



# Embracing an “African Ethos” to facilitate African immigrants participation in medical genetics and genomics research

Aaron G. Buseh, PhD, MPH, MSN<sup>a,\*</sup>, Patricia E. Stevens, RN, PhD, FAAN<sup>a</sup>,  
Sandra Millon-Underwood, PhD, FAAN<sup>a</sup>, Sheryl T. Kelber, MS<sup>b</sup>,  
Leolia Townsend, MS, MA<sup>a</sup>

<sup>a</sup>University of Wisconsin-Milwaukee, College of Nursing, Milwaukee, WI

<sup>b</sup>Center for Nursing Research and Evaluation, University of Wisconsin-Milwaukee, College of Nursing, Milwaukee, WI

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## ABSTRACT

**Background:** Limited published research exists on perceptions and potentials for black African immigrants’ participation in medical genetics and genomics research.

**Purpose:** This study explores the inclination—of and disinclination—of African immigrants to be involved in genetics and genomics research.

**Methods:** In-depth qualitative interviews were employed in which a sample of black African immigrants 18 years and older ( $n = 34$ ) were interviewed.

**Discussion:** Barriers included contrary beliefs and customs about disease and the human body that differs from Western conceptions, and lack of genuine connection to the health care system. Facilitators included promotion of an “African ethos,” wherein Africans unite with one another in a communal extension of self and robust community involvement across the life span of genetic studies.

**Conclusion:** It is important for researchers and genetic counselors to understand the sociocultural underpinnings of African immigrants about genetics and genomics research as an initial step to encouraging their participation.

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## Introduction

Hailed as a new frontier in medicine, genetics, and genomics also raises a myriad of important ethical challenges. Studies have suggested that ethnic minority groups tend to take part in genomic research at disproportionately lower levels than others in the

general population, in part due to medical mistrust, a history of research abuse, and questions about equitable distribution of accrued benefits (Buseh, Underwood, Stevens, Townsend, & Kelber, 2013). Structural factors (e.g., time, cost; Giuliano et al., 2000) and personal factors (e.g., knowledge about genetics; Schmotzer, 2012) have also been found to influence ethnic/racial minority group research participation.

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\* Corresponding author: Aaron G. Buseh, University of Wisconsin-Milwaukee, College of Nursing, 1921 East Hartford Avenue, P. O. Box 413, Room 689, Milwaukee, WI 53201.

E-mail address: [aaronbg@uwm.edu](mailto:aaronbg@uwm.edu) (A.G. Buseh).

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For some ethnic/racial minority and immigrant groups, fatalistic thoughts about disease, fears of receiving bad news, and issues of language and cultural difference inhibit participation in genetic and other clinical studies (Gany, Herrera, Avallone, & Changrani, 2006). People of African ancestry are particularly underrepresented in human genome research and biobanks, putting pressure on the field to reach out to these communities (Ramsay, Tiemessen, Choudhury, & Soodyall, 2011; Wonkam & Mayosi, 2014).

Black African immigrants and refugees in the United States comprise a population that is not being fully engaged and whose contribution to genomic science may have particular implications for understanding interactions between environment and genetics in determining health. In the context of migration policy, whether an individual is categorized as a *refugee* (one who is forced to leave a home country due to persecution or reprisal) or an *immigrant* (one who voluntarily leaves a home country to relocate elsewhere) can make a difference in a host country's admission decision (United Nations High Commission for Refugee [UNHCR], 2015). Considered in a broader context, refugee is one of many subcategories that comprise immigrants as a whole. In this article, we use the term immigrant to refer to black Africans who were born in Africa and now live in the United States regardless of reasons for leaving their home countries.

Over the last several decades, the number of immigrants immigrating to the United States from Sub-Saharan Africa has been on the rise (Capps, McCabe, & Fix, 2012). According to a 2015 report from the Pew Research Center, there were 1.8 million African immigrants living in the United States in 2013, up from 881,000 in 2000 and a substantial increase from 1970, when the United States was home to only 80,000 foreign-born Africans. In 2013, Africans accounted for 4.4% of the immigrant population in the United States (Pew Research Center, 2015). Yet, to a large extent, the health of black African immigrant populations remains an unexplored area (Venters & Gany, 2011). National surveys monitoring morbidity and mortality patterns do not identify black African immigrants from Sub-Saharan Africa as a separate group and do not routinely collect, analyze, and report health data by immigrant status or country of origin (Singh, Rodriguez-Lainz, & Kogan, 2013). Rather, health data collected from black African immigrants are included in the federal census category called "black and/or African American." This approach to data collection makes it challenging to assess or disseminate the benefits of advancements in clinical research science to African immigrant groups.

From 2010 to 2012, as part of the Wisconsin Genomic Initiative, we conducted community-based, participatory research to investigate how best to secure and sustain engagement with black African immigrant communities in genetic and genomic initiatives. In partnership with the Pan-African Community Association (PACA), a local, community-based organization

(CBO) that helps resettle and build capacity among African immigrants, we carried out a three-staged, mixed methods study. First, we met in focus groups with 27 prominent opinion makers and gatekeepers in the black African immigrant community to learn their views on issues surrounding genetics, genomics, and biobanking. Results of this stage are reported elsewhere (Buseh et al., 2013). Second, we went to the constituencies of these community leaders, conducting in-depth interviews with 34 individuals to ascertain barriers and facilitators to participation in genetic and genomic research. Results of this stage are reported in this article. Third, we did a population-based survey of 200 black African immigrants to document their knowledge, attitudes, and beliefs about genetics and genomics. Results of this stage are reported elsewhere (Buseh, Kelber, Underwood, Stevens, & Townsend, 2014).

## Methods

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In Stage 2 of the larger study, 34 black African immigrants fluent in English were recruited from a large Midwest City to participate in semistructured, in-depth interviews about their inclinations to be part of or reject participation in genetics initiatives. A qualitative approach was chosen in an effort to gain insights about the feelings, reactions, attitudes, and expectations of individual community members with regard to the potentially controversial issues surrounding genetic and genomics (DiCicco-Bloom & Crabtree, 2006). Participants were recruited, either through flyers distributed by staff members at the partnering organization, PACA, or via word of mouth by participants themselves who spoke positively about the study to their associates (Biernacki & Waldorf, 1981). Participants ranged in age from 34 to 73 years ( $M = 49.76$  years, standard deviation = 9.81). They had lived in the United States anywhere from 1 to 55 years; average length of time in the United States was 19 years (standard deviation = 12.82). Over three fourths (79%) of the participants were married. They were highly educated, with 50% having completed graduate degrees and an additional 29% having completed a 4-year college degree (Table 1).

Volunteers initiated contact with the project coordinator, who negotiated a convenient private location and time for the interview. Informed consent was obtained before any data were collected. A semistructured interview guide based on literature about the low participation rates of ethnic minorities in clinical and genetic studies (Gollust et al., 2005, 2012) was developed in collaboration with PACA. The guide was used to pose open-ended questions about what would motivate and what would discourage participation in genetics and genomics research including biobanking. The digitally recorded interviews lasted 1 to 2 hr and were conducted by the principal investigator or project coordinator. An

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