interest and rapid enrollment. We sought to represent varying levels of income, insurance, education, and previous research participation in our groups. Inclusion criteria included self-identification as Black, living in Harlem, and English speaking. Interested community members could receive more information by responding via email, telephone, or texting. Participants were provided with a light meal, round- trip public transportation and a $20.00 gift certificate. Each focus group was limited to twelve participants with final groups ranging from six to eight participants and lasting for 90 minutes each. We sought to balance the sessions for gender, age and recruitment site with a goal of maximum variation. To provide the best balance possible, we tried to include as many different voices at the table as we could, therefore our exclusion criteria was not based on any specific factors but rather striving for maximum representation and bringing forward those whose voices were most at risk for not being heard. Focus groups started three weeks after recruitment opened, and ended seven weeks later when the data had reached saturation and no new themes were identified.

Procedure for Focus Groups

Sessions were held at centrally located community centers that were handicappedaccessible and convenient to public transportation. We selected this non-academic setting because these community centers are familiar and comfortable for residents. Moreover, regulations of a university setting often require photo identification, security checks and ID badges, which can be intimidating to visitors.

Six focus groups were conducted, three during the day and three in the evening. The sessions were co-facilitated by an academic nurse scientist (EC) and the community investigator (MH) who had served for over 25 years as a coordinator of a women and children’s program. Both had formal facilitator training. Field notes were taken during the sessions by a nursing student and a bioethics student who served as voluntary members of the study team. Written informed consent was obtained and a demographic survey was completed before the focus group which was used to collect basic information about age, education level, and income, history of research participation, insurance and employment status. We chose to have the participants complete the surveys before the group started to provide a short buffer of time for those who arrived early and also because we wanted to be available to help those who needed assistance with the forms.

Field notes included the interaction between participants, i.e., whether comments were directed towards the investigators or if participants were responding directly to each other, how questions or issues were resolved within the group, and if participants changed their views during the session (Duggleby, 2005; Rothwell, 2010). An example of how a

participant's view might change would be if someone initially stated that they were unwilling to participate in research, but later decided that they would be willing to participate based on new information or the discussion about the pros and cons of participation. Sessions were tape-recorded using two tape recorders and transcribed verbatim.

Printed questions were available for focus group participants at their seats and at registration (Table 1). Discussions were overall robust and most of the participants fully engaged.

Many participants remained in the room after the focus group adjourned exchanging contact information. We had scheduled the focus groups to run ninety minutes and we wanted to be respectful of those who allocated only that amount of time for the program, but because the secondary purpose was to engage the community, we reserved the room for an additional hour and stayed if people wanted to continue talking. The topics of the discussions after the focus groups officially ended were more social than scientific, exploring mutual acquaintances, asking what kind of work we had done before, and if focus groups on other topics would be held, and how we came to work in Harlem.

Data Analysis

Verbatim transcripts were analyzed using content analysis (Krippendorff, 2013) and ATLAS.ti Version-7 (ATLAS.ti, Berlin, Germany). Four raters were trained in the analytic techniques: the academic and community principal investigators, a graduate student in bioethics, and a graduate student in nursing who had an undergraduate degree in linguistics. Before beginning the study, these individuals completed an on-line module on coding of focus group transcripts available from Sage Publishers (Morgan, Krueger, & King, 1998). A procedure for analysis was developed, discussed, and agreed upon before transcripts were distributed. Coders independently read the transcripts, first for context, and a second time for meaning. Each person coded the first focus group transcript line-by-line. Following independent coding, the results were compared. Discrepancies were resolved by consensus, and codes were agreed upon as part of the process. After the first set of transcripts was coded, a code-book, with a definition for each code was developed for reading the subsequent transcripts. If a new topic appeared in the data in a subsequent meeting, a code was added to the code book. The process of independent coding followed by group discussion and consensus and addition of new codes was continued for each transcript. During the process of coding all the transcripts, the analytic team began to identify common themes or topics within which similar codes could be grouped. Furthermore, quotes that illustrated common themes were identified and agreed upon (Graneheim & Lundman, 2004; Krippendorff, 2013).

ATLAS.ti was used twice during the analysis. Initially the transcripts were coded using the "Auto Coding" feature of ATLAS.ti to identify frequently used words and concepts. The results of the Auto Coding were reviewed to determine if any additional codes were suggested by ATLAS.ti that had not been identified by the content analysis review. The second ATLAS.ti analysis was done after the documents were coded using the themes identified to assure that we had not missed any passages that might have fit with our coded themes.

After each group concluded we examined and critiqued the field notes on group process in order to identify whether any changes were needed to the physical space and to examine more closely the group dynamics that may have influenced the content and nature of the discussion.

We adjusted for several situations in both of these categories. One of our settings proved to be adjacent to a busy hallway which distracted our participants and interrupted the discussion, so we relocated future sessions. Because the groups were serving both to build capacity and to explore the topic of participation in biobanking, differing levels of participation needed to be appreciated and managed. We developed strategies around several of our most common group dynamic issues; participants who dominated the discussion or who spoke not at all and how to create an environment that could support opposing opinions, especially given that participants were selected for maximum variation and it could be anticipated that they might fundamentally disagree. We decided that at 25 minutes before the scheduled end of the session, we would ask anyone who had not spoken to add their observations and thoughts to the discussion. This strategy was suggested and initiated by the community investigator to assure that each member of the community had an opportunity to be heard.

We developed several strategies for a situation in which a single person dominated the discussion. First, we took those discussions off-line, asking the person to contact us after the session if there was a topic that had clearly touched a raw nerve. We explained that we would stay after the session, but we were also available in follow-up if people had serious, unresolved concerns. When a participant dominated the discussion in a less obvious but unproductive manner, the researcher allowed the speaker to complete their thought and thanked them for their input. We then asked that for the sake of time we needed to hear the voice of each person at the table, the goal was respect for the individual and their viewpoint but also assuring the time and space for other participants.

Saturation was reached in group five after no new codes or themes were identified and no new information was added to our notes. We conducted one additional focus group after saturation to be sure that we had not missed a concern or opinion, and did not find new information. At the conclusion of the focus group meetings the research team provided contact phone numbers and email addresses, and encouraged community members to follow up with any further thoughts or questions. Printed thank you notes were sent with information about contacting researchers to facilitate continued conversation.

After coding was complete and agreement between coders was reached, *member checking* was used to assure that we had correctly represented the views of the community leaders and participants (Whittemore, Chase, & Mandle, 2001). We returned the results to all the participant community members with two types of member-checking sessions. At the first member checking session we described and demonstrated how transcripts were coded and presented a preliminary set of themes and quotes. This provided an opportunity for feedback at an intermediate stage, demonstrated transparency in the process, and assured participants that discussion, comments and questions were welcomed. Although no changes were made to our document, it sparked continued discussion and dialogue about our process, and

community members expressed an interest in how similar the comments were at each of the six original sessions. At the second member checking session quotes and the final themes were approved by the group.

Results

Demographic Characteristics

A total of 46 community members completed the entire study. All who enrolled completed the initial focus group and at least one of the member checking sessions. The majority self-identified as Black or African American (89%), with four identifying as Black and Hispanic (9%) and one identifying as Black and Native American (2%). Most were female (74%). About one-third (37%) of participants were employed, 43% unemployed, and 20% retired. Most were insured with either private or public insurance (70%) with the remaining uninsured. They ranged in age from 18 to 72 with the mean age of 56 years. Ten (22%) had previously participated in a clinical trial, six (13%) were invited to participate in previous research but had declined due to being skeptical or uncertain, and greater than half of the group had never been asked to participate in a research study (65%).

Themes

Three themes were identified across all focus groups: (1) the potential contribution of biobanking to individual and community health, (2) the societal context of the science, and (3) the commitment of the researchers to community health as an outcome of capacity building.

Themes are presented with supporting quotes.

Theme 1: The potential contribution of biobanking to individual and community health—Individual participants expressed a desire to be pro-active and involved. They wanted to be part of the solutions instead of reacting to a disparate health situation. *If you come to us before the crisis and say we can do this as a preventive measure then it changes the dynamics and I feel like I'll contribute something instead of feeling like I am being singled out for something*. Statements like this highlighted the importance to the community of finding ways to engage people early on in learning and talking about genomics, while clinical or research processes are developing, rather than simply soliciting them as subjects providing samples. People wanted to understand more about what was entailed in developing a research partnership. *We need to have more open forums, more opportunities where we can come together in a safe space and have a discussion and really talk about what this means for us—in a partnership—going forward*. Participants were concerned with how it would benefit them, their family and their community.

Most focus groups contained a mix of people who had and had not previously participated in research. Several participants spoke about their experiences. The most compelling input in favor of early participation was from a community member who had partnered with researchers and made a significant contribution over time.

I have been living with the HIV virus for over 20 years. [I was the first female patient my doctor had] and that helped shape me into the person I am, and he into the person he is. The idea of learning and having the support of the medical professional beside me made me want to participate in research. It removed the mystery because I knew that I was a fighting part of the situation.

This was in contrast to stories told of experimentation on people who were incarcerated which were not reports of personal experience, but rather a negative impression about research in the prison setting. *If you are lucky or unlikely enough to become ill while incarcerated, [drugs] will get tested on you, [on the] the inmate population across the state*. This demonstrated the powerful impact of positive and negative testimonials about research participation in the community.

The effect of the environment on health was identified as a point of concern and interest by the community. *I would like to know if there's some way we could prevent other folks from being affected by anything triggered from themselves or something from the outside. These are the types of things I would like to know more about, to work together on*.

Environmental health conditions such as increased rates of asthma near the areas around a large bus depot, and the use of Bisphenol-A (BPA) in plastics were issues around which the community could envisage building capacity and working together using genomic science. Biobanking was regarded as a potentially helpful idea, if it could lead to improving health in individuals and in the community. There were questions about the effect of the environment on health, and a demonstrated interest in learning more about how genomics and biobanking could be used to examine and improve the health of the individuals and the community.

Theme 2: The societal context of the science—Building capacity for research takes place within the broader ethical, legal and societal context. Collectively the groups summed up these implications as respecting the past, accepting the present, and protecting the future.

Ethical issues were identified as the need to "heal the wounds" that have been created by transgressions in research and medicine for Blacks, specifically in African Americans. References to Tuskegee (Corbie-Smith, 1999a, 1999b; Reverby, 2008, 2010) and the Immortal Life of Henrietta Lacks (Nisbet & Fahy, 2013; Shiber & Foxwell, 2013) were illustrative of the injustices in the past and those that have continued to exist over time.

You want to recognize where we came from, because unless we know where we came from we can't go forward, so you have to address that first and talk about the mistrust then gradually bring us forward to the possibility of participating in up and new coming research opportunities and why we would be beneficial.

Community members discussed at length the intersection of law and medicine especially in consideration of the New York State DNA 2012 ruling (State of New York, 2103) under which New York became the first state to have an "all crimes DNA database" requiring anyone convicted of a felony or penal law misdemeanor to provide a DNA sample. Most states and the federal government maintain a DNA database that is used to match DNA from crime scenes to those registered in the database ("National DNA Index System-Combined

DNA Index System ", 2013). Four states have familial searching laws (2013; Colorado Bureau of Investigation, 2013; Commonwealth of Virginia, 2013; "National DNA Index System-Combined DNA Index System ", 2013; "Texas CODIS," 2013). Familial searching is used when there is not an exact match for DNA at a crime scene, but 'close matches' in the biobank are used to identify and question possible suspects on the theory that blood relatives will have similar DNA traits. *When people are arrested, in jail or incarcerated they take DNA samples. So, people always wonder where does that DNA sample go? Of course for the investigation, but do they also end up in biobanks? What's the difference between the DNA database and a biobank, would there ever be a chance that they would 'talk' to each other*.

Community members asked the research team if there could ever be a case where blood would be taken and tested or DNA results would be released without their consent. *Have there been instances when they take some of your blood without your permission? I would just like to be aware*. These questions were not easy to answer. Although research regulations and policies exist and institutional review boards are charged with protection of subjects' rights, community members were aware of recent occurrences of release of information and breeches of confidentiality. Therefore a critical issue for the community regarding participation in biobanks was the potential risk to individuals if their DNA were used beyond the purpose for which they agreed.

Theme 3: The researchers' commitment to community health as an outcome— Capacity-building for biobank research was seen as an opportunity to work collaboratively to improve health for the community in the future. *This type of partnership is important for our next generation. With more meetings like this, where we are introduced not as an underserved community but as an equal part of contributing to the research, then that changes the equation*. Specific strategies for capacity building were suggested by community members. *Well, doing what you're doing now. Give us your phone number, let us know that we can call. Send us an update, let us know what other opportunities there are. How we can get more information or just find out what's happening*.

Community members identified that a demonstrated commitment on the part of the researchers to the community as a whole was a critical factor for capacity building. Participants referred to prior studies in which people were recruited but when the study ended, the communication ceased. In the rare instances when the investigators did return the results of studies to the community, that signaled the end of the communication. These experiences became a barrier to meaningful on-going engagement for the Central Harlem community. Participants stressed that communication need not be frequent—once a month was sufficient— but it did need to be consistent. *It's the commitment—people want to be able to trust. It is knowing that you are invested in the health of this community; five months from now, five years from now, ten years from now*. Every focus group identified that on-going communication with the community was expected and necessary. *If the research solved a problem or answered a question, tell us how our contribution helped. If it led to a new project, what was that new project and what will happen next in this work. Keep us posted even if there is no news, even if it is just to say we are still working out this problem*. Throughout their participation, focus group members stressed the importance of a firm and

lasting relationship, and creating a structure for ongoing communication between researchers, individual research participants, and the larger community.

Discussion

Essential aspects of capacity building and factors affecting decisions to participate in genomic biobank research in this community were identified. First, community members sought information about genetics, genomics and biobaking and were interested in understanding how their individual participation and the participation of their families and communities would improve health. They expressed an interest in education tailored to their specific health risks and if genomics could be used in a predictive way, to identify an increased risk for disease development. They further expressed an interest in learning more specifically about how genomics could be used to identify environment-related health risks and inform local policy. These findings support and extend the work of Kittles and Williams who focused on how genomics can be leveraged in minority populations for environmental health (R. Kittles, 2012; R. A. Kittles et al., 2006; Monda et al., 2013).

Second, DNA research takes place in the larger context of society. An early and intentional plan to address minority representation while biobanks are still in development has the potential to overcome some of the barriers identified by the members of the community in this study, and supports the idea that individuals and communities can play a more collaborative role in genomic research. The stories of mistrust and implicit and explicit references to Henrietta Lacks and experiments of Tuskegee were common, as has been the case over time in other studies (Nisbet & Fahy, 2013; Shiber & Foxwell, 2013). However, our process notes indicated that when focus group members changed their mind from non-participation to participation, it was because of compelling stories from those who had participated in research. Testimonies in Black and African American history are powerful reflections of beliefs, traditions and communication (Thompson et al., 2013) and we heard a balance of stories that reflected a variation of experiences with research and researchers. This study provides additional insight demonstrating that stories of satisfactory—even empowering—experiences as partners in research would help begin to heal some of the wounds, and may provide opportunities for new types of experiences to be shared.

Concerns about the potential use of stored DNA samples for purposes outside of the scope of the study to which individuals consented were highlighted. State and federal laws, and use of DNA for forensic purposes are important considerations to all members of the public, and procedures for biobank collection, storage, and future use of DNA should be thoroughly analysed and thoughtfully constructed. Findings from this study suggest that these issues are best discussed openly and in an ongoing manner between researchers and community members, especially as laws change and new regulations are issued.

Third, we provide an example of capacity building to add to the literature on engagement for emerging biomedical science research. Our study and findings advance the work of Luque et al. (Koskan et al., 2012; Luque et al., 2012) and Noel-Thomas (Susman, 2010) who describe and anecdotally demonstrate that early engagement such as development of community advisory boards and conducting community tours of biobanks both informs the public and

helps them make more knowledgeable decisions about biobanking. Findings from this study add to accumulating evidence from surveys of the public in Canada (Etchegary, Green, Parfrey, Street, & Pullman, 2013) and focus groups in the United States (Jamal et al., 2013) that report an expectation of ongoing contact with investigators who collect genomic information about research participants. To this, we add the model of ongoing partnership for community research as a demonstration of the type of research capacity that can be built with communities. Our findings support development of tangible mechanisms for maintaining an on-going two-way dialogue and presence in the community such as a regular meetings, annual conferences, and email or on-line newsletters. Understanding that this may be time consuming our study seeks to illumine the types of communication that are acceptable to the community and attainable by researchers. This year we have held a community health fair that specifically explored genetics and genomics and developed an on-going health ministry series that is being delivered in churches which explains basic concepts, current utility and what is known and not known about biobanks and sequencing. Of those projects we have piloted, these two seem to be the most popular. We are scheduled to conduct a community-academic conference in this next year focused on the ethical, legal and social issues of neurologic, psychologic and behavioral genetics. Our institution does not currently have a biobank; however this work sets the stage for representative enrollment from a minority population. Our geographic area has several biobanks but our focus group members reported that they would not know how to access a biobank to enroll. Some biobanks such as the UT Southwestern Medical Center (Wormser, 2011) have started intentional campaigns to recruit minorities; our findings suggest that this information, combined with public education efforts and understanding the issues underlying participation will be crucial to increasing research capacity and enrollment.

Limitations

Data from our focus groups cannot necessarily be applied to other groups since the sample was limited to an urban population. Most of the community members were female, and all were independently residing in the community and primarily healthy. We did not collect a full set of demographics on the people who we contacted but who did not attend the groups or those who were not invited to participate, and they may be different from the group who did participate. This study is subject to selection bias since participation was voluntary and limited to those who contacted us to participate. Our goal was to identify the viewpoints of a community at risk of being under-represented in biobanks however our participants may be those who are more motivated or interested in genomics.

Clinical Implications

A broad sampling in biobanks is necessary for genomics to advance the health of our nation. We explored the process of capacity building as one possible method of obtaining representative sampling especially in communities at risk for being underrepresented. Capacity building is strongly recommended by the National Center for Advancing Translational Sciences and the Clinical and Translational Science Awards of the National Institutes of Health (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011). Our work demonstrates a bi-directional mechanism for exploring shared

research interests between an academic medical center and an at-risk community. Although, community engagement requires an initial commitment of time and resources, having a sustained partnership can speed future research efforts because the community is ready to collaborate around them. Research based on capacity building can help prepare communities and health professionals to collaborate to advance health outcomes through the use of genetics and genomics as it evolves.

Research Implications

Future directions for research in this area include a continuing exploration of the methods of engagement, education, and outreach with under-represented communities. Our data suggest that narratives about the range of experiences in research may balance some of the stories of injustice, especially as some of our participants expressed that they felt empowered by participation in research. An example of patient stories on video is available at: http://www.geneticalliance.org.uk/video-self-management.htm, which shows how testimonials can be shared. Although these focus on patients sharing the experience of living with a rare disease, we could envision similar videos on sharing research experiences. Videos designed to encourage participation would also include a list of resources and how to access clinical research such as ResearchMatch, Patients Like Me and ClinicalTrials.Gov. This would reflect our findings that seeing positive testimonials and having direct access to information on how to enroll are necessary first steps in increasing enrollment. The approach of informing patients about how to obtain information and enroll in clinical research would also address findings of Millon Underwood et al. (Millon Underwood, Buseh, Kelber, Stevens, & Townsend, 2013) that nearly 90% (88.7%) of the participants in her community focus group were willing to participate, but had never been offered the opportunity.

How the environment impacts community health was identified by our participants as an interesting starting point for on-going dialogue and future research. Working with communities on the areas they identify as important is the foundation of community-based participatory research (Isler, Sutton, Cadigan, & Corbie-Smith, 2013). Finally, we note that we had high retention in our study, which further supports research methods that engage the community over time in a meaningful way.

Conclusion

There is a renewed interest in capacity building as part of translational science to improve the health outcomes (Brand, 2012; Hacker et al., 2012; Williams, 2012; Zimmern & Khoury, 2012), and as important tools for increasing the representation of minority populations in research (Gill et al., 2013; Redwood & Gill, 2013). This study identified key factors in capacity building for genomic studies: the potential contribution of biobanking to individual and community health, societal context of the science, and researchers' commitment to community health as an outcome. While the concept of capacity building has been supported, (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011) and a process for evaluation of community engagement in programs has been developed (Gaglio, Shoup, & Glasgow, 2013; Glasgow et al., 2013; Kessler et al., 2013) this research unites capacity building and emerging genomic science. However, formative challenges

remain in the areas of: developing tools to evaluate a readiness for engagement, pragmatic tools for encouraging engagement, information on how to access study and biobank enrollment locally and nationally, and tools for evaluating the engagement process and productivity.

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Table 1

Semi-structured interview guide for focus groups

1	What comes to mind when you think about genomics, genetics and DNA testing? (probe: heritage and ancestry)
2	Has anyone here or do you know of anyone who has participated in a study where they were asked to provide specimens of blood or cheek swabs for DNA? What do you think about that experience? (Describe the difference between genetic testing, genomic sequencing and show picture of a biobank)
3	What is the advantage of participating in a genomic study where your specimens will be stored and tested? What would you expect it to do for your health? For that of your family and those that you care about?
4	What are your concerns about genomic testing about having your specimens stored and how it might impact you and people you care about?
5	If you decided to participate in a biobanks what protection would you like to see?
6	Many institutions, Columbia included, are interested in maintaining an on-going dialogue about genomic testing and biobank storage with members of the community. What do you think would be the most effective way of maintaining an exchange of ideas and information? Your choice can be anything, email communication, dinners, e-newsletters, printed newsletters, in-person consultation hours, what do you think would work best?
7	Is there anything else you would want us to know?