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Black African immigrant community leaders' views on participation in genomics research and DNA biobanking

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ABSTRACT

Background: The emergence of DNA biobanks and the power they lend to genomics research promise substantial advances in disease prevention and treatment. Greater participation of racial/ethnic minority populations is necessary to assure a future of personalized medicine for all.

Purpose: The purpose of this study was to explore perspectives on genomics research and DNA biobanking among black African immigrants, an often overlooked US subpopulation.

Methods: As part of a larger staged study using community-based participatory research (CBPR) methods, we conducted four focus groups with 27 leaders in the black African immigrant community, exploring perceptions about genomics, barriers, and facilitators to participation in DNA biobanks and ethical ways to engage communities.

Findings/Discussion: Prominent in their views on genomics research was the legacy of colonial mistreatment and exploitation by Western researchers in their home countries in sub-Saharan Africa. The central dilemma for participants was balancing responsibilities to protect their people from harm and to find solutions for African generations to come. They insisted that nothing short of a transformation of research practice would elicit the full and sustained participation of African immigrants in the genomics enterprise.

Conclusion: To better align practice and policy in the field of genomics research and DNA biobanking with values expressed by African immigrant leaders, it is recommended that the field adopt a CBPR model for research and a benefit-sharing model for policy.

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Genomics, the study of genes in the human body and their interaction with each other and with the environment, is a rapidly advancing field that has the potential to revolutionize medicine and make significant improvements in longevity and disease control (Hamburg & Collins, 2010). The term "personalized medicine" is increasingly used for a clinical future in which an individual's cellular and genomic traits are assessed alongside health history to guide disease prevention, diagnosis, and therapeutic choices (Ginsburg & Willard, 2009; Khoury et al., 2012).

Conventional practice in which research teams collect their own biological specimens is not adequate for the rapid pace of genomics; large-scale studies

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necessary to propel the science require access to biobank repositories holding biological samples from thousands of people with links to their medical records (Greely, 2007). For U.S. biobanks to facilitate the transition to personalized medicine for everyone, it is essential they hold the widest range of diversity in genotype arrays (Scott, Caulfield, Borgelt & Illes, 2012). African Americans and other people of African ancestry are grossly under-represented in the mainstream of human genome research, putting pressure on the field to reach out to these communities (Sheikh et al., 2009), despite limited empirically based information about how to do so successfully (Withall, Jago, & Fox, 2011).

An avenue for meeting diversity goals for genomics science in the U.S. is biobank enrollment of black African immigrants, especially given evidence that DNA sequence variation is linked to geographic ancestry and historical patterns of gene flow and genetic drift, rather than to the contemporary social construct of “race” (Royal & Dunston, 2004). A repository of genetic materials from this subpopulation could facilitate discoveries for all people with ancestral roots in Africa and answer contemporary questions about the interplay of genes and environmental change that are raised by evidence that, over time, the health status of immigrants begins to resemble that of the majority in their host country (Oza-Frank, Stephenson, & Narayan, 2011).

As the first stage in community-based participatory research (CBPR) (Israel, Eng, Schulz, & Parker, 2005), the purposes of this study were to investigate perspectives of leaders in the black African immigrant community about genomics science and biobanking and to discern from them how best to invite and sustain engagement of black African immigrants in these endeavors. Research questions were: a) How do black African immigrant leaders view health research involving human subjects in general and genomics research and biobanking in particular? b) What are their perceptions of the risks and benefits of participation for their community? and c) Under what conditions would they endorse genomics research involving black African immigrants?

Black Africans are a small, but rapidly increasing, immigrant population in the United States. They comprise approximately 3% of the total U.S. immigrant population, and 3% of the country’s 39 million who identify as black (Capps, McCabe, & Fix, 2011). Between 2000 and 2010 their numbers doubled to 1.1 million (US Department of Homeland Security, 2011). For this subpopulation, environmental factors such as acculturation, social networks, transition pressures, and length of time in the U.S. may be important to consider in interaction with genetic makeup as personalized medicine becomes the norm (Gong et al., 2008; Singh & Miller, 2004). A broader implication for engaging black African immigrants in genomics research is that knowing DNA sequence variation in African and African Diaspora populations is essential to probing the influence of gene-environment interactions in many of the race- and ethnicity-based health disparities seen in the U.S. (Royal & Dunston, 2004).

Alongside intensifying focus on genomics in healthcare come new ethical dilemmas about the impact of genomics in people’s private lives and how new models of research dependent on biobanks can be conducted to guarantee protection and justice for human subjects. As Scott et al. (2012) point out, “Biobanks sit outside the purview of existing national regulatory bodies that oversee laboratory testing, human-subject research, patient-privacy assurance and drug approvals” (p. 144). Biobank donors typically consent to storage of their DNA and de-identified personal health information for general, unspecified research purposes over a substantial period of time, often their lifespan and beyond (Ormond, Cirino, Helenowski, Chisholm, & Wolf, 2009). Data sharing of this magnitude brings with it confidentiality concerns because complete de-identification of medical records may be impossible. Unlike other medical studies, biobank participants may not be informed about who is doing research with their data and for what purpose, nor might they receive the results from those studies. It is also not standard to provide donors with feedback about their own genetic findings, even if future studies yield clinically relevant discoveries. Although the scientific community sees biobanks as necessary for cutting edge research, and full participation across population groups is desired, ethical questions about consent, recruitment, confidentiality, and accountability abound, especially for underserved and vulnerable aggregates (Armstrong et al., 2012).

Methods

From 2010 to 2012, the research team partnered with a pan-African community-based organization (CBO) in a large Midwest metropolitan area to plan and execute a three-stage, mixed-methods CBPR study about engagement of black African immigrants in genomics research. Stage 1 involved focus groups with 27 community leaders to explore issues related to genomics and biobanking, perceptions of risks and benefits, and conditions necessary for engagement. Building from the process and findings of Stage 1, Stage 2 comprised semi-structured interviews with a purposive sample of 32 African immigrant adults eliciting their thoughts and feelings about similar phenomena. From these group- and individual-level qualitative findings, we proceeded in Stage 3 to construct a quantitative survey measuring knowledge, beliefs, and attitudes about genomics that we administered to a convenience sample of 200 adult members of the African immigrant community. Community partners were involved at each stage in recruitment, data collection, analytic discussion of data, validation of findings, and dissemination to community members and local/state policymakers. We report the findings of Stage 1 in this article.

In this study, 27 formal and informal community leaders were identified and participated in four focus