

Barriers to African American and Other Minority Population Participation in Genomic-Related Health Research: A Systematic Literature Review

Karyn Onyeneho¹, Linda Thompson², Priscilla Okunji², Thomas Fungwe², and Gina Brown²

¹Howard University

²Affiliation not available

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Abstract

The paucity of data for African Americans (AAs) participating in health-related research (e.g., genomic health research) is often attributed to difficulty in recruitment and retention. The COVID-19 pandemic, which has resulted in hundreds of thousands of deaths, particularly in AA communities, has amplified the problem. Reasons for not participating remain unclear and may account for health disparities observed in these communities. Failure and unwillingness to participate in research in general influences health disparities, which may lead to missed economic opportunities, inequalities, poor health, reduced quality of life, and premature death. This review assesses barriers to acceptance of genomic-related health research among AAs and other marginalized populations. To investigate barriers to participating in health-related research involving deoxyribonucleic acid (DNA), 38 studies published in PubMed and Scopus between January 2008 and December 2018 were reviewed. Results were based on feedback collected by trained research assistants and phlebotomists during structured group, face-to-face, and telephonic. Reason for non-participation in genomic related research were pervasive and included perceived and/or actual experiences of mistrust and deceptiveness by investigators, misuse of genomic data, unethical research practices, healthcare system distrust, privacy concerns, socioeconomic influences, cultural beliefs, and other influences associated with psychosocial factors. These results are consistent with diminishing participation of AAs in DNA-related research attributable to a range of factors leading to health disparities. Addressing these factors among marginalized communities, and AAs who have not largely been represented in DNA-related research, will guide insights on how to conduct research in these communities.

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